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Secondary Health Conditions, Participation, and Psychosocial Long-term Outcomes in Adults with Pediatric-onset Spinal Cord Injury

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Secondary Health Conditions, Participation, and Psychosocial Long-term Outcomes in Adults
with Pediatric-onset Spinal Cord Injury

A Dissertation

Presented in

Partial Fulfillment of the

Requirements for the Degree of

Doctor of Philosophy

By

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June 9, 2021

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Abstract

Spinal cord injury (SCI) is a complex medical condition that refers to an acute spinal cord lesion that affects sensation, muscle control, and autonomic functioning. One fifth of injuries occur in youth, and adults with pediatric-onset SCI may have unique experiences and outcomes compared to those with adult-onset injuries due to the impacts of SCI on development. A socioecological disability framework can provide a critical perspective into how individual and environmental factors interact and impact the experiences of individuals with SCI. Individuals with SCI often have significant secondary health conditions with chronic pain and pressure injuries as two of the most common. SCI and related medical issues can significantly impact community participation including mobility (e.g., using transportation), occupational functioning (e.g., finding a job or going to school), and social integration (e.g., spending time with family and friends). Secondary medical conditions and participation can also influence psychosocial outcomes such as depression, anxiety, satisfaction with life (SWL), and posttraumatic growth (PTG). The current study utilizes a subset of 180 adults with pediatric-onset SCI from a continuous, longitudinal study with data from a 10-year period and up to nine time points. Data were collected through a hospital system in the U.S. and are part of a larger study that explores long-term medical and psychosocial outcomes. The study explores the relationships between medical complications (e.g., pain severity and pressure injuries), community participation (i.e., mobility, occupational functioning, and social integration), and psychosocial outcomes in the form of depression, anxiety, SWL, and PTG over time. Positive coping strategies (e.g., religion/spirituality, use of emotional support, acceptance) were studied as moderators for the relationship between medical complications and participation over time, with higher levels of coping strategies predicted to buffer against the negative impact of medical complications on participation. Descriptive

statistics and correlations were examined for all relevant variables and hierarchical linear modeling (HLM) was utilized for main analyses. Over time, experiencing a pressure injury in the past year was associated with lower community participation, higher levels of pain severity were associated with higher levels of depression symptoms, and higher levels of community participation were associated with lower levels of depression symptoms and higher levels of SWL. Mobility was specifically related to depression symptoms and occupational functioning was related to SWL over time. Coping was not found to moderate relationships between secondary medical conditions and community participation. This study builds upon the SCI literature by focusing on longitudinal data and key relationships over time in adults with pediatric-onset SCI. While much of the literature focuses on immediate effects of SCI on functioning, this study examines individuals' functioning years after their injuries. Results suggest that prevention of secondary medical conditions such as pressure injuries may be an avenue for facilitating community participation and that strategies focused on increasing participation may lead to positive psychosocial functioning over time. Implications for research, practice, and policy are discussed.

Introduction

Spinal cord injury (SCI) is a complex medical condition that refers to an acute spinal cord lesion that can impact sensation, muscle control, and autonomic functioning (Chen & DeVivo, 2018). Individuals with SCI experience significant medical complications that have both acute and long-term effects (Sezer et al., 2015), as well as increased risk for psychological and socioemotional impairment (Craig et al., 2009). There is significant variability among SCI based on etiology, level and severity of the SCI, age of onset, and a number of additional contributing factors. The age at which an individual sustains an injury may be especially important, as the experiences of individuals injured in childhood or adolescence can be different from those who sustain injuries in adulthood (Vogel et al., 2004). Understanding how SCI in youth affects development and impacts adult outcomes can be beneficial for providing appropriate healthcare and support for this population.

According to the National Spinal Cord Injury Statistical Center (2020), there are an estimated 296,000 individuals with SCI living in the United States, with about 17,900 new SCI cases each year. Approximately one fifth of SCIs are sustained in youth (National Spinal Cord Injury Statistics Center, 2020; Zebracki & Vogel, 2012). Altogether, SCI leads to significant monetary costs for medical and rehabilitative care and living expenses, which become greater the earlier an individual obtains the injury. Further, there are indirect costs in adulthood of approximately \$78,633 per year that include loss of wages and productivity (National Spinal Cord Injury Statistics Center, 2020). Beyond monetary costs, individuals with SCI experience mental health issues such as depression and anxiety at higher rates than the general population (Post & Leeuwen, 2012). Despite the physical, emotional, and financial burden incurred by SCI, many individuals with SCI experience positive outcomes and demonstrate resilience (January et

al., 2015; Weitzner et al., 2011). Community psychology and a socioecological perspective on disability offers an approach to exploring SCI and the factors that lead to greater participation, satisfaction with life (SWL), and posttraumatic growth (PTG) after an injury.

A Socioecological Disability Framework

Research on disability has historically been influenced by a medical model that focuses on individuals' weaknesses and deficiencies (Tate & Pledger, 2003; Weitzner et al., 2011). However, there is significant evidence that demonstrates many individuals with SCI find strengths through their experiences and achieve areas of personal growth and new meaning (Carpenter, 1994; DeSanto-Madeya, 2006; Weitzner et al., 2011). There are numerous examples of individuals with disabilities who have positive life experiences (Kalpakjian et al., 2014). For example, in one study exploring long-term outcomes of individuals with pediatric-onset SCI, 99% of participants indicated that they had experienced one or more positive life changes related to their injuries (January et al., 2015).

Recent models and frameworks have focused on a socioecological perspective that highlights the importance of the individual and environmental levels of analysis and how they interact, defining disability through how an individual functions within their environment (Pledger, 2003; Tate & Pledger, 2003). A socioecological framework for exploring disability focuses on person-environment interactions, consumer input and ideas, and an integrative approach between professionals in the medical and social sciences and individuals with disabilities (Tate & Pledger, 2003). The interaction between individual-level factors and the environment has been applied specifically to individuals with SCI, and participation has been explored as a major outcome of this interaction (Fougeyrollas et al., 2002). Individual injury characteristics, functioning, and demographics may impact adaptation to one's environment,

while environmental characteristics may lead to secondary impairments (Fougeyrollas et al., 2002). Exploring strengths within the context of SCI, along with variables such as participation that focus on person-environment interaction, may provide greater insight into how individuals with pediatric-onset SCI utilize their assets to lead to positive long-term outcomes.

Community psychology offers a unique perspective for exploring the impacts of SCI on long-term psychosocial outcomes, as the major tenants of community psychology include a focus on strengths, exploration of multiple ecological levels of analysis, and the importance of context (Kloos et al., 2012). Empowerment, a core aspect of community psychology, is a concept that has frequently been explored in the psychology literature including in the context of physical disability. Often, empowerment highlights the importance of gaining autonomy, participation, and control in circumstances in which an individual or group of people may lack power (Fawcett et al., 1994; Zimmerman & Warschausky, 1998). Individuals with SCI may be presented with circumstances due to their injuries, in which they have less control and independence than prior to injury onset. For example, injuries often impact many aspects of daily life from social relationships to the ability to work in the same capacity. Individuals often experience a decrease in autonomy in that that they may become dependent on others for daily self-care activities. Mobility and transportation can also become more challenging and potentially affect community participation (Carpenter et al., 2007). Exploring the construct of empowerment in the context of SCI can provide stakeholders (e.g., individuals with SCI, their families, caregivers, medical providers) with information and support around increasing influence and independence in a population that experiences sudden and unexpected changes following onset.

Within the field of community psychology, empowerment approaches have been utilized to explore factors that facilitate an increase in power, independence, and control with individuals

with disabilities (Fawcett et al., 1994). Related to a socioecological framework on disability, a contextual-behavioral model of empowerment refers to psychological and individual-level processes and outcomes, as well as group-level factors (Fawcett et al., 1994). For individuals with SCI, gaining autonomy and independence can be central goals, but group-level variables such as family support and community-level variables such as accessibility may determine the extent to which individuals with SCI have opportunities to increase empowerment. On the individual level, individuals with SCI utilize strategies such as goal-setting, learning from others in the SCI community, planning/organizing, and asking and accepting help from others to facilitate independence, participation, and self-determination (van de Ven et al., 2008). A contextual-behavioral model of empowerment highlights the transactional relationship between multiple levels of analysis (e.g., individual and community) and emphasizes that one's individual autonomy and independence is affected by one's surroundings. The environment plays an essential role in facilitating individual-level empowerment. For instance, communities that have public transportation that can be accessed with a wheelchair, may promote greater social integration for individuals with SCI. Likewise, individuals can affect their environments through a variety of methods including advocacy and coalition building (Fawcett et al., 1994). A contextual-behavioral model may be applied to SCI by centering on the factors that relate to individuals with injuries increasing control and independence in their daily lives, while exploring the individual-environmental interactions that affect outcomes.

SCI is a multifaceted medical condition, often incurred through a traumatic experience such as a motor vehicle crash, gun shot, or sports injury. These types of experiences have profound effects on individuals' psychosocial functioning and physical health. The wide-ranging effects that serious injuries (e.g., paralysis, neurogenic bladder/bowel, chronic pain) have on

individuals, demonstrate a need for a framework that highlights this complexity and focuses on increasing positive outcomes for individuals across multiple settings. This is especially true for those who experience SCI in childhood, as they are exposed to these challenges during important times during their development and must learn to cope with the effects of injuries through their entire adult lives. A socioecological approach within the SCI population emphasizes the context surrounding physical disability (e.g., the environment, support systems, culture, societal norms) and the interaction between individual and environment that affects one's experience of SCI. By increasing understanding of this relationship, healthcare professionals and the SCI community may be better able to collaborate in a way that improves psychosocial and health outcomes.

An Overview of Spinal Cord Injury

There has been substantial research on the epidemiology of SCI that focuses on specific risk factors and trends for injuries (Chen & DeVivo, 2018) including demographic risk factors for incurring SCI such as sex and race/ethnicity. In addition, injury characteristics that include age at the time of injury, etiology, and level and severity of injury represent factors that can affect overall impairment, functioning, and capabilities.

Age

While the average age of SCI today is 43 years old (National Spinal Cord Injury Statistical Center, 2020), approximately 20% of SCI occurs in individuals younger than 21 years old, with 3 to 5% of injuries occurring in those younger than 15 years old (Nobunaga et al., 1999; Zebracki & Vogel, 2012). The incidence of SCI is generally low for younger pediatric populations at approximately 10.0 cases per million between the ages of 0 and 15, but rates of injury increase to approximately 66.5 cases per million in later adolescence and early adulthood (16 to 21 years old; Saunders et al., 2015). The average incidence of SCI across all ages is

around 54 cases per million population in the United States (National Spinal Cord Injury Statistical Center, 2020). Through middle to late adulthood, incidence of injuries generally decreases with age until there is an increase in injuries for elderly populations (Chen & DeVivo, 2018).

Etiology

SCI can occur from a number of different circumstances and situations. Based on data exploring SCI across all ages, motor vehicle crashes are responsible for the greatest number of injuries (38.2%; National Spinal Cord Injury Statistical Center, 2020), although this percentage has decreased over time with greater injury prevention and safety efforts (Chen & DeVivo, 2018). Falls (32.3%), violence (14.3%), sports (7.8%), and medical/surgical incidents (4.1%) represent additional causes for SCI (National Spinal Cord Injury Statistical Center, 2020). Etiology can differ by age of onset. There are multiple causes for pediatric SCI, and consistent with the larger SCI population, the most common etiology is motor vehicle crashes (Vogel & Anderson, 2003; Vogel et al., 2019; Zebracki & Vogel, 2014). Violence and sports injuries are the second and third most common causes of injury in youth. Furthermore, there are some etiologies that are unique to pediatric SCI that include injuries at birth, child abuse, injuries related to car lap belts, and transverse myelitis (Vogel & Anderson, 2003; Vogel et al., 2019).

Gender

Gender differences also appear within the SCI population, as males are about three to four times more likely to incur SCI than females, although this difference is less pronounced in the younger pediatric populations (Chen & DeVivo, 2018; DeVivo, 2012). The gender gap is largely nonexistent in younger children (ages 0 to 5), but increases through adolescence into emerging adulthood, as males are more likely to experience SCI than females (Vogel et al.,

2019). In those who sustain an SCI between 13 and 15 years old, 69% occur in males and 31% in females. In those who sustain an SCI between 16 and 21 years old, 83% occur in males and 17% in females (DeVivo & Vogel, 2004; Zebracki & Vogel, 2012). This gender gap has often been attributed to etiology as tendencies for increased risk-taking behaviors, violence-related injuries, and sports injuries increase in males compared to females during adolescence and adulthood (Chen & DeVivo, 2018). The major causes of SCI in early childhood are medical and motor vehicle accidents, which are equally common across males and females (Zebracki & Vogel, 2012).

Race/Ethnicity

There are also racial differences in SCI incidence with African Americans and Hispanics experiencing a higher incidence of SCI compared to White Americans (Chen & DeVivo, 2018). This is largely due to African Americans and Hispanics having an increased risk of injury related to violence (e.g., gunshot wounds) compared to White individuals (Chen & DeVivo, 2018; Zebracki & Vogel, 2012). From the ages of 16 to 21 years old, violence-related injuries account for 50% of SCI experienced by Hispanic individuals and 64% of injuries experienced by African American individuals, compared to 6% of injuries incurred by White individuals (Zebracki & Vogel, 2012).

Level of Injury and Level of Impairment

The level and severity (i.e. completeness) of an SCI determine the level of functioning an individual will have after the injury. The spinal cord connects the brain to the rest of the body and consists of different levels, with the cervical level (neck) being the highest, followed by the thoracic (upper back and abdomen), lumbar (lower back), and sacral (below lumbar and above tailbone) levels. Outcomes can vary drastically based on where the spinal cord is impacted, as

injuries to higher levels of the spinal cord are largely indicative of greater range of impairments (Kirshblum & Solinsky, 2018). The majority of injuries occur at the cervical level and result in tetraplegia, meaning that an individual with SCI at this level would have partial or complete paralysis of both the arms and legs (Chen & DeVivo, 2018; DeVivo, 2012). Thoracic level injuries, which occur in the region immediately below the cervical level, are the second most common region for injury, followed by the lumbar level (Chen & DeVivo, 2018). SCI at lower levels of the spine (i.e., thoracic, lumbar, and sacral) result in paraplegia, meaning that the individual has partial or complete paralysis of the legs and lower body with preserved functioning in upper limbs (Kirshblum & Solinsky, 2018). More than half of traumatic spinal cord injuries lead to tetraplegia (59.8%) compared to paraplegia (39.6%; National Spinal Cord Injury Statistical Center, 2020). Etiology of an injury may impact the expected neurological level (Chen & DeVivo, 2018), as individuals with violent etiology and those injured through medical reasons are more likely to experience paraplegia and individuals injured through sports or falls are more likely to experience tetraplegia (National Spinal Cord Injury Statistical Center, 2020). For the pediatric-onset SCI population between the ages of 0 and 12, lower level injuries (thoracic, lumbar and sacral injuries or paraplegia) are more common than cervical injuries (Zebracki & Vogel, 2012). This is often due to the types of injuries that are more common in youth such as SCI due to medical causes or car lap belt injuries. Approximately half of the individuals with pediatric-onset SCI incurred in adolescence have paraplegia compared to about two thirds of children 12 years and younger (Vogel et al., 2019; Zebracki & Vogel, 2014).

While level of injury is one of the major factors that determine overall functioning, the second is impairment group, or level of motor and sensory preservation post injury (American Spinal Injury Association (ASIA), 2019). SCIs can either be complete, in that there is complete

loss of motor and sensory function below the injury, or incomplete, in that some level of motor or sensory functioning below the injury is preserved (ASIA, 2019). The range of functioning is determined through the American Spinal Injury Association Impairment Scale (AIS), a scale that provides five categories to describe functioning (ASIA, 2019). AIS A represents a “complete injury” in which the individual has “no sensory or motor function” indicating no “sacral sparing,” or sensation around the anal region. AIS B (i.e. “sensory incomplete”), C (i.e. “motor incomplete”), and D (i.e. “motor incomplete”) represent various levels of incomplete injuries in which some form of sensory and/or motor function is preserved, including “sacral sparing” (ASIA, 2019). For individuals with AIS B, “sensory but not motor function is preserved below the neurological level.” For individuals with AIS C or D, some level of sensory and motor function is preserved with individuals with AIS C having less than half of key muscle functions below the neurological level of injury with muscle grades at three or greater and AIS D having half or more of key muscle functions below the neurological level of injury with muscle grades at three or greater (ASIA, 2019). AIS E indicates that an individual has normal neurological functioning post injury (ASIA, 2019). The majority of individuals who sustain an SCI have incomplete injuries in which some sensory and motor functioning is preserved (67.1%), while approximately 32.3% of individuals experience complete injuries (National Spinal Cord Injury Statistical Center, 2020). The majority of lesions in pediatric-onset SCI are complete, although children 12 years and younger are more likely to have complete lesions (about two thirds) than adolescents (55-57%; Vogel et al., 2019).

Mortality

Overall, individuals with SCI have lower life expectancies than the general population and individuals with paraplegia live longer than those with tetraplegia (National Spinal Cord

Injury Statistical Center, 2020). Individuals with incomplete injuries (lower impairment groups) are more likely to live longer than individuals with complete injuries (DeVivo, 2012). Despite increased risk of mortality in the population, the majority of SCI patients live with their injuries for over twenty years (National Spinal Cord Injury Statistical Center, 2020). Straus et al. (2006) highlight that while the mortality rate within the first two years following injury has significantly decreased by about 40% from the 1970s to the early 2000s, the mortality rate has remained relatively stable since the early 2000s. Related to age-of-onset, one study determined that mortality rates are higher for individuals injured before they are 16 years old compared to those injured later (increased annual odds of dying by 31%), likely related to additional medical complications in pediatric-onset SCI (Shavelle et al., 2006). Overall, individuals with pediatric-onset SCI will live with their injuries longer than adults with adult-onset SCI. Life expectancies vary by the level and severity of injury, as individuals with greater neurological deficits are more likely to have decreased lifespans (Vogel et al., 2019).

Secondary Health Conditions

Secondary health conditions can impact the long-term medical and psychosocial outcomes of individuals with SCI. Health complications following SCI can be acute or chronic and they can impact a number of different systems (Sezer et al., 2015). The majority of SCI patients experience multiple complications and some of the most common are bladder and bowel control, pressure injuries (Piatt et al., 2016), chronic pain, and urinary tract infections (Adriaansen et al., 2016). Level of injury (paraplegia versus tetraplegia), completeness of injury (complete versus incomplete), and age of onset can all impact the types of medical complications individuals endure (Kirshblum & Solinsky, 2018). In addition, secondary health complications can affect socioemotional well-being and quality of life (Adriaansen et al., 2016). For example,

severe urinary tract infections, pressure injuries, and pain are associated with decreased life satisfaction (Vogel et al., 2002). Complications such as pressure injuries, infections, hospitalizations within the past year, and depression are associated with decreased life expectancy and mortality (Krause & Saunders, 2011).

Pain

The International Association for the Study of Pain's (IASP) most recent definition of pain states that pain is “an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissues damage” (Raja et al., 2020, p. 1). Chronic pain is one of the most common complications that occurs after traumatic SCI (Adriaansen et al., 2016; Sezer et al., 2015), as approximately 65% of individuals experience pain after injury (Siddall & Loeser, 2001). About one third of those who experience chronic pain report that their pain is severe (Siddall & Loeser, 2001). While pain is often at its worst during the acute care and initial rehab hospitalization, a majority of patients continue to experience pain after discharge when they have moved back into their communities (Donnelly & Eng, 2005). Many individuals with pain are able to improve their symptoms through both pharmacological and nonpharmacological treatments (Widerström-Noga & Turk, 2003). Some of the common drug treatments include opioids, nonsteroidal anti-inflammatory drugs (NSAIDs), anticonvulsants, and antidepressants (Widerström-Noga & Turk, 2003), although there have been efforts to decrease opioid prescriptions due to the effects of the opioid epidemic (Atkins et al., 2014). Nonpharmacological treatments such as massage and heat or ice therapies have also been successful in managing pain in the short-term (Widerström-Noga & Turk, 2003).

Pain is often categorized as nociceptive, meaning that it is related to musculoskeletal or visceral pain, or neuropathic, meaning that it is related to the nervous system. While some pain is

related to the specific injury and its impact on the spinal cord, nociceptive pain can occur related to mobility and the physical demands related to life changes post injury (Sezer et al., 2015). Neuropathic pain is variable across the patient population and can be present above the injury, below the injury, or at the level of injury (Sezer et al., 2015). Related to neuropathic pain, many individuals with SCIs report dysesthesia, or unpleasant sensations that can include pain, burning, or itchiness resulting from nerve damage occurring without noxious stimulation (Finnerup et al., 2001). One estimate indicates that approximately 48% of those with injuries experience dysesthesia such as sensations of hot and/or cold (Finnerup et al., 2001). Research studies suggest that there are not significant differences in overall neuropathic pain across gender or completeness of injury (Werhagen et al., 2004). However, neuropathic pain increases with age of onset for injury (Werhagen et al., 2004).

Research studies indicate that pain characteristics such as location and intensity of pain, as well as patterns of pain, are largely consistent over time. Some of the most common patterns include nociceptive pain in the upper limbs for patients with tetraplegia (often related to overuse) and neuropathic pain below the injury (Cruz-Almeida et al., 2005). Individuals who experience pain have been demonstrated to have lower mood and psychological functioning along with lower levels of social integration (Jensen et al., 2005). Chronic pain is also associated with poorer sleep quality (Cruz-Almeida et al., 2005) and sleep interference (e.g., falling asleep and staying asleep; Widerström-Noga et al., 2001). Individuals with moderate to high levels of chronic pain also report lower levels of life satisfaction compared to individuals with no chronic pain or minimal chronic pain (Tonack et al., 2008). Beyond sleep, chronic pain can interfere with the ability to exercise, work, and complete household chores, which may ultimately affect independence (Widerström-Noga et al., 2001). Pain intensity and interference are also negatively

related to community integration (Donnelly & Eng, 2005). Individuals with high levels of pain interference are more likely to experience deficits in participation, specifically related to mobility, social integration, and economic self-sufficiency (Putzke et al., 2000). Because of the negative effects of pain on daily activities such as exercise, work, and household chores (Widerström-Noga et al., 2001), pain may serve as a major contributing factor for hindering participation in the community. While research has explored the relationship between pain and community participation (Donnelly & Eng, 2005; Jensen et al., 2005), there has been limited research exploring the relationship with a pediatric-onset population. Since many individuals with pediatric-onset SCI have experienced pain related to their injuries since their youth, this may impact how they participate as adults.

Pressure Injuries

Another common secondary health complication in the SCI population is pressure injuries, which refers to “localized damage to the skin and underlying soft tissue usually over a bony prominence or related to a medical or other device” (Edsberg et al., 2016, p. 586). The severity of pressure injuries is often described using a staging system with Stage 1 pressure injuries as the least severe (e.g., not open sores) and Stage 4 pressure injuries as the most severe (e.g., deep pressure injuries with significant tissue loss; Edsberg et al., 2016). One study found that approximately 27% of participants had at least one episode of pressure injuries at Stage 2 or higher in a sixteen-year period (Chen et al., 2005). Prevalence of pressure injuries was higher when individuals were fifteen years postinjury (Chen et al., 2005). Overall, pressure injuries occurred at higher rates in men, the elderly, the unemployed, individuals who were not married, and participants with lower education (i.e., less than high school; Chen et al., 2005). Other risk factors for pressure injuries include being underweight, tobacco use, and taking medications for

spasticity and pain (Krause et al., 2001). A number of factors may protect against the development of pressure injuries including communication and self-advocacy skills, stability and access to resources, and participating in meaningful activity such as work and education (Sleight et al., 2016). Pressure injuries may specifically affect one's ability to participate actively in the community, as severe cases can require hospitalizations and surgeries (Richards et al., 2004).

Community and Social Participation

After sustaining an SCI, many individuals find that their abilities to participate in certain activities and within their communities change. The SCI population faces a number of medical challenges and environmental barriers that may decrease overall participation in their community and impact social relationships. Participation can be assessed through both individual and societal perspectives. An individual-level approach to examining participation is more subjective and focuses on the individual's own experiences, while a societal-level approach focuses on objective participation by comparing the capabilities of individuals with disability to able-bodied individuals (Noreau et al., 2005). Participation is a multifaceted concept and can refer to a range of components including community access and mobility, social integration, and occupation (Carpenter et al., 2007).

Community Access and Mobility

Community and social participation in the SCI population are frequently influenced by access to the community through transportation, social integration, education, work, and other available opportunities. Transportation often influences whether individuals with SCI are able to participate, and access to transportation can vary by community (Barclay et al., 2015). An individual's ability to access public transportation or the ability to drive has strong impacts on participation in terms of increased social activity (Carpenter et al., 2007). Limited transportation

options and opportunities can be major barriers, leading to increased social isolation (Barclay et al., 2015). Overall, an individual's level of mobility can significantly impact SWL (Dijkers, 1999; Putzke et al., 2002). Further, depression in the SCI population has been associated with lower levels of mobility (January et al., 2014a). Technology can be an important facilitator for social participation by connecting individuals with others outside the home through social networking sites and messaging, especially when mobility may be limited (Barclay et al., 2015). Mobility is a key component of community participation, as mobility can facilitate participation across other domains by increasing access.

Occupational Functioning

A key component of participation is occupational functioning, and individuals with SCI are employed at lower rates than the general population (Lidal et al., 2009). For many who are injured in adulthood, the decision to return to work after injury is complex and requires individuals to weigh a number of factors, such as financial considerations, physical capabilities, and personal values (Fadyl & McPherson, 2010). Some individuals who sustain SCI are able to return to their preinjury occupations and positions, while others may need additional education and training to be prepared for reentry into their professions (Krause, 2003). On average, an individual with SCI takes approximately 5 years to begin their first post-injury job (Krause, 2003). In the SCI population, those who are White, younger at the time of injury, and have paraplegia are more likely to have better employment outcomes (Krause et al., 1998). There is a correlation between social participation and employment status, as those who report low social participation are significantly more likely to be unemployed (Craig, Perry, Guest, Tran, & Middleton, 2015). Employment is associated with greater satisfaction with life, community integration, and income (Anderson & Vogel, 2002). Despite positive outcomes associated with

employment, many individuals with disabilities experience workplace discrimination, and research indicates that individuals with physical impairments are especially at risk (Graham et al., 2019).

Pediatric-onset populations are unique, as many young people with SCI may be too young to have a job or pre-employment experience. For these individuals, they may have to reassess career goals and navigate finding their first jobs post injury. Compared to individuals with adult-onset SCI, individuals with pediatric-onset SCI can often choose their first occupations to align with their current strengths and skills post injury. SCI in the pediatric-onset population can also impact decisions related to education, which may impact future employment (Vogel & Anderson, 2003). One study that explored longitudinal employment outcomes in adults with pediatric-onset SCI indicated that approximately 49.5% were employed with about 47.0% holding a baccalaureate or post-baccalaureate degree (Hwang et al., 2014b). Women, individuals who were married, and individuals who held college degrees demonstrated increased odds of employment over time (Hwang et al., 2014b). Those who remained employed over time demonstrated greater SWL, while those who remained unemployed were at increased risk for depression. A multitude of factors may influence whether individuals find a job or return to work, but there appear to be benefits to occupational functioning in the population.

Social Integration

Participation is impacted by others in the community and in one's social network. Community engagement and participation can be affected by healthcare professionals, peer mentors, and the support of loved ones, as positive relationships may encourage greater engagement (Barclay et al., 2015). Likewise, negative experiences with medical professionals and poor peer and family relationships might serve as barriers to participation in the community

(Barclay et al., 2015). Assistance and service barriers related to access to medical care, education opportunities, and help in the home can make participation more challenging for the SCI community (Tsai et al., 2017). Access to social support is a major factor in terms of an individual's perceived concerns with participation and individuals that have inadequate social support are significantly more likely than those with stronger support networks to perceive issues with their participation (Lund et al., 2005). Social support is related to a number of positive outcomes including psychological well-being (Hampton, 2004). Müller et al. (2012) determined, through a systematic literature review, that social support was significantly related to adjustment, positive coping skills, physical and mental health outcomes, and SWL. Further, individuals with SCI who live with others report significantly greater life satisfaction than those who live alone (Carpenter et al., 2007).

Factors Related to Participation

Participation may be affected by numerous factors including injury characteristics (e.g., level of injury), primary and secondary impairment, demographic factors such as age and gender, and environmental factors including physical environment and accessibility or social opportunities such as organized activities and groups (Noreau et al., 2005). For instance, younger age at the time of injury is related to higher levels of social participation (Craig, Perry, Guest, Tran, & Middleton, 2015) and secondary health complications such as neurogenic bladder and pressure injuries are related to lower levels of social participation (Piatt et al., 2016). Those with more education are also more likely to participate and be involved in their communities (Geyh et al., 2012). Self-esteem and self-efficacy have been positively associated with participation (Geyh et al., 2012), while mental health conditions such as depression (Barclay et al., 2015) serve as hindrances to participation in activities outside the home. Research on participation has often

focused on the barriers that prevent individuals from participating in their communities (e.g. Barclay et al., 2015). Because of the negative effects of certain health complications (Piatt et al., 2016), there is a need to better understand the relationship between secondary medical complications and participation over time in the pediatric-onset SCI population.

Because both secondary medical conditions and participation have been demonstrated to be associated with psychosocial outcomes like depression (January et al., 2014b), research that focuses on how these variables are related may be beneficial. Participation and psychosocial outcomes such as depression and satisfaction with life (SWL) have been explored in a number of ways. However, research has often studied participation as an outcome, in which mental health symptoms are studied as predictors of participation. But, one's level of participation may also influence mental health symptoms and other psychosocial outcomes. Understanding how secondary health conditions, participation, and psychosocial outcomes are related may be instructive for medical and mental health providers in providing recommendations for patients with SCI.

Psychosocial Outcomes

Extensive research has examined the psychosocial effects of experiencing SCI including depression, anxiety, SWL, and PTG. Understanding mental health outcomes and the factors that are associated with or lead to positive outcomes can provide essential information to medical and mental health professionals working with the population as well as information for individuals with SCI and their families and friends.

Depression

Research demonstrates that individuals with SCI have higher rates of psychological disorders than the general population (Craig, Perry, Guest, Tran, Dezarnaulds, et al., 2015; Post

& Leeuwen, 2012), and depression symptoms specifically are prevalent among individuals who have experienced traumatic SCI (Hoffman et al., 2011; Krause et al., 2000). However, rates of depression tend to be lower in pediatric-onset SCI than adult-onset (January et al., 2014a). Estimates from a longitudinal study suggest that about 21% of individuals one year after their injuries and 18% five years after their injuries experience symptoms indicative of major depression (Hoffman et al., 2011). Another study indicates that the rate of depression greater than 6 months after injury is as high as 37% (Migliorini et al., 2008). Gender, race, and ethnicity are related to depression symptoms, as symptoms tend to be more common among females and ethnic minorities (Krause et al., 2000). Individuals who report greater pain, declining health, and unsafe alcohol consumption are more likely to experience depression (Hoffman et al., 2011), and those who reach criteria for probable major depressive disorder (MDD) report lower life satisfaction and greater impairment in daily functioning (Bombardier et al., 2004). Patients who experience higher levels of depression symptoms demonstrate less functional independence, which can potentially impact motivation for rehabilitation (Kennedy et al., 2011). In addition, depressed individuals with SCI are less likely to receive treatment in the form of antidepressants or counseling in comparison with those who are depressed in the general population (Fann et al., 2011). Income level and years of education can serve as protective factors for experiencing symptoms (Krause et al., 2000).

Anxiety

Individuals who have sustained SCIs are also at risk for experiencing anxiety symptoms and developing anxiety disorders (Craig et al., 2009). Anxiety is one of the most commonly reported mental health concerns among this population, with estimates ranging from approximately 13% to 40% (Post & Leeuwen, 2012) and anxiety is a frequently comorbid with

depression (Migliorini et al., 2008). In addition, anxiety has been associated with continuous pain and poor sleep quality (Norrbrink Budh et al., 2005). Overall, some research demonstrates that individuals report higher anxiety immediately after their injuries and during the months prior to discharge from the hospital (Kennedy & Rogers, 2000). After discharge from a hospital setting, anxiety appears to decrease (Kennedy & Rogers, 2000).

Satisfaction with Life

Satisfaction with life (SWL), which has frequently been utilized as a measure of well-being, involves a comparison between one's current circumstances and what an individual believes to be the standard for one's life (Diener et al., 1985). Individuals who have sustained SCI are at an increased risk of having lower SWL compared to the general population (Post & Leeuwen, 2012). Within the SCI population, there are multiple factors that are related to poor life satisfaction including being male and unemployed (Putzke et al., 2002). The number of hospitalizations in the previous year (Dijkers, 1999), poor perceived health (Putzke et al., 2002), and chronic pain (Norrbrink Budh & Österåker, 2007) have also been associated with lower SWL. Mental health symptoms such as depression and anxiety, which are often related to pain, may influence SWL (Norrbrink Budh & Österåker, 2007). Further, components of community participation such as mobility, occupation, and social integration are significantly correlated with SWL (Dijkers, 1999; Putzke et al., 2002). Even though there are greater risks for lower SWL, many in the SCI population demonstrate high levels of overall well-being, and adapt well to their lives after injury (Post & Leeuwen, 2012).

Posttraumatic Growth

Despite the challenges endured by individuals who sustain an SCI, many experience positive changes, gain greater appreciation, and identify new opportunities after their injuries

occur. PTG is a term used to describe positive changes that may occur in response to difficult life circumstances and/or trauma (Tedeschi & Calhoun, 2004). Some examples of positive changes occur related to spirituality, relationships, and discovering personal strengths (Tedeschi & Calhoun, 1996). Research demonstrates that the majority of individuals who experience SCI report at least some form of positive change postinjury, but some components of PTG are more common than others in the SCI population (Kalpakjian et al., 2014). For example, closeness to others and changes in life priorities are reported more than greater spiritual change and new opportunities (Kalpakjian et al., 2014). Individuals with SCI experience PTG in different ways, such as through changes in meaningful relationships with family members, engagement and participation, and appreciation of life (Chun & Lee, 2008). With regard to meaningful relationships, individuals with SCI may feel greater emotional intimacy and trust with loved ones after their injuries. Some report a greater recognition of their own strengths, opportunities to participate in leisure activities and form friendships, and positive emotion as a result of engagement with others (Chun & Lee, 2008). Research demonstrates that coping strategies and hope play major roles in determining PTG (Byra, 2016). For example, higher levels of basic hope along with positive coping strategies such as religion, humor, and focusing on the problem are related to greater growth, while avoidance coping such as substance use is related to lower growth (Byra, 2016). Even though positive changes and experiences occur for many after injury, growth does not necessarily eliminate psychological challenges or negative symptomology that may also occur with SCI (Griffiths & Kennedy, 2012). Relative to depression, anxiety, and SWL, there is less research that explores the effects of secondary medical complications and participation on PTG, as PTG is a relatively new construct and area of research. Exploring PTG

as an outcome may provide insight into how healthcare providers, caregivers, and family can encourage growth and positive outcomes in individuals with SCI.

While there is a vast body of literature on many psychosocial outcomes in the larger SCI population, less research has been completed with a pediatric-onset population. Because individuals injured in childhood or adolescence have their injuries throughout their entire adult lives, they may have different experiences with their injuries which can impact their mental health symptoms, SWL, and PTG. Furthermore, much of the existing literature explores individual-level factors as predictors of these outcomes. However, each of these outcomes is related to a multitude of factors on individual and environmental levels of analysis, and from a socioecological perspective, it is important to explore variables such as participation which focus on individual-environment fit.

SCI and Coping Strategies

Research demonstrates that individuals with SCI use a variety of coping strategies and that the majority of individuals with pediatric-onset SCI use positive strategies (Anderson et al., 2008; Kennedy et al., 2015). Some examples of positive coping strategies include acceptance, positive reframing, active coping (e.g., taking action), emotional support, humor, and participating in religion (Anderson et al., 2008). Overall, there is significant evidence that demonstrates the importance of coping strategies as it relates to the adjustment of individuals with SCI (Chevalier et al., 2009). The use of certain coping strategies appears to be consistent over time (Kennedy et al., 2000) and there is evidence that psychological interventions that include coping skills training have been successful in decreasing depression symptoms in the SCI population (Kennedy et al., 2003; Mehta et al., 2011). Much of the research on coping in SCI has focused on how coping effects psychological outcomes such as depression and SWL

(Anderson et al., 2008). Research has also explored the effects of coping on participation, but to a lesser extent (Anderson et al., 2008). There is significant evidence that learning coping skills can facilitate greater adjustment following injury (Mehta et al., 2011), and the use of active coping strategies such as cognitive restructuring are related to increased participation in both formal and informal activities in youth with SCI (Lindwall, 2012). While research has illustrated the importance of coping strategies, studies have largely focused on coping in cross sectional studies and there is a dearth of longitudinal research (Chevalier et al., 2009). Exploring coping skills as moderators for the relationship between secondary medical complications and participation over time may provide insight into supporting individuals with SCI and facilitating positive rehabilitation outcomes.

Religion/Spirituality

Many individuals with disabilities use spirituality and/or religion to cope with disability, impairment, or illness and research has explored the relationship between spirituality/religion and health in the context of rehabilitation psychology (Kilpatrick & McCullough, 1999). While there has been limited research exploring spirituality and religion in the SCI population, one study demonstrated that greater existential spirituality (e.g. life perspective/purpose) is related to positive outcomes that include higher levels of life satisfaction and social quality of life, as well as better general health (Matheis et al., 2006). Religious spirituality, which is described as one's relationship with God, was not indicative of the same positive outcomes, highlighting that the benefits of spirituality might not be tied to specific religions and practices (Matheis et al., 2006). Positive outcomes have also been linked to spiritual coping in adults with pediatric-onset SCI, as greater use of spiritual coping is related to increased life satisfaction (Chlan et al., 2011). In

addition, over half of the pediatric-onset SCI sample reported the use of spiritual coping and indicated that religion was important to them (Chlan et al., 2011).

Emotional Support

Having consistent social support after injury is beneficial for individuals with SCI and being able to rely on emotional support from friends and loved ones is an important form of coping. Social support can be measured in terms of its quantity or quality and research supports that the quality of social support may be more directly associated with depression and hopelessness than quantity of relationships (Beedie & Kennedy, 2002). Greater emotional support is related to lower levels of depression symptoms, indicating the importance of promoting support from family and friends of individuals with SCI (Huang et al., 2015). Overall, social support is associated with both positive physical and mental health outcomes such as decreased mortality and greater life satisfaction (Müller et al., 2012) and the use of emotion-focused coping may be related to greater social reintegration post injury (Song, 2005). Having support, and knowing when to use one's supports, represents a valuable coping skill that may impact participation and psychological outcomes.

Acceptance

Acceptance related to injury is one of the most common coping strategies used by adults with pediatric-onset SCI (Anderson et al., 2008). Acceptance of the reality of the injury is significantly associated with increased life satisfaction (Anderson et al., 2008). Research also demonstrates that individuals with SCI use acceptance as a coping strategy more often over time with longer duration of the injury (Anderson et al., 2008; Kennedy et al., 2015). The use of acceptance strategies may also be related to appraisals of one's injury, and in turn, the psychological adjustment of individuals with SCI (Chevalier et al., 2009).

Pediatric-Onset SCI

SCI in children and adolescents comes with unique concerns compared to adult-onset SCI, as these individuals must learn to cope with a significant injury that will impact their development into adulthood and throughout the majority of their lives (Vogel et al., 2004). The experiences of individuals with pediatric-onset SCI are significantly different from those with adult-onset SCI, as children and adolescents with SCI will live longer with their injuries (Zebracki & Vogel, 2012). Because individuals with pediatric-onset SCI must cope with injuries during their youth and development, they are susceptible to unique medical complications that are uncommon in adult-onset SCI, such as scoliosis, as well as long-term complications that develop through sedentary living (e.g., cardiovascular disease; Zebracki & Vogel, 2012).

Individuals with pediatric-onset SCI are at risk for numerous medical complications that are common in the general SCI population. For example, individuals with pediatric-onset SCI are at risk for autonomic dysreflexia, urinary tract infections, and pneumonia and respiratory failure in adulthood (Hwang et al., 2014a). Additionally, individuals with pediatric-onset SCI are more vulnerable to conditions associated with inactive lifestyles such as cardiovascular disease and overuse syndromes (e.g. upper extremity pain). Because many pediatric-onset SCIs occur before skeletal maturity, conditions like scoliosis occur more frequently (Zebracki & Vogel, 2012). Consistent with adult-onset SCI, blood pressure and heart rate are affected, as individuals generally show increasing blood pressure and decreasing heart rate as they grow older. The pediatric-onset population also has high rates of Vitamin D deficiency (Zebracki et al., 2013). Pain and other medical conditions are associated with poor sleep into adulthood for the pediatric-onset population (January et al., 2017).

Because of the unique experiences of children and adolescents who have sustained SCI, exploring the long-term psychosocial outcomes and trajectories of this patient population into adulthood is important. In general, many adults with pediatric-onset SCI experience symptoms of depression (21%), anxiety (29%), and drug and alcohol abuse (26%; January et al., 2014a). Mental health symptoms are significantly related to a range of negative medical outcomes. For example, individuals with pediatric-onset SCI who experience depression are more likely to have an increased number of hospitalizations, urinary tract infections, and pressure injuries while individuals with anxiety symptoms are likely to experience more hospitalizations and pain (January et al., 2014a). Research demonstrates that while many individuals with pediatric-onset SCI do not experience significant mental health concerns, depression symptoms vary over time (January et al., 2014b). Increased pain, bowel accidents and bladder incontinence, hazardous drinking, and less community participation predicted depression symptoms over time (January et al., 2014b). Even though many individuals with pediatric-onset SCI experience mental health symptoms in adulthood, the vast majority of this patient population does not develop depression, anxiety, or substance abuse, demonstrating strong resilience (January et al., 2014a). Further, many adults with pediatric-onset SCI report positive changes that occurred as a result of injuries with greater PTG related to increased SWL and happiness (January et al., 2015).

Research has also provided insight into educational and occupational outcomes for the pediatric-onset SCI population into adulthood (Hwang et al., 2015; Vogel et al., 2011). Compared to the general population, adults between the ages of 25 and 34 with a pediatric-onset injury graduate from college with a degree at equal or higher rates (Hwang et al., 2014b; Vogel et al., 2011). However, this medical population's employment rate (42-69%) is significantly lower than the general population's rate (93-94%) for young adults between 25 and 34 years old

(Vogel et al., 2011). Despite this discrepancy, individuals with pediatric-onset SCI have significantly greater employment outcomes than those with adult-onset SCI (Vogel et al., 2011). Individuals with pediatric-onset SCI are employed in a variety of fields including education, law, community service, business and finance, computer engineering, and healthcare (Hwang et al., 2015). The majority of those employed in this patient population demonstrate strong job satisfaction (Hwang et al., 2015). Overall, level of physical functioning and education are related to the type of occupations that individuals with pediatric-onset SCI ultimately choose (Hwang et al., 2015). In addition, those who are married demonstrate greater independence and social integration, which are also related to stronger employment (Hwang et al., 2015).

The majority of research on physical, psychological, and social outcomes in SCI has explored individuals who incur an injury during adulthood, but there are significant differences between pediatric-onset and adult-onset injuries (Zebracki & Vogel, 2012). Specifically, children and adolescents at the time of their injuries have developed less independence, while many adults who experience injuries are more likely to have already demonstrated more autonomy and control over their lives. This may impact participation in adulthood. Those who experience pediatric-onset SCI transition to adulthood having experienced their lives with SCI for at least some part of their youth. Because of differences between the experiences of individuals with pediatric- and adult-onset SCI, there is a need to better examine the adult outcomes and developmental trajectories of individuals who sustain SCI in childhood or adolescence.

Current Study

Pediatric-onset SCI is a complex medical condition, in which individuals must cope with the challenges of physical disability from their youth through adulthood. Injuries that occur in childhood come with additional complications that may lead to differences in long-term

psychosocial outcomes in comparison to the larger SCI population. Pain may be one specific complication that affects pediatric-onset SCI differently, as individuals must learn to cope with pain earlier in life and live with it for more years than individuals with adult-onset injuries. A contextual-behavioral model of empowerment offers a socioecological approach to SCI that focuses on individual-environment interaction, and community participation is a key factor affected by an interaction between individual characteristics and the environment. Focusing on participation in the form of mobility, social integration, and occupational functioning may be an important mechanism for improving psychosocial outcomes in this population. A socioecological approach may provide greater insight into the relationship between medical complications and psychosocial outcomes, exploring the impact of complications such as pain and pressure injuries, as well as which individuals experience positive outcomes despite experiencing additional medical issues. Positive coping strategies (e.g., religion, use of emotional support, and acceptance) may facilitate greater participation and provide valuable information for patient care in rehabilitation and the larger health care system.

The current study uses a longitudinal dataset to explore the effects of medical complications such as pain severity and pressure injuries on community participation, and community participation on depression, anxiety, SWL, and PTG outcomes over time. The study also explores the relationship between medical complications and psychosocial outcomes. Moreover, the current study examines the effect of specific components of participation (e.g., mobility, social integration, & occupation) on psychosocial outcomes over time to better understand the most influential aspects of participation. In addition, positive coping strategies (e.g., religion/spirituality, the use of emotional support, & acceptance) are examined as moderators for the relationships between medical complications and participation to better

understand how coping may affect the relationship. The following specific hypotheses were tested to investigate these relationships:

Research Hypotheses

1a. Decreased pain severity will be associated with increased community participation over time.

Figure 1. Summary of Hypothesis 1a



1b. Experiencing a pressure injury within the past year will be associated with decreased community participation over time.

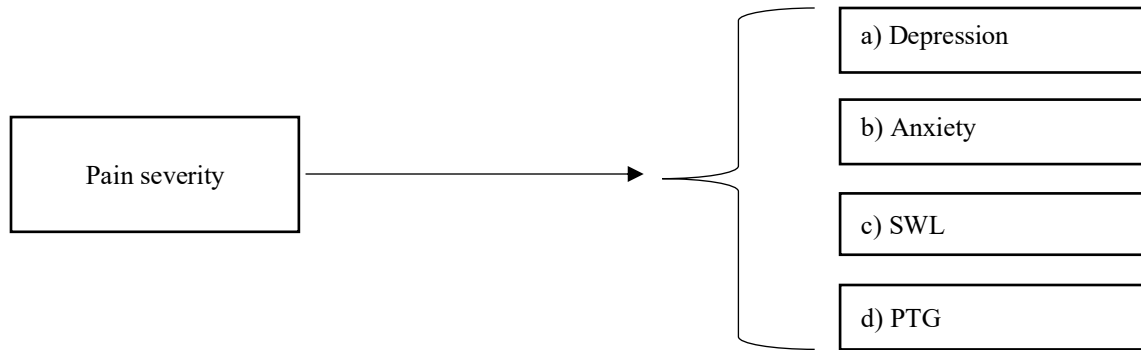
Figure 2. Summary of Hypothesis 1b



2. Decreased pain severity will be related to the following outcomes over time:

- a) Decreased depression symptoms
- b) Decreased anxiety symptoms
- c) Increased SWL
- d) Increased PTG

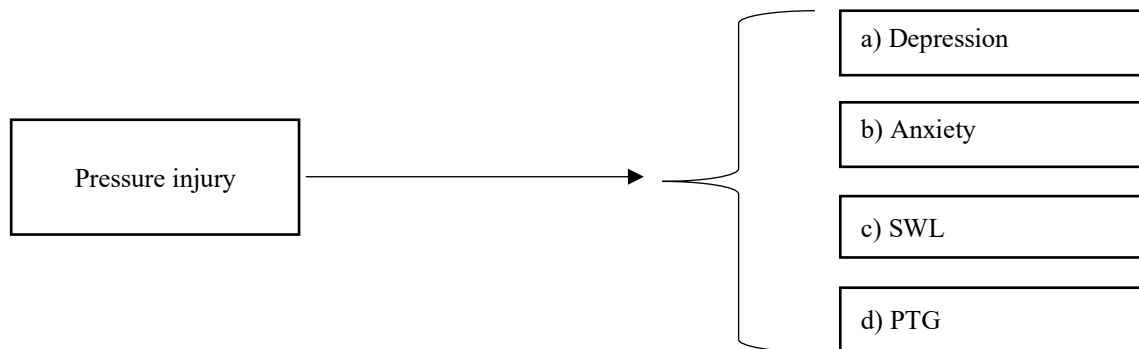
Figure 3. Summary of Hypotheses 2a-d



2. Experiencing a pressure injury within the same year will be related to the following outcomes over time:

- e) Increased depression symptoms
- f) Increased anxiety symptoms
- g) Decreased SWL
- h) Decreased PTG

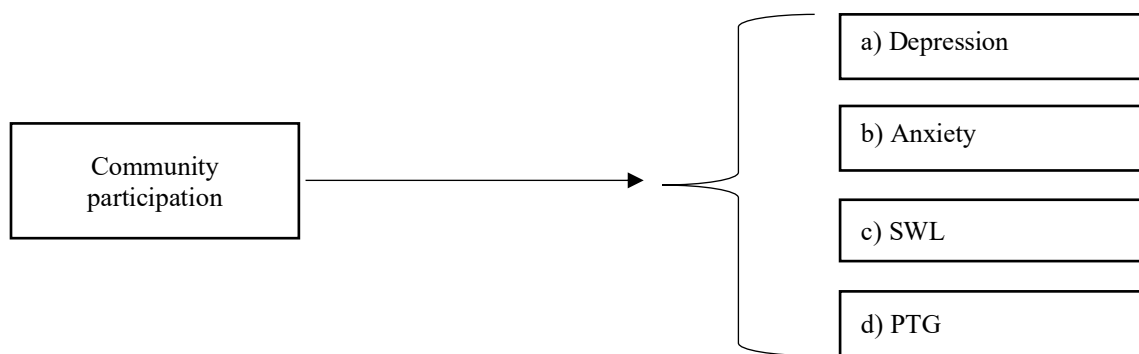
Figure 4. Summary of Hypothesis 2e-h



3. Increased community participation will be related to the following outcomes over time:

- a) Decreased depression symptoms
- b) Decreased anxiety symptoms
- c) Increased SWL
- d) Increased PTG

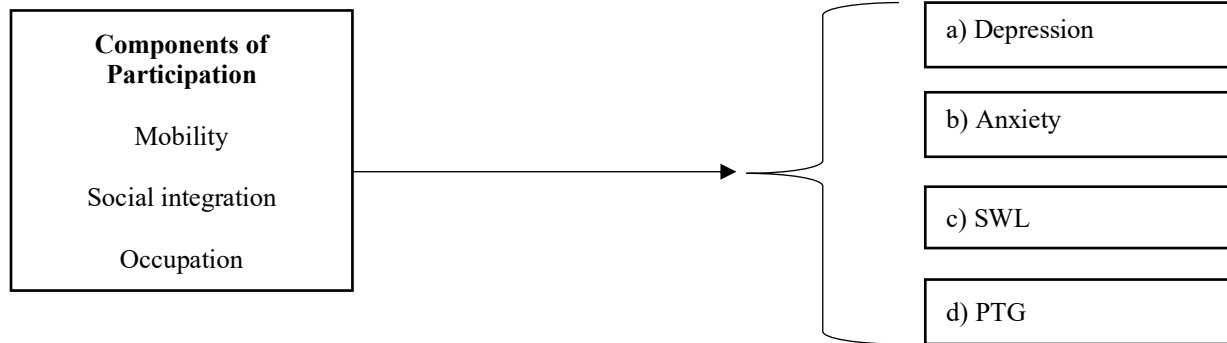
Figure 5. Summary of Hypothesis 3



4. Increased levels of participation in the form of mobility, social integration, and occupational functioning will be related to the following outcomes over time:

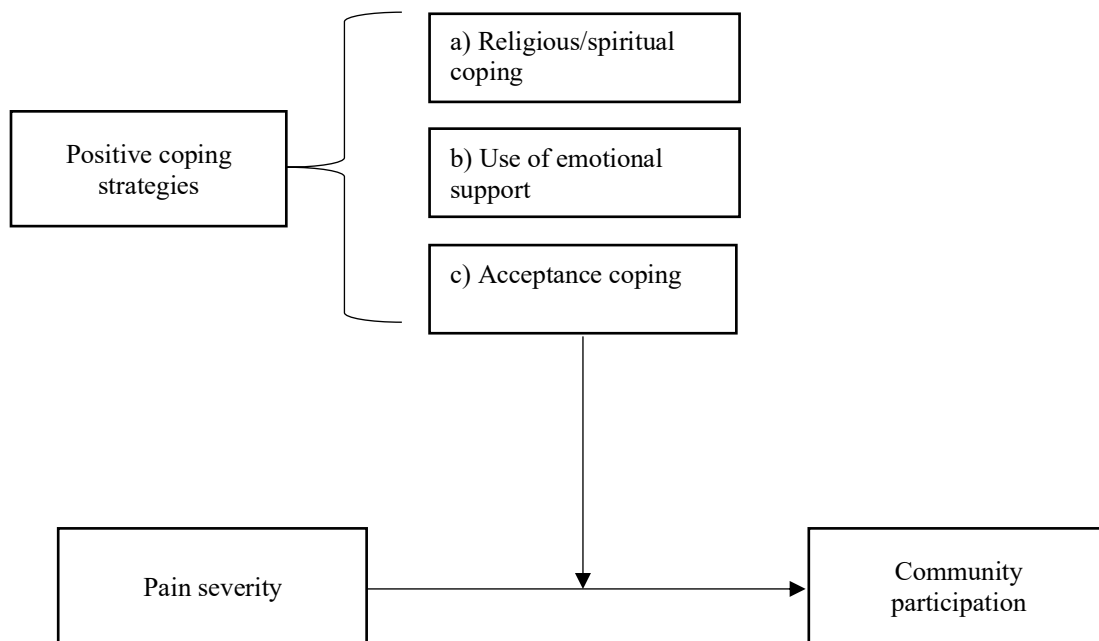
- a) Decreased depression symptoms
- b) Decreased anxiety symptoms
- c) Increased SWL
- d) Increased PTG

Figure 6. Summary of Hypothesis 4.



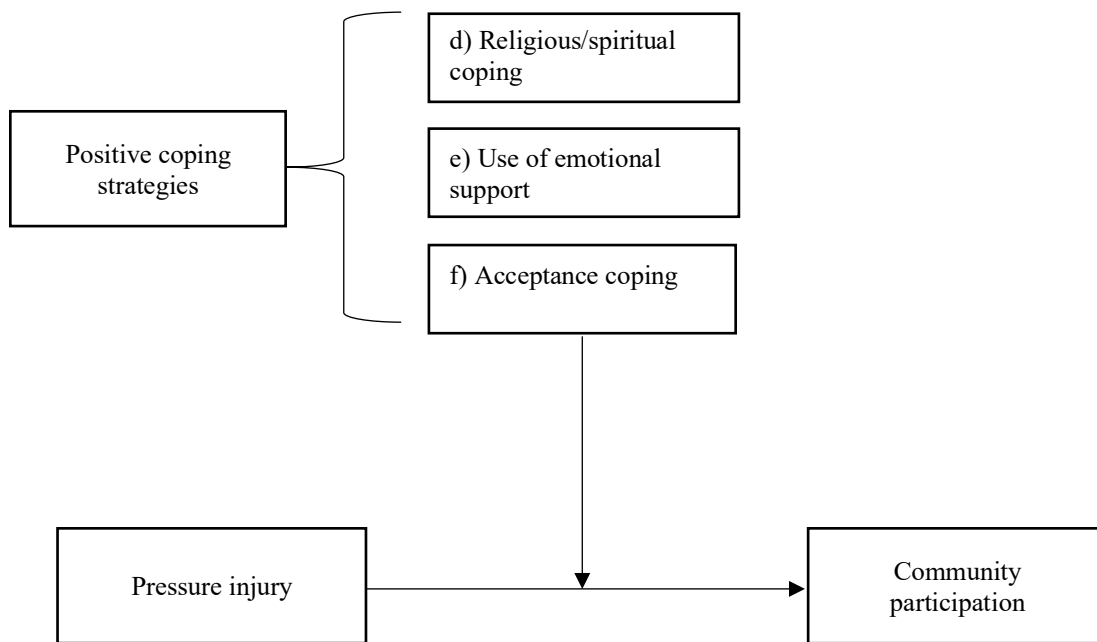
5a - 5c. Each positive coping strategy (e.g., religious/spiritual coping, use of emotional support, and acceptance) will moderate the relationship between pain severity and community participation over time. High levels of positive coping strategies will attenuate the effect of increased pain severity on decreased participation.

Figure 7. Summary of Hypothesis 5a - 5c



5d - f. Each positive coping strategy (e.g., use of emotional support, religious/spiritual coping, and acceptance) will moderate the relationship between experiencing a pressure injury within the past year and community participation over time. High levels of positive coping strategies will attenuate the effect of experiencing a pressure injury within the past year on decreased participation.

Figure 8. Summary of Hypothesis 5d - 5f



Methods

Participants

Participants were individuals with pediatric-onset SCI who were involved in a continuous, longitudinal research project that began in 1996. The study measures have been revised since the study's start time to examine additional variables related to long-term functioning of individuals with pediatric-onset injuries. Participants completed approximately annual, structured interviews that assess medical, psychological, and socioemotional outcomes. All participants received pediatric care through Shriners Hospitals for Children at one of three

locations, which have catchment areas across the United States, Canada, and Mexico. Although most participants came from across the U.S., some participants were international patients at the hospital. However, individuals must have been English-speaking to participate. While there are a total number of 502 participants enrolled in the study, the current study utilized a subset of 180 participants that received at least two interviews from 2010 to 2019 when all relevant variables were being collected. Individuals had between 2 and 9 interviews with 138 participants having at least three, 94 having at least four, 70 having at least five, 55 having at least six, 38 having at least seven, 13 having at least eight, and three having all nine interviews. Because the larger study is ongoing, individuals' baseline interviews for the current study were not taken at the same time.

All participants were at least 19 years old at their first time point and individuals sustained their SCI between 0 and 18 years old. The average age at the time of their baseline interview was about 33 years old. Approximately 63.3% of the sample was male and the majority of participants were White (83.3%). Of the participants who did not identify as White, 8.3% identified as Hispanic/Latinx, 5.6% as African American, 2.2% as Asian, and 0.6% as American Indian. The average age at the time of injury was 13.42 years old and the average duration of injury at participants first interview was 19.11 years. The most common etiology in the sample was vehicular or pedestrian accidents (49.4%), followed by sports injuries (23.3%), medical/surgical causes (12.2%), falling or flying objects (8.9%), and violence (6.1%). About 56.7% of participants have injuries that resulted in tetraplegia, compared to paraplegia (43.3%). The majority of injuries were also complete (70.6%), resulting in no sensory or motor functioning below the level of injury. The sample is consistent with data from the larger study. Some analyses utilize a subset of this sample (158 participants) because PTG was only recorded

for those whose injuries occurred after age 6. The demographics for this subset are similar to the sample of 180 participants with the exception of higher average age at the time of injury (14.69 years), average duration of injury (21.06 years), and fewer injuries from medical/surgical causes (8.1%). Overall, the sample is representative of pediatric-SCI in the general population, with the exception of race, as the current study's sample has a greater number of White participants than would be expected given the larger pediatric-SCI population (~60 to 70%; Zebracki & Vogel, 2012).

Measures

The survey instrument included questions about demographic information including gender, race and ethnicity, education, and marital status. Medical charts were utilized prior to the current study to determine information related to SCIs including level of injury, completeness, etiology, and age of onset. SCIs were classified according to the International Standards for the Neurological Classification of Spinal Cord Injury guidelines (ASIA, 2019).

Demographic Information/Injury Characteristics

At baseline, participants reported on demographic information that included gender, age, race and ethnicity, educational attainment, marital status, and work status. Injury characteristics reported include age at the time of injury, level of injury (paraplegia versus tetraplegia), impairment level (complete versus incomplete), etiology, and the presence of secondary health conditions, such as muscle spasms, urinary tract infections, and bowel and bladder incontinence. Participants also reported if they were in counseling for mental health concerns and/or taking antidepressants.

Pain

The general level of pain intensity was determined by asking participants at each visit to answer the following question: “In general, what is the level of your pain from 0-10?” On the scale, 0 represents “no pain” while 10 represents “very intense pain.” This is an example of a Number Rating Scale (NRS) that has strong evidence for construct validity. It is easy to score and administer and has been demonstrated to be especially effective for telephone interviews, when visual cues cannot be provided (Von Korff et al., 2000). Pain intensity has frequently been measured using this scale in medical settings and for research studies. NRS scales have been compared to a number of pain intensity measures including the Visual Analogue Scale (VAS), the 6-point Behavioral Rating Scale (BRS-6), and 4- and 5-point Verbal Rating Scales (VRS), and have similar results and predictive validity (Jensen et al., 1986). In addition, NRS measures show responsiveness to medical treatments that affect pain (Jensen & Karoly, 2001).

Pressure Injuries

Pressure injuries were measured with a dichotomous yes/no question. At each time point, participants were asked, “In the past year, have you had a pressure ulcer?” Participants received a score of 1 if they answered “yes” and 0 if they answered “no.”

Community Participation

Participation and integration were assessed through items of the revised Craig Handicap Assessment & Reporting Technique (CHART), a measure that was created to better assess rehabilitation outcomes (Hall et al., 1998; Whiteneck et al., 1992; see Appendix A). The CHART measures the extent to which impairment and disability relate to participation through six major domains (e.g. physical independence, cognitive independence, mobility, occupation, social integration, and economic self-sufficiency). Participants receive a score between 0 and 100 for each domain in which higher scores indicate greater independence and participation and 100

indicates an absence of “handicap.” Each of the six scores from the major domains are added to create a total score ranging from 0 to 600. The CHART demonstrates strong test-retest reliability ($r = .93$), as well as strong validity as demonstrated by analyses that explored the scores of low-participation and high-participation individuals with SCI (Whiteneck et al., 1992). The current study utilizes three of the six major domains which highlight community-based participation and engagement, each of which demonstrates acceptable reliability: mobility ($r = .95$), occupation ($r = .89$), and social integration ($r = .81$; Whiteneck et al., 1992).

Because the instrument was originally intended to detect whether “handicap” was present, the highest score for each domain was capped at 100 (Whiteneck et al., 1992). Due to this ceiling effect with the CHART in which 44.5% of participants in the current study received the maximum score of 100 on occupation, 50.0% on mobility, and 61.4% on social integration, the measure was adapted to provide more variability across participants and assess higher levels of participation on the three individual domains. The ranges for these domains were expanded by removing the maximum cut-off at 100. Because the new maximum score for each domain was different from one another, standardized z-scores were used for each domain. A composite score for occupation, mobility, and social integration was calculated by averaging the three relevant z-scores from individual domains. The standardized z-score composite of participation was utilized for analyses in Hypotheses 1, 2, and 5. Analyses for Hypothesis 4 explored standardized z-scores of each of the three relevant domains separately.

Depression

The Patient Health Questionnaire (PHQ-9), which is a 9-item self-report depression screen based on the DSM-IV depression criteria, was utilized to measure depressive symptoms (Kroenke et al., 2001; see Appendix B). The PHQ-9 asks participants about nine problems and

how often they occurred over the past two weeks. Each item is answered on a scale of 0 to 3 where 0 represents “not at all,” 1 represents “several days,” 2 represents “more than half the days,” and 3 represents “nearly every day.” Scores range from 0 to 27, where higher scores represent greater levels of depression symptomology. The PHQ-9 has strong internal consistency ($\alpha = .89$) and test-retest reliability ($r = .84$) as well as criterion and construct validity (Kroenke et al., 2001).

Anxiety

The current study utilized the Beck Anxiety Inventory (BAI) to measure symptoms of anxiety. The measure is a 21-item self-report measure, in which the participant is provided a list of 21 symptoms and must determine the frequency of that symptom “during the past week, including today” (Beck et al., 1988; see Appendix C). Participants must rate each symptom on a scale of 0 to 3, in which 0 indicates that the symptom was experienced “not at all,” 1 indicates “Mildly-It did not bother me much,” 2 indicates “Moderately-It was very unpleasant,” and 3 indicates “Severely-I could barely stand it.” The overall score ranges from 0 (indicating no symptoms reported) to 63 (indicating all symptoms were experienced and rated as “severe”; Beck et al., 1988). The measure demonstrates acceptable test-retest reliability ($r = .75$) over one week and strong internal consistency ($\alpha = .92$; Beck et al., 1988). The BAI also demonstrates appropriate convergent validity with other measures of anxiety such as Diary Anxiety and divergent validity with measures of depression (Fydrich et al., 1992).

Satisfaction with Life

SWL was measured using the self-report Satisfaction with Life Scale (SWLS), a 5-item scale that demonstrates strong psychometric properties including high temporal reliability and internal consistency (Diener et al., 1985; see Appendix D). The measure assesses global life

satisfaction and is correlated with various measures of subjective well-being (Diener et al., 1985). Participants respond to five statements on a scale of 1 (strongly disagree) to 7 (Strongly agree) and a total score is calculated by adding the scores from each of the participant's responses. Some example items include "In most ways my life is close to my ideal" and "I am satisfied with my life."

Posttraumatic Growth

Posttraumatic growth was assessed through the self-report Posttraumatic Growth Inventory (PTGI), which is a 21-item instrument with strong internal consistency ($\alpha = .90$) and acceptable test-retest reliability ($r = .71$; Tedeschi & Calhoun, 1996; see Appendix E). The 21 items map onto five major factors that include personal strength, relating to others, new possibilities, appreciation of life, and spiritual change (Tedeschi & Calhoun, 1996). Respondents provide a score from 0 to 5 for each item in which 0 represents "I did not experience this change as a result of my SCI" and 5 represents "I experienced this change to a very great degree as a result of my SCI." A total score is calculated by adding participants' scores on each of the individual items. The measure was only used for individuals who incurred their injuries after age 6, as earlier injuries may make reflection on changes from before their injuries challenging. The current study examined the total PTGI score as a dependent variable.

Coping

Specific components of coping were measured through the Brief Cope, which is an adapted measure from the frequently-used COPE inventory (Carver, 1997; see Appendix F). The Brief Cope is a 28-item measure that explores 14 types of positive and negative coping and demonstrates acceptable reliability. Researchers are not required to administer the entire instrument and are instead able to choose specific areas of interest (Carver, 1997). This version

of the measure specifically asked participants about coping with their injuries. The current study explored two items that measure the “use of emotional support” ($\alpha = .71$), two items that measure “religion/spirituality,” ($\alpha = .82$), and two items that measure “acceptance” ($\alpha = .71$; Carver, 1997). While the reliability is not as strong for “acceptance” compared to “use of emotional support” and “religion/spirituality,” this form of coping has been shown to be especially important in the SCI population (Anderson et al., 2008) and the reliability is considered to be minimally acceptable (Carver, 1997). The following items were used to measure “use of emotional support”: 1) I get emotional support from others. 2) I get comfort and understanding from someone. The following items were used to measure “religion/spirituality”: 1) I try to find comfort in my religion or spiritual beliefs. 2) I pray or meditate. The following items were used to measure “acceptance”: 1) I accept the reality of the fact that it has happened. 2) I learn to live with it. For each item, participants respond with a number from 1 to 4 in which 1 indicates “I don’t do this at all,” 2 indicates “I do this a little bit,” 3 indicates “I do this a medium amount,” and 4 indicates “I do this a lot.” Overall scores for components of coping were calculated by adding the scores from the two associated items. The current study included coping as a categorical variable. Composite scores for each type of coping that fell between 2 and 5 indicated “low usage” of the coping strategy and scores between 6 and 8 indicated “high usage” of the coping strategy.

Procedures

The current project utilized data from an ongoing longitudinal study approved through the Western Institutional Review Board. Researchers followed all relevant institutional and governmental guidelines and regulations for working ethically with human participants. Study

participants completed annual telephone or in-person interviews. Prior to interviews, researchers attained informed consent. Participants did not receive compensation for involvement.

Data Analysis Plan

Preliminary Analyses

Descriptive statistics and correlations were explored for all variables. Data was analyzed for kurtosis, skewness, and extreme outliers. Demographic variables and injury characteristics including gender, age, race and ethnicity, education attainment, marital status, age at the time of injury, level of injury (paraplegia versus tetraplegia), level of impairment (complete versus incomplete), etiology, the presence of common secondary health complications (e.g. muscle spasms, urinary tract infections, bowel and bladder control), participation in mental health counseling, and use of antidepressants were explored in relation to primary variables. Relevant demographic variables and injury characteristics significantly related to at least one of the dependent variables or indicated by previous research were controlled for in primary analyses.

Primary Analyses

Hierarchical linear modeling (HLM) with restricted maximum likelihood estimation was the primary method for analyzing hypotheses due to the use of multiple time points and repeated measurements over time. HLM allows for time (Level 1) to be nested within the individual (Level 2), taking advantage of all existing data points and providing greater degrees of freedom and power. HLM is also a beneficial approach for uneven datasets in which participants are not all assessed at a uniform time (Woltman et al., 2012). For the current study, years since baseline was used to measure time to best account for inconsistency in timing across individuals' interviews. It is assumed that data are missing at random. HLM does not use listwise deletion for Level 1 missing data, and therefore, data imputation was not necessary. However, HLM treats

missing data on Level 2 differently and excludes participants who have missing data on Level 2 variables.

Hypothesis 1

Hypothesis 1 addressed the relationship between medical complications (i.e., pain severity and pressure injury) and community participation over time using an HLM model that accounts for medical complications as Level 1 variables (measured at each time point). This hypothesis includes two models, one using pain severity as the main independent variable and one using pressure injury as the main independent variable. The HLM equation using pain severity as the main independent variable looks as follows:

$$\text{Level 1: (Participation)}_{ti} = \pi_{0i} + \pi_{1i}(\text{Time})_{ti} + \pi_{2i}(\text{Pain Severity})_{ti} + e_{ti}$$

$$\text{Level 2: } \pi_{0i} = \beta_{00} + r_{0i}$$

$$\pi_{1i} = \beta_{10} + r_{1i}$$

$$\pi_{2i} = \beta_{20} + r_{2i}$$

Hypothesis 2

The second hypothesis focused on the relationship between medical complications (e.g., pain severity and pressure injury) and the major psychosocial outcomes. Four HLM analyses were run exploring the effect of pain severity on each of the outcomes (e.g., depression, anxiety, SWL, and PTG) and four HLM analyses were run exploring the effect of pressure injury on each of the outcomes (e.g., depression, anxiety, SWL, and PTG). Below is an example of an HLM equation for Hypothesis 3 with pain severity as the predictor and depression as the outcome variable.

$$\text{Level 1: (Depression)}_{ti} = \pi_{0i} + \pi_{1i}(\text{Time})_{ti} + \pi_{2i}(\text{Pain Severity})_{ti} + e_{ti}$$

$$\text{Level 2: } \pi_{0i} = \beta_{00} + r_{0i}$$

$$\pi_{1i} = \beta_{10} + r_{1i}$$

$$\pi_{2i} = \beta_{20} + r_{2i}$$

Hypothesis 3

The next hypothesis explored the relationship between community participation and the major psychosocial outcomes. In total, four separate HLM analyses were run, one for each of the outcomes (e.g., depression, anxiety, SWL, and PTG). The following is an example of an HLM equation for Hypothesis 2 with depression as the outcome variable:

$$\text{Level 1: (Depression)}_{ti} = \pi_{0i} + \pi_{1i}(\text{Time})_{ti} + \pi_{2i}(\text{Participation})_{ti} + e_{ti}$$

$$\text{Level 2: } \pi_{0i} = \beta_{00} + r_{0i}$$

$$\pi_{1i} = \beta_{10} + r_{1i}$$

$$\pi_{2i} = \beta_{20} + r_{2i}$$

Hypothesis 4

To address the fourth hypothesis, the relationship between the three relevant components of participation (e.g. mobility, social integration, and occupation) and the major psychosocial outcomes (e.g. depression, anxiety, SWL, and PTG) were explored. Separate HLM analyses were utilized to determine if specific components of participation are related to each of the major psychosocial outcomes. An example of HLM equations for examining the relationship between occupation, mobility, and social integration on depression over time is listed below.

$$\text{Level 1: (Depression)}_{ti} = \pi_{0i} + \pi_{1i}(\text{Time})_{ti} + \pi_{2i}(\text{Occupation})_{ti} + \pi_{3i}(\text{Mobility})_{ti} + \pi_{4i}(\text{Social Integration})_{ti} + e_{ti}$$

$$\text{Level 2: } \pi_{0i} = \beta_{00} + r_{0i}$$

$$\pi_{1i} = \beta_{10} + r_{1i}$$

$$\pi_{2i} = \beta_{20} + r_{2i}$$

$$\pi_{3i} = \beta_{30} + r_{3i}$$

$$\pi_{4i} = \beta_{40} + r_{4i}$$

Hypothesis 5

To explore whether forms of positive coping such as use of emotional support, religious/spiritual coping, and acceptance buffer against the negative effects of medical complications (e.g., pain severity and pressure injury) on participation, separate HLM analyses were utilized to determine main and interaction effects for each medical complication and form of coping. In total, hypothesis 5 included six HLM models, three with pain severity as the main predictor and three with pressure injury as the main predictor. Medical complications and participation were considered Level 1 variables because they were measured at each time point while forms of coping were considered Level 2 variables, as scores were based on participants' baseline time points only. This is consistent with literature that indicates many forms of coping are consistent over time (Kennedy et al., 2000). The following represents an example of HLM equations for examining the use of religious/spiritual coping as a moderator in the relationship between pain severity and participation over time.

$$\text{Level 1: (Participation)}_{ti} = \pi_{0i} + \pi_{1i}(\text{Time})_{ti} + \pi_{2i}(\text{Pain Severity})_{ti} + e_{ti}$$

$$\text{Level 2: } \pi_{0i} = \beta_{00} + \beta_{01}(\text{Religion/spirituality}) + r_{0i}$$

$$\pi_{1i} = \beta_{10} + \beta_{11}(\text{Religion/spirituality}) + r_{1i}$$

$$\pi_{2i} = \beta_{20} + \beta_{21}(\text{Religion/spirituality}) + r_{2i}$$

Each of the analyses explored relationships involving medical complications (e.g., pain severity and pressure injury), participation, and/or psychosocial variables (e.g., depression, anxiety, SWL, and PTG). The first analysis explored the relationship between medical complications and participation over time. The second analysis explored the relationship between

participation and each of the psychosocial outcome variables. The third analysis explored the relationship between medical complications and each of the psychosocial outcome variables. The fourth analyses focused on the relationships between specific components of participation (e.g. occupation, mobility, and social integration) and psychosocial outcomes. The final analysis examined positive coping strategies (e.g., emotional support, religious/spiritual coping, and acceptance) as moderators for the relationship between medical complications and participation.

Results

Preliminary Results

All main variables in the study were tested for skewness and kurtosis to assess the assumption of normality in HLM. Pain severity, SWL, PTG, and the adapted participation composite demonstrated skewness and kurtosis within normal limits. Depression scores were generally positively skewed, ranging from .56 to 2.63 across time points. Kurtosis was variable across time points, ranging from -.68 to 9.87. Anxiety scores were also positively skewed, ranging from 1.97 to 4.20 across time points. Kurtosis was leptokurtic across time points, ranging from 3.34 to 23.69. Natural log transformations were performed to improve skewness and kurtosis for anxiety and depression, allowing for inclusion as dependent variables in HLM. Some models utilized binomial independent variables including pressure injuries and coping. Control variables included in primary models were also dichotomous. HLM allows for the use of dichotomous independent variables.

Table 1 provides descriptive statistics for all major variables measured at all time points. Overall, participants in the study reported relatively low levels of both depression and anxiety compared to what would be expected in the larger SCI population (e.g., Hoffman et al., 2011; Post & Leeuwen, 2012). At baseline, 137 participants (76%) reported no or minimal depressive

symptoms (score of 0 to 4), 26 (14%) reported mild depressive symptoms (score of 5-9), and 14 (8%) reported moderate to severe depressive symptoms (score greater than 9 and often used as the clinical cutoff for major depressive disorder). This is consistent with national estimates of depression among U.S. adults aged 20 and over (8.1%; Brody et al., 2018). For anxiety, 148 participants (82%) reported no significant anxiety symptoms (score of 0 to 7), 21 (12%) reported mild anxiety symptoms (score of 8 to 15), and nine (5%) reported moderate to severe anxiety symptoms (score greater than 15). While estimates of the prevalence of anxiety disorders vary across studies, these scores appear to be more consistent with the lower end of those estimates (Remes et al., 2016). Participants also generally reported high levels of SWL at baseline with 86 participants reporting that they were satisfied or extremely satisfied (48%) and 35 reporting that they were slightly satisfied (19%). The participation composite score was calculated by standardizing scores based on the sample's mean, so that 0 represents the average participation score across all interviews (individual time points). The three subscales (Mobility, Occupation, and Social Integration) are represented as mean total scores after the ceiling score of 100 was removed for each subscale. Scores at 100 and above indicate no handicap and higher levels of participation. The three coping variables utilized in the study (e.g., acceptance, religion/spirituality, and emotional support) were explored at baseline as level 2 variables in hypothesis 5 models. The mean acceptance score for participants at baseline was 7.62 with 173 participants (96.1%) reporting high levels of acceptance coping. The mean religion/spirituality score at baseline was 5.09 with 89 participants (49.4%) reporting high levels of religion/spirituality coping. The mean emotional support score at baseline was 5.68 with 100 participants (55.6%) reporting high levels of emotional support coping.

Table 1. Means and Standard Deviations for Main Variables at Each Year After Baseline

	Baseline N=180	1 N=116	2 N=112	3 N=95	4 N=77	5 N=71	6 N=60	7 N=36	8 N=24
Pain severity	3.83 (2.51)	3.47 (2.41)	3.78 (2.51)	3.31 (2.36)	3.53 (2.55)	3.61 (2.19)	3.25 (2.39)	3.39 (2.32)	3.29 (2.63)
Pressure Injury	.28	.28	.32	.31	.23	.37	.33	.25	.25
Participation - Composite	.03 (.74)	-.06 (.80)	.04 (.80)	.02 (.85)	.05 (.77)	-.05 (.86)	.09 (.83)	-.06 (.88)	.10 (.78)
Participation – Mobility	94.80 (23.16)	93.52 (22.69)	96.69 (21.62)	95.83 (23.81)	97.29 (19.85)	91.89 (23.91)	97.78 (21.05)	91.83 (20.84)	96.92 (17.70)
Participation – Occupation	91.94 (52.64)	85.27 (55.77)	95.16 (57.06)	88.03 (50.14)	91.46 (56.02)	91.73 (60.04)	108.18 (69.03)	89.53 (65.13)	92.83 (57.51)
Participation -Social Integration	107.55 (23.20)	105.94 (25.07)	106.11 (24.63)	107.17 (28.09)	106.74 (24.57)	106.48 (24.56)	102.72 (26.40)	106.56 (25.51)	109.52 (25.30)
Depressive symptoms	2.96 (4.03)	2.94 (3.44)	2.51 (3.43)	4.16 (5.09)	3.51 (3.47)	2.87 (4.01)	3.12 (3.81)	3.67 (4.26)	2.75 (2.72)
Anxiety symptoms	3.88 (6.35)	3.21 (6.04)	2.72 (4.13)	4.17 (6.62)	3.86 (5.77)	3.01 (5.01)	3.75 (7.05)	3.53 (6.91)	4.46 (7.20)
SWL	23.79 (7.31)	24.47 (7.00)	24.13 (6.78)	23.45 (7.65)	22.83 (7.43)	23.65 (7.76)	24.33 (7.70)	23.28 (7.38)	22.04 (6.97)
PTG	61.62 (24.81)	61.15 (24.56)	61.92 (22.56)	59.09 (20.21)	58.22 (20.12)	62.55 (21.07)	58.80 (23.77)	66.00 (21.50)	63.35 (22.00)

Note. SWL = Satisfaction with life; PTG = Posttraumatic growth

Table 2 provides correlations at baseline for all continuous variables of interest. Tables 3 through 11 provide correlations between each of the continuous independent variables and each of the dependent variables across time points.

Table 2. Correlations Among Demographics, Injury Characteristics, and Study Variables at Baseline

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1. Age	-	.82**	.14	-.09	-.19*	-.05	.04	.15*	-.06	-.05	-.14	.02	.23*	.09
2. Duration of injury		-	.06	-.07	-.12	-.02	.00	.13	-.16*	.02	-.15	.07	.17*	.08
3. Pain Severity			-	-.26**	-.34**	-.20**	-.09	.26**	.20**	-.14	.10	.03	.13	.08
4. Participation – Composite				-	.79**	.80**	.74**	-.24**	-.16*	.38**	-.10	.09	-.03	.01
5. Participation – Mobility					-	.46**	.32**	-.18*	-.12	.23**	-.06	-.07	-.08	-.08
6. Participation – Occupation						-	.41**	-.19**	-.08	.31**	-.01	.10	-.06	.02
7. Participation – Social Integration							-	-.21**	-.15*	.32**	-.15	.16*	.04	.12
8. Depression symptoms								-	.52**	-.45**	.04	-.19*	.02	.06
9. Anxiety symptoms									-	-.36**	.14	-.13	.02	.04
10. SWL										-	.11	.30**	.17*	.14
11. PTG											-	.08	.32**	.22**
12. Coping – Acceptance												-	.10	.22**
13. Coping - Religious/Spiritual													-	.31**
14. Coping – Emotional Support														-

Note. **p < .01, *p < .05

SWL = Satisfaction with life; PTG = Posttraumatic growth

Table 3. Correlations Between Pain Severity and Community Participation (Composite Score) Over Time

	Pain Severity Baseline	Pain Severity Time 1	Pain Severity Time 2	Pain Severity Time 3	Pain Severity Time 4	Pain Severity Time 5	Pain Severity Time 6	Pain Severity Time 7	Pain Severity Time 8
Participation Baseline	-.26**	-.18	-.18	-.16	-.07	-.04	-.14	-.29	-.10
Participation Time 1	-.32**	-.16	-.14	-.07	-.06	-.18	-.28	-.27	.02
Participation Time 2	-.31**	-.13	-.15	-.10	-.08	-.20	-.26	-.29	-.06
Participation Time 3	-.33**	-.04	.10	-.19	-.12	-.22	-.06	-.30	-.12
Participation Time 4	-.25*	-.21	-.26	-.27	-.09	-.13	-.13	-.29	-.25
Participation Time 5	-.26*	-.25	-.22	-.37**	-.34*	-.27*	-.41*	-.26	-.02
Participation Time 6	-.23	-.15	-.28	-.07	.01	-.28	-.18	-.25	-.13
Participation Time 7	-.28	-.31	-.48**	-.26	.12	-.20	-.48*	-.43**	-.07
Participation Time 8	.05	-.30	-.26	-.38	-.11	-.30	-.21	-.20	-.15

Note. ** $p < .01$, * $p < .05$

Table 4. Correlations Between Pain Severity and Depression Symptoms Over Time

	Pain Severity Baseline	Pain Severity Time 1	Pain Severity Time 2	Pain Severity Time 3	Pain Severity Time 4	Pain Severity Time 5	Pain Severity Time 6	Pain Severity Time 7	Pain Severity Time 8
Depression Symptoms Baseline	.26**	.21*	.22*	.19	.21	.22	.25	.42*	.30
Depression Symptoms Time 1	.17	.15	.09	.12	-.03	.26	.28	.26	.40
Depression Symptoms Time 2	.15	.09	.12	.13	.06	.33*	.20	.00	.20
Depression Symptoms Time 3	.34**	.23	.03	.20	.10	.31*	.47**	.44*	.41
Depression Symptoms Time 4	.25*	.14	.16	.21	.21	.11	.15	.14	.28
Depression Symptoms Time 5	.08	.15	.09	.07	.11	.29*	.31	-.04	.05
Depression Symptoms Time 6	.37**	.21	.18	.40*	-.01	.22	.32*	.30	.40
Depression Symptoms Time 7	.40*	.22	.21	.23	.13	.28	.34	.34*	.32
Depression Symptoms Time 8	-.02	.17	.59*	.25	.30	.12	.06	.46	.37

Note. ** $p < .01$, * $p < .05$

Table 5. Correlations Between Pain Severity and Anxiety Symptoms Over Time

	Pain Severity Baseline	Pain Severity Time 1	Pain Severity Time 2	Pain Severity Time 3	Pain Severity Time 4	Pain Severity Time 5	Pain Severity Time 6	Pain Severity Time 7	Pain Severity Time 8
Anxiety Symptoms Baseline	.21**	.18	.17	.15	.13	.04	.10	.05	.17
Anxiety Symptoms Time 1	.13	.13	-.04	-.03	-.20	.21	-.09	.11	-.11
Anxiety Symptoms Time 2	.09	.06	.15	.15	-.06	.42**	.05	-.01	.04
Anxiety Symptoms Time 3	.29**	.39**	.08	.27**	.22	.20	.27	.35	.17
Anxiety Symptoms Time 4	.22	.22	.05	.16	.22	.34*	.15	.03	.03
Anxiety Symptoms Time 5	.13	.07	-.05	.10	.26	.31**	.53**	-.10	.27
Anxiety Symptoms Time 6	.22	.27	-.02	.15	.06	.15	.06	-.10	.11
Anxiety Symptoms Time 7	.16	.05	.02	.35	.02	.18	.01	.23	.14
Anxiety Symptoms Time 8	-.09	.42	.40	.16	.08	.04	.20	.29	.45*

Note. ** $p < .01$, * $p < .05$

Table 6. Correlations Between Pain Severity and Satisfaction with Life Over Time

	Pain Severity Baseline	Pain Severity Time 1	Pain Severity Time 2	Pain Severity Time 3	Pain Severity Time 4	Pain Severity Time 5	Pain Severity Time 6	Pain Severity Time 7	Pain Severity Time 8
SWL Baseline	-.14	-.12	-.09	-.13	.11	-.14	-.19	-.46**	-.55**
SWL Time 1	-.10	-.17	-.31**	-.07	.17	-.09	-.24	-.49**	-.40
SWL Time 2	-.17	-.22	-.13	-.09	.08	-.25	-.43**	-.43*	-.45
SWL Time 3	-.17	-.15	-.06	-.13	.11	-.27	-.13	-.47*	-.32
SWL Time 4	-.10	-.09	-.09	-.10	.05	-.24	-.25	-.44*	-.10
SWL Time 5	-.13	-.08	-.28*	-.29*	-.12	-.24*	-.27	-.30	-.19
SWL Time 6	-.25	-.23	-.32*	-.19	-.01	-.52*	-.24	-.59**	-.33
SWL Time 7	-.20	-.40*	-.26	-.25	.07	-.42*	-.47*	-.32	-.50
SWL Time 8	.07	-.38	-.53*	-.20	-.27	-.38	-.04	-.25	-.13

Note. ** $p < .01$, * $p < .05$

SWL = Satisfaction with Life

Table 7. Correlations Between Pain Severity and Posttraumatic Growth Over Time

	Pain Severity Baseline	Pain Severity Time 1	Pain Severity Time 2	Pain Severity Time 3	Pain Severity Time 4	Pain Severity Time 5	Pain Severity Time 6	Pain Severity Time 7	Pain Severity Time 8
PTG Baseline	.10	.26**	.04	.05	.30*	-.08	-.05	.12	-.04
PTG Time 1	.14	.24*	.11	.05	.15	.05	-.04	.03	-.15
PTG Time 2	.07	.07	-.02	.01	.25	-.15	-.09	.06	.24
PTG Time 3	.18	.23	.08	.05	.54**	-.04	-.13	-.04	-.28
PTG Time 4	.13	-.05	-.06	-.03	.29*	-.16	-.18	-.04	-.03
PTG Time 5	-.06	.05	-.02	-.17	.16	-.09	-.05	-.09	.18
PTG Time 6	-.01	.13	-.11	-.22	.06	-.12	-.09	.32	.49
PTG Time 7	-.35	-.19	-.19	-.48*	.09	-.31	-.60**	-.10	.01
PTG Time 8	-.06	.19	.17	-.05	-.11	.02	-.19	.44	.33

Note. ** $p < .01$, * $p < .05$

PTG = Posttraumatic Growth

Table 8. Correlations Between Community Participation (Composite Score) and Depression Symptoms Over Time

	Part Baseline	Part Time 1	Part Time 2	Part Time 3	Part Time 4	Part Time 5	Part Time 6	Part Time 7	Part Time 8
Depression Symptoms Baseline	-.24**	-.22*	-.23*	-.32*	-.28*	-.35**	-.34**	-.42*	-.20
Depression Symptoms Time 1	-.22*	-.21*	-.28*	-.38**	-.14	-.28*	-.29	-.27	-.12
Depression Symptoms Time 2	-.19*	-.17	-.23*	-.19	-.04	-.21	-.13	-.05	-.22
Depression Symptoms Time 3	-.41**	-.50**	-.29*	-.41**	-.36*	-.39**	-.45**	-.51**	-.34
Depression Symptoms Time 4	-.14	-.11	-.06	-.27	-.19	-.13	-.23	-.23	-.13
Depression Symptoms Time 5	-.06	-.19	-.17	-.26	-.14	-.25*	-.21	-.14	-.25
Depression Symptoms Time 6	-.28*	-.35*	-.11	-.40**	-.36*	-.47**	-.27*	-.38	.00
Depression Symptoms Time 7	-.20	-.27	-.13	-.43*	-.26	-.14	-.38	-.32	-.03
Depression Symptoms Time 8	-.05	-.14	-.20	-.31	-.33	-.46*	-.46	-.33	-.36

Note. ** $p < .01$, * $p < .05$

Part = Community Participation

Table 9. Correlations Between Community Participation (Composite Score) and Anxiety Symptoms Over Time

	Part Baseline	Part Time 1	Part Time 2	Part Time 3	Part Time 4	Part Time 5	Part Time 6	Part Time 7	Part Time 8
Anxiety Symptoms Baseline	-.16*	-.12	-.30**	-.17	-.19	-.26*	-.11	-.22	-.23
Anxiety Symptoms Time 1	-.14	-.04	-.15	-.14	-.11	-.09	.01	-.26	-.41
Anxiety Symptoms Time 2	-.15	-.14	-.20*	-.08	-.11	-.07	-.06	-.14	-.37
Anxiety Symptoms Time 3	-.28**	-.29*	-.19	-.22*	-.19	-.22	-.18	-.34	-.14
Anxiety Symptoms Time 4	-.04	.02	-.05	.04	-.07	-.02	.10	.11	-.19
Anxiety Symptoms Time 5	-.22	-.30*	-.31*	-.32*	-.04	-.37**	-.44**	-.06	-.24
Anxiety Symptoms Time 6	-.15	-.05	-.26	-.31*	-.05	-.38*	-.05	-.09	.01
Anxiety Symptoms Time 7	-.13	-.28	.01	-.29	.08	-.02	.03	-.25	-.17
Anxiety Symptoms Time 8	-.15	.00	-.15	-.27	-.38	-.43	-.45	-.40	-.27

Note. ** $p < .01$, * $p < .05$

Part = Community Participation

Table 10. Correlations Between Community Participation (Composite Score) and Satisfaction with Life Over Time

	Part Baseline	Part Time 1	Part Time 2	Part Time 3	Part Time 4	Part Time 5	Part Time 6	Part Time 7	Part Time 8
SWL Baseline	.38**	.27**	.35**	.39**	.39**	.38**	.46**	.45**	.46*
SWL Time 1	.40**	.36**	.39**	.27*	.42**	.18	.58**	.53**	.51*
SWL Time 2	.39**	.28*	.38**	.37**	.41**	.30*	.42**	.46*	.22
SWL Time 3	.39**	.20	.29*	.44**	.38**	.39**	.34*	.45*	.29
SWL Time 4	.38**	.21	.33*	.29	.38**	.39*	.41*	.40*	.41
SWL Time 5	.31*	.30*	.45**	.43**	.38*	.46**	.43**	.45*	.50*
SWL Time 6	.41**	.39*	.44**	.45**	.49**	.57**	.51**	.56**	.32
SWL Time 7	.30	.40*	.52**	.49*	.56**	.33	.42*	.45**	.34
SWL Time 8	.04	.10	.28	.29	.15	.43	.18	.45	.35

Note. ** $p < .01$, * $p < .05$

Part = Community Participation, SWL = Satisfaction with Life

Table 11. Correlations Between Community Participation (Composite Score) and Posttraumatic Growth Over Time

	Part Baseline	Part Time 1	Part Time 2	Part Time 3	Part Time 4	Part Time 5	Part Time 6	Part Time 7	Part Time 8
PTG Baseline	-.10	-.17	-.01	-.20	.00	-.22	.01	-.15	-.16
PTG Time 1	.03	-.01	.25*	-.05	.24	-.35*	.06	-.06	-.23
PTG Time 2	-.14	-.11	-.12	-.17	.00	-.20	.01	.00	-.26
PTG Time 3	-.37**	-.32*	-.08	-.20	.00	-.09	-.14	-.08	-.03
PTG Time 4	-.18	-.11	-.01	-.15	-.01	-.16	.16	.02	.11
PTG Time 5	-.20	.01	-.01	-.03	-.23	-.03	-.09	-.02	-.06
PTG Time 6	-.02	.10	-.03	.07	-.03	-.04	.06	.11	.07
PTG Time 7	-.08	.12	.20	.14	.25	.12	.08	.16	.03
PTG Time 8	-.58**	-.47	-.02	-.33	-.34	-.25	-.04	-.40	-.15

Note. ** $p < .01$, * $p < .05$

Part = Community Participation, PTG = Posttraumatic Growth

Independent samples t-tests were used for binary variables to explore mean differences across the main outcome variables (overall participation, depression, anxiety, SWL, and PTG). There were significant differences in participation based on race (White/non-White), as White participants ($M = .08$, $SD = .72$) reported higher participation scores than non-White participants ($M = -.30$, $SD = .76$; $t(172) = 2.47$, $p = .01$). There were also significant mean differences in participation and SWL based on level of injury (paraplegia/tetraplegia). Individuals with tetraplegia ($M = -.10$, $SD = .78$) had lower participation than individuals with paraplegia ($M = .17$, $SD = .65$; $t(172) = 2.47$, $p = .02$). Individuals with tetraplegia ($M = 22.59$, $SD = 7.27$) also had lower SWL scores than individuals with paraplegia ($M = 25.36$, $SD = 7.12$; $t(178) = 2.56$, $p = .01$). Participants who experienced a pressure injury in the past year ($M = -.27$, $SD = .74$) reported lower participation than participants who did not experience a pressure injury ($M = .13$, $SD = .71$; $t(172) = 3.22$, $p < .01$). Individuals who experienced a pressure injury in the past year ($M = .55$, $SD = .42$) also experienced higher depression scores than those who did not have a pressure injury ($M = .37$, $SD = .35$; $t(175) = -2.74$, $p = .01$). Similarly, individuals who experienced a pressure injury in the past year ($M = .55$, $SD = .48$) reported higher anxiety scores than individuals without pressure injuries ($M = .39$, $SD = .42$; $t(176) = -2.12$, $p = .04$). Further, individuals with pressure injuries in the past year ($M = 22.04$, $SD = 6.83$) reported lower SWL compared to individuals without pressure injuries ($M = 24.48$, $SD = 7.41$; $t(178) = 2.04$, $p = .04$). Participants who experienced muscle spasms that required medication in the past year ($M = -.13$, $SD = .76$) reported lower participation scores than participants who did not have spasms requiring medication in the past year ($M = .18$, $SD = .68$; $t(172) = 2.88$, $p = .01$). Participants with muscle spasms requiring medication in the past year also reported higher PTG ($M = 66.72$, $SD = 23.25$) than individuals who did not have spasms that required medication ($M = 56.04$, SD

= 25.41; $t(153) = -2.73, p = .01$). There were no significant mean differences across the main outcome variables for the following: gender, bowel accidents (no/yes), bladder accidents (no/yes), UTI requiring hospitalization in the past year (no/yes), and impairment level (complete/incomplete). One-way ANOVAs were completed to determine if there were mean differences across main outcome variables based on etiology of injuries, but no significant differences were found.

Marital status (single/married), employment status (unemployed/employed) and education (no college degree/college degree) were also explored to examine mean differences across outcome variables, but were not considered for subsequent analyses due to being a part of the calculation of the overall participation composite in the CHART. Participants who were married ($M = .48, SD = .55$) had higher participation compared to participants who were not married ($M = -.20, SD = .71; t(171) = -6.39, p < .01$). Married participants ($M = .33, SD = .36$) also had lower depression scores than non-married participants ($M = .46, SD = .38; t(174) = 2.14, p = .03$). In addition, married participants ($M = 27.37, SD = 5.31$) had higher SWL scores than non-married participants ($M = 22.07, SD = 7.54; t(177) = -4.77, p < .00$). Participants who were employed ($M = .44, SD = .58$) had higher participation than those who were unemployed ($M = -.44, SD = .69; t(148) = -8.49, p < .01$). Employed participants ($M = .29, SD = .32$) also reported lower depression scores than unemployed participants ($M = .53, SD = .39; t(150) = 4.20, p < .01$). Additionally, employed participants ($M = .31, SD = .37$) reported lower anxiety scores than unemployed participants ($M = .58, SD = .46; t(151) = 4.11, p < .01$). Employed participants had higher SWL scores ($M = 25.41, SD = 6.54$) than unemployed participants ($M = 22.21, SD = 7.67; t(153) = -2.81, p = .01$). Participants with a college degree or higher ($M = .19, SD = .70$) had higher participation than those without a college degree ($M = -.16, SD = .74; t(172) = -3.16, p <$

.01). Participants with a college degree or higher ($M = .37$, $SD = .40$) had lower anxiety scores than participants without a college degree ($M = .51$, $SD = .48$; $t(176) = 2.22$, $p = .03$).

Based on independent t-tests for level of injury and research that demonstrates injury characteristics as factors in determining participation (Fougeyrollas & Noreau, 2000) and psychosocial functioning (e.g., Khazaeipour et al., 2015, Post et al., 1998), level of injury (paraplegia versus tetraplegia) and level of impairment (complete versus incomplete) were controlled for in all subsequent primary analyses. Because there were significant differences in community participation between White and non-White participants at baseline, race as a dichotomous variable was included in subsequent analyses as well.

Primary Analyses

Primary analyses were completed using HLM. All level-1 predictors were lagged in the primary models to control for the effect of the previous time point. Participants who only had two time points and did not have data on the lagged predictors at baseline were excluded from analyses, as they did not have the necessary data to explore effects over time. All primary analyses excluded five participants who did not have complete data on their injury characteristics (e.g., missing data on complete versus incomplete injuries), as these were considered Level 2 control variables. One participant had missing data for Level 2 acceptance coping and was excluded from Hypothesis 5 models that utilized acceptance coping as a predictor. Models that include PTG as the dependent variable include only participants who incurred their injuries after 6 years old, and therefore have a smaller sample size. Time in the following models is included as years since baseline, where 0 represents participants at baseline. Intercept and slope were specified as random effects at Level 2 with unstructured covariance matrices for all models, allowing estimations of variance and covariance to come from the data and maximizing model

fit. Level 1 or repeated effects covariance matrices were specified as scaled identity across models.

Hypotheses 1a & 1b

Two separate HLM models were conducted to examine the relationship between each of the secondary medical conditions of interest (pain severity and pressure injuries) and community participation over time. Pain severity and pressure injuries were considered level-1 predictors, as they were measured at each time point. The community participation composite was a level-1 dependent variable. Contrary to hypothesis 1a, the effect of pain severity on community participation was not significant ($p = .42$; see Table 3). However, hypothesis 1b was confirmed, as there was a significant effect of experiencing a pressure injury in the past year on community participation in that experiencing a pressure injury was associated with lower community participation over time ($p = .02$; see Table 4). There was no main effect of time in either model. Level of injury was significant across both models, indicating that participants with tetraplegia reported lower levels of participation than those with paraplegia. Race was also significant across both models, indicating that White participants reported higher levels of participation than non-White participants.

Table 12. Hypothesis 1a: Pain Severity and Community Participation

n = 173	b (SE)	95% CI		t
		LL	UL	
Intercept	.23 (.11)	.02	.43	2.15*
Level 1				
Time	-.01 (.01)	-.03	.01	-1.15
Pain severity ^a	-.01 (.01)	-.02	.01	-.76
Level 2				
Level of injury ^b	-.27 (.12)	-.50	-.04	-2.27*
Level of impairment ^c	-.06 (.13)	-.32	.20	-.43
Race ^d	-.36 (.16)	-.66	-.05	-2.29*

Note. CI = Confidence interval, LL = Lower limit, UL = Upper limit

^a Lagged predictor

^b 0 = paraplegia, 1 = tetraplegia

^c 0 = complete, 1 = incomplete

^d 0 = White, 1 = non-White

** $p < .01$, * $p < .05$, + $p < .10$

Table 13. Hypothesis 1b: Pressure Injuries and Community Participation

n = 174	b (SE)	95% CI		t
		LL	UL	
Intercept	.23 (.10)	.03	.42	2.28*
Level 1				
Time	-.01 (.01)	-.03	.01	-.95
Pressure injury ^a	-.11 (.05)	-.20	-.02	-2.35*
Level 2				
Level of injury ^b	-.26 (.12)	-.49	-.03	-2.20*
Level of impairment ^c	-.07 (.13)	-.32	.19	-.51
Race ^d	-.36 (.15)	-.66	-.05	-2.33*

Note. CI = Confidence interval, LL = Lower limit, UL = Upper limit

^a Lagged predictor

^b 0 = paraplegia, 1 = tetraplegia

^c 0 = complete, 1 = incomplete

^d 0 = White, 1 = non-White

** $p < .01$, * $p < .05$, + $p < .10$

Hypotheses 2a-2h

Eight HLM models were utilized to explore the relationships between secondary medical conditions and psychosocial stressors. The first four models explored the impact of pain severity on depression, anxiety, SWL, and PTG over time (Hypotheses 2a-2d). Hypothesis 2a was confirmed, as there was a significant main effect of pain severity on depressive symptoms, indicating that higher levels of pain severity were related to higher levels of depressive symptoms over time ($p = .03$; see Table 5). Further, there was a significant main effect of time on depressive symptoms in which more years since baseline was associated with higher levels of depressive symptoms ($p = .01$; see Table 5). Level of impairment was related to depressive

symptoms, as individuals with incomplete injuries had higher depressive symptoms than individuals with complete injuries ($p = .03$; see Table 5).

Hypothesis 2b was not confirmed, although the main effect of pain severity on anxiety symptoms was approaching significance, with higher levels of pain severity associated with higher levels of anxiety symptoms over time ($p = .06$; see Table 5). The main effect of time on anxiety was significant with more years since baseline related to higher levels of anxiety symptoms ($p = .04$; see Table 5). Hypothesis 2c was not confirmed and demonstrated no significant relationship between pain severity and SWL over time. However, there was a significant effect of time on SWL with more years since baseline associated with lower levels of SWL ($p = .01$; see Table 5). Hypothesis 2d was not confirmed, as pain severity did not predict PTG scores over time

Table 14. Hypothesis 2a-2d: Pain Severity on Psychosocial Outcomes

	Depression (n = 174)				Anxiety (n = 174)				SWL (n = 174)				PTG (n = 150)			
	b (SE)	95% CI		t	b (SE)	95% CI		t	b (SE)	95% CI		t	b (SE)	95% CI		t
		LL	UL			LL	UL			LL	UL			LL	UL	
Intercept	.31 (.05)	.21	.41	6.22**	.27 (.06)	.16	.39	4.64**	26.11 (.97)	24.19	28.03	26.81**	57.86 (3.46)	51.05	64.67	16.74**
Level 1																
Time	.02 (.01)	.00	.03	2.62*	.02 (.01)	.00	.03	2.07*	-.29 (.10)	-.50	-.08	-2.76**	.50 (.40)	-.30	1.29	1.25
Pain severity ^a	.01 (.01)	.00	.03	2.19*	.01 (.01)	.00	.03	1.84+	-.05 (.09)	-.22	.12	-.55	-.36 (.39)	-1.13	.40	-.93
Level 2																
Level of injury ^b	.04 (.05)	-.06	.14	.86	.08 (.06)	-.04	.19	1.33	-1.91 (1.07)	-4.02	.20	-1.79+	4.18 (3.30)	-2.34	10.70	1.27
Level of impairment ^c	.12 (.06)	.01	.23	2.16*	.03 (.06)	-.09	.16	.52	-1.05 (1.18)	-3.39	1.28	-.89	3.03 (3.56)	-4.02	10.08	.85
Race ^d	.01 (.07)	-.12	.14	.18	.06 (.08)	-.09	.22	.81	-.51 (1.40)	-3.28	2.26	-.36	6.19 (4.08)	-1.87	14.25	1.52

Note. SWL = Satisfaction with life; PTG = Posttraumatic growth; CI = Confidence interval, LL = Lower limit, UL = Upper limit

^a = Lagged predictor

^b 0 = paraplegia, 1 = tetraplegia

^c 0 = complete, 1 = incomplete

^d 0 = White, 1 = non-White

** $p < .01$, * $p < .05$, + $p < .10$

An additional four models explored the impact of experiencing a pressure injury on each of the psychosocial outcomes (Hypotheses 2e-2h). Each of these hypotheses was not confirmed, as experiencing a pressure injury in the past year did not predict depressive symptoms, anxiety symptoms, SWL, or PTG over time. Similar to the models above, there were significant main effects of time on depressive symptoms ($p = .01$; see Table 6) and SWL ($p = .01$; see Table 6), with more time since baseline associated with greater depression symptoms and lower SWL. Level of impairment was also significant with depressive symptoms ($p = .02$; see Table 6), with individuals with incomplete injuries demonstrating greater depressive symptoms than individuals with complete injuries.

Table 15. Hypothesis 2e-2h: Pressure Injury on Psychosocial Outcomes

	Depression (n = 175)				Anxiety (n = 175)				SWL (n = 175)				PTG (n = 151)			
	b (SE)	95% CI LL UL		t	b (SE)	95% CI LL UL		t	b (SE)	95% CI LL UL		t	b (SE)	95% CI LL UL		t
Intercept	.35 (.04)	.26	.44	7.81**	.31 (.05)	.21	.41	5.86**	26.03 (.92)	24.21	27.84	28.31**	56.64 (3.15)	50.42	62.87	17.96**
Level 1																
Time	.02 (.01)	.00	.03	2.57*	.02 (.01)	.00	.03	1.93+	-.28 (.10)	-.49	-.07	-2.70**	.56 (.40)	-.23	1.35	1.41
Pressure injury ^a	.05 (.03)	-.02	.11	1.40	.06 (.04)	-.02	.13	1.44	-.38 (.44)	-1.25	.48	-.87	-2.70 (1.99)	-6.60	1.21	-1.36
Level 2																
Level of injury ^b	.04 (.05)	-.06	.14	.76	.07 (.06)	-.04	.19	1.23	-1.88 (1.06)	-3.97	.22	-1.76+	4.77 (3.27)	-1.70	11.24	1.46
Level of impairment ^c	.13 (.06)	.02	.24	2.25*	.04 (.07)	-.09	.17	.61	-1.09 (1.18)	-3.42	1.23	-.93	2.80 (3.55)	-4.22	9.82	.79
Race ^d	.02 (.07)	-.11	.15	.25	.07 (.08)	-.09	.22	.87	-.52 (1.40)	-3.28	2.24	-.37	6.39 (4.06)	-1.62	14.41	1.58

Note. SWL = Satisfaction with life; PTG = Posttraumatic growth; CI = Confidence interval, LL = Lower limit, UL = Upper limit

^a = Lagged predictor

^b 0 = paraplegia, 1 = tetraplegia

^c 0 = complete, 1 = incomplete

^d 0 = White, 1 = non-White

** $p < .01$, * $p < .05$, + $p < .10$

Hypotheses 3a-3d

To examine the relationship between community participation and psychosocial outcomes, four separate HLM models were completed for each of the outcomes of interest (e.g., depression, anxiety, SWL, & PTG). Community participation was a level-1 predictor, measured at each time point. Hypothesis 3a was confirmed, as there was a significant main effect of participation on depressive symptoms, in which higher levels of participation were associated with lower levels of depression scores over time ($p = .00$; see Table 7). There was also a significant main effect of time on depressive symptoms, as more years since baseline was associated with higher levels of depression scores ($p = .01$; see Table 7). There was not enough evidence to confirm Hypothesis 3b, although the main effect of participation on anxiety symptoms was approaching significance ($p = .07$; see Table 7). Hypothesis 3c was supported. The model demonstrated a significant main effect of participation on SWL, as higher levels of participation was associated with higher levels of SWL over time ($p = .01$; see Table 7). In addition, there were significant main effects of time on SWL, as more years since baseline was associated with lower levels of SWL. Hypothesis 3d was not confirmed. A main effect of participation on PTG was approaching significance in the opposite direction of what was predicted, as higher levels of participation were associated with lower levels of PTG ($p = .06$; see Table 7).

Table 16. Hypothesis 3a-3d: Community Participation and Psychosocial Outcomes

	Depression (n = 173)				Anxiety (n = 173)				SWL (n = 173)				PTG (n = 149)			
	b (SE)	95% CI LL UL		t	b (SE)	95% CI LL UL		t	b (SE)	95% CI LL UL		t	b (SE)	95% CI LL UL		t
Intercept	.38 (.04)	.30	.47	8.79**	.34 (.05)	.23	.44	6.38**	25.81 (.89)	24.05	27.56	28.97**	56.76 (3.16)	50.53	62.98	17.99**
Level 1																
Time	.02 (.01)	.00	.03	2.69**	.01 (.01)	.00	.03	1.83+	-.30 (.10)	-.50	-.10	-2.96**	.47 (.41)	-.35	1.29	1.15
Participation ^a	-.10 (.03)	-.15	-.05	-4.09**	-.05 (.03)	-.11	.01	-1.70+	1.06 (.40)	.27	1.86	2.64**	-2.63 (1.55)	-5.68	.41	-1.70+
Level 2																
Level of injury ^b	.03 (.05)	-.07	.12	.58	.08 (.06)	-.04	.19	1.27	-1.67 (1.03)	-3.71	.37	-1.62	4.25 (3.31)	-2.30	10.79	1.28
Level of impairment ^c	.09 (.05)	-.01	.20	1.73+	.01 (.07)	-.12	.14	.13	-1.06 (1.15)	-3.33	1.21	-.93	2.67 (3.60)	-4.45	9.78	.74
Race ^d	-.05 (.07)	-.18	.08	-.70	.04 (.08)	-.12	.20	.50	-.60 (1.39)	-3.34	2.14	-.44	3.97 (4.19)	-4.31	12.25	.95

Note. SWL = Satisfaction with life; PTG = Posttraumatic growth; CI = Confidence interval, LL = Lower limit, UL = Upper limit

^a = Lagged predictor

^b 0 = paraplegia, 1 = tetraplegia

^c 0 = complete, 1 = incomplete

^d 0 = White, 1 = non-White

***p* < .01, **p* < .05, +*p* < .10

Hypotheses 4a-4d

Hypothesis 4 examined the relationship between three separate components of participation (mobility, occupational functioning, and social integration) and each of the psychosocial outcomes of interest utilizing four models. Hypothesis 4a was partially confirmed, as higher mobility scores were associated with lower levels of depressive symptoms over time ($p = .00$; see Table 8). There were no significant main effects for occupational functioning or social integration. Consistent with previous models, more time since baseline was related to higher levels of depressive symptoms ($p = .01$; see Table 8). Hypothesis 4b was not confirmed, as there were no significant main effects of the participation subscales on anxiety symptoms. Hypothesis 4c was partially confirmed with higher occupational functioning associated with higher SWL scores over time ($p = .00$; see Table 8). Mobility and social integration were not significantly associated with SWL scores. Similar to previous models that explored SWL as the dependent variable, more time since baseline was associated with lower SWL scores ($p = .00$; see Table 8). Hypothesis 4d was not confirmed, as there were no significant main effects of the participation scales on PTG.

Table 17. Hypothesis 4a-4d: Components of Participation on Psychosocial Outcomes

	Depression (n = 173)				Anxiety (n = 173)				SWL (n = 173)				PTG (n = 149)			
	b (SE)	95% CI LL UL		t	b (SE)	95% CI LL UL		t	b (SE)	95% CI LL UL		t	b (SE)	95% CI LL UL		t
Intercept	.39 (.04)	.31	.48	8.96**	.34 (.05)	.24	.45	6.50**	25.90 (.90)	24.13	27.68	28.78**	56.80 (3.17)	50.55	63.05	17.94**
Level 1																
Time	.02 (.01)	.00	.03	2.58*	.02 (.01)	.00	.03	1.86+	-.32 (.10)	-.52	-.12	-3.14**	.46 (.41)	-.36	1.28	1.12
Mobility ^a	-.07 (.02)	-.11	-.03	-3.24**	-.04 (.02)	-.08	.01	-1.51	-.08 (.31)	-.68	.53	-.25	-1.08 (1.28)	-3.60	1.43	-.85
Occupation ^a	-.03 (.02)	-.07	.01	-1.66+	-.03 (.02)	-.07	.01	-1.32	.81 (.27)	.28	1.34	3.02**	-.57 (1.14)	-2.81	1.68	-.50
Social Integration ^a	-.01 (.02)	-.05	.03	-.54	.01 (.02)	-.03	.05	.50	.23 (.26)	-.28	.75	.90	-1.00 (1.15)	-3.26	1.26	-.87
Level 2																
Level of injury ^b	.01 (.05)	-.09	.11	.24	.06 (.06)	-.06	.18	1.01	-1.76 (1.05)	-3.83	.31	-1.68+	4.24 (3.34)	-2.36	10.85	1.27
Level of impairment ^c	.10 (.05)	-.01	.20	1.81+	.01 (.07)	-.12	.14	.20	-1.05 (1.16)	-3.33	1.24	-.91	2.66 (3.61)	-4.47	9.80	.74
Race ^d	-.05 (.07)	-.18	.08	-.73	.04 (.08)	-.12	.20	.52	-.77 (1.40)	-3.53	1.99	-.55	3.91 (4.20)	-4.40	12.22	.93

Note. SWL = Satisfaction with life; PTG = Posttraumatic growth; CI = Confidence interval, LL = Lower limit, UL = Upper limit

^a = Lagged predictor

^b 0 = paraplegia, 1 = tetraplegia

^c 0 = complete, 1 = incomplete

^d 0 = White, 1 = non-White

***p* < .01, **p* < .05, +*p* < .10

Hypotheses 5a-5f

Hypothesis 5 was examined by looking at six HLM models. Hypotheses 5a through 5c explored each of the types of coping as moderators for the relationship between pain severity and community participation (See Table 9). Hypotheses 5a through 5c were not confirmed. There were no significant main effects of coping on participation or any interaction effects with pain severity and coping. Consistent with Hypothesis 1a, there were no significant main effects of pain severity on participation in any of the models.

Table 18. Hypothesis 5a-5c: Coping as a Moderator in the Relationship Between Pain Severity and Community Participation

	Religious/spiritual (n = 173)				Emotional Support (n = 173)				Acceptance (n = 172)			
	b (SE)	95% CI LL UL		t	b (SE)	95% CI LL UL		t	b (SE)	95% CI LL UL		t
Intercept	.20 (.13)	-.05	.45	1.55	.16 (.13)	-.10	.43	1.21	.03 (.72)	-1.39	1.44	.04
Level 1												
Time	-.02 (.01)	-.04	.01	-1.30	-.02 (.01)	-.05	.01	-1.50	-.03 (.09)	-.22	.15	-.34
Pain severity ^a	.00 (.01)	-.03	.03	.02	.00 (.01)	-.03	.02	-.08	-.05 (.12)	-.28	.18	-.45
Level 2												
Coping	.06 (.14)	-.22	.34	.39	.12 (.14)	-.17	.40	.81	.21 (.72)	-1.20	1.63	.30
Level of Injury ^b	-.27 (.12)	-.51	-.03	-2.26*	-.27 (.12)	-.50	-.03	-2.25*	-.27 (.12)	-.51	-.04	-2.30*
Level of Impairment ^c	-.06 (.13)	-.32	.21	-.42	-.05 (.13)	-.31	.21	-.37	-.05 (.13)	-.32	.21	-.40
Race ^d	-.35 (.16)	-.66	-.05	-2.27*	-.34 (.16)	-.65	-.03	-2.15*	-.34 (.16)	-.65	-.03	-2.15*
Interactions												
Time x Coping	.01 (.02)	-.02	.05	.71	.02 (.02)	-.02	.05	1.03	.02 (.10)	-.16	.21	.25
Pain severity ^a x Coping	-.01 (.02)	-.05	.02	-.72	-.01 (.02)	-.05	.02	-.75	.05 (.12)	-.18	.27	.39

Note. CI = Confidence interval, LL = Lower limit, UL = Upper limit

^a = Lagged predictor

^b 0 = paraplegia, 1 = tetraplegia

^c 0 = complete, 1 = incomplete

^d 0 = White, 1 = non-White

** $p < .01$, * $p < .05$, + $p < .10$

Hypotheses 5d through 5f examined each of the types of coping as moderators for the relationship between experiencing a pressure injury and community participation (See Table 10). Hypotheses 5d through 5f were not confirmed, as there were no significant main effects of coping on participation or any interaction effects with pressure injuries and coping. The model examining hypothesis 5e, using emotional support as the form of coping, yielded a main effect of pressure injuries on community participation ($p = .03$; see Table 10), consistent with findings from hypothesis 1b.

Table 19. Hypothesis 5d-5f: Coping as a Moderator in the Relationship Between Pressure Injuries and Community Participation

	Religious/spiritual (n = 174)				Emotional Support (n = 174)				Acceptance (n = 173)			
	b (SE)	95% CI LL UL		t	b (SE)	95% CI LL UL		t	b (SE)	95% CI LL UL		t
Intercept	.22 (.12)	-.01	.45	1.88+	.20 (.13)	-.05	.45	1.55	-.10 (.47)	-1.03	.82	-.22
Level 1												
Time	-.01 (.01)	-.04	.01	-1.15	-.02 (.01)	-.05	.01	-1.31	-.08 (.10)	-.28	.12	-.81
Pressure injury ^a	-.08 (.06)	-.20	.05	-1.24	-.14 (.07)	-.27	-.01	-2.15*	.34 (.28)	-.21	.90	1.21
Level 2												
Coping	.02 (.13)	-.23	.27	.12	.04 (.13)	-.21	.30	.34	.35 (.47)	-.58	1.28	.74
Level of Injury ^b	-.26 (.12)	-.49	-.03	-2.20*	-.26 (.12)	-.49	-.02	-2.18*	-.26 (.12)	-.49	-.03	-2.20*
Level of Impairment ^c	-.07 (.13)	-.32	.19	-.50	-.06 (.13)	-.32	.20	-.47	-.07 (.13)	-.32	.19	-.50
Race ^d	-.36 (.15)	-.66	-.05	-2.33*	-.34 (.16)	-.65	-.03	-2.15*	-.36 (.15)	-.66	-.05	-2.31*
Interactions												
Time x Coping	.01 (.02)	-.02	.05	.64	.02 (.02)	-.02	.05	.93	.08 (.10)	-.13	.28	.73
Pressure injury ^a x Coping	-.06 (.09)	-.24	.12	-.65	.07 (.09)	-.11	.24	.73	-.46 (.29)	-1.02	.10	-1.62

Note. CI = Confidence interval, LL = Lower limit, UL = Upper limit

^a = Lagged predictor

^b 0 = paraplegia, 1 = tetraplegia

^c 0 = complete, 1 = incomplete

^d 0 = White, 1 = non-White

** $p < .01$, * $p < .05$, + $p < .10$

Discussion

This study explored relationships between secondary medical issues such as pain and pressure injuries, community participation, and psychosocial functioning (i.e., depression, anxiety, SWL, and PTG) utilizing HLM. The study builds upon existing literature to gain a greater understanding of these relationships over time in adults with pediatric-onset SCI by using a socioecological framework of disability to consider individual-level factors and interaction with the environment through a focus on community participation. Findings demonstrate that experiencing a pressure injury in the past year was associated with lower community participation over time while increased pain severity was related to higher levels of depression over time. Community participation was significantly related to depression and SWL. When breaking down the construct of community participation, higher levels of mobility were related to lower levels of depression over time and higher levels of occupational functioning were associated with higher levels of SWL over time. These findings emphasize that psychosocial outcomes of adults with pediatric-onset SCI are determined by multiple factors including secondary medical conditions and community participation.

Secondary Medical Conditions and Participation (Hypothesis 1)

Approximately 28% of study participants experienced a pressure injury in the past year at baseline. Compared to studies examining pressure injuries in the larger SCI population, pressure injuries were slightly less common in this sample, as Krause et al. (2001) found that approximately 40.2% and Lala et al. (2014) found that approximately 33.5% of individuals with SCI experienced at least one pressure injury in the past year. In the current study, experiencing a pressure injury in the past year was associated with decreased community participation over time in adults with pediatric-onset SCI. This finding is consistent with previous research that

demonstrates pressure injuries reduced participation in many community activities and ADLs such as communication with others, independent grooming and feeding, and using transportation (Lala et al., 2014). Because pressure injuries can potentially lead to infections, extended hospital admissions, and surgical interventions while limiting mobility and independence (Richards et al., 2004), community participation can be greatly affected. Prevention of pressure injuries may play a valuable role in encouraging community participation among individuals with SCI. Even though some pressure injuries may be unpreventable (Lemmer et al., 2019), weight shifts and seated movement through functional activities can decrease risk of developing pressure injuries (Sonenblum & Sprigle, 2018).

While pressure injuries are a secondary medical condition that can lead to significant pain, participant-reported pain severity was not specifically related to community participation over time. Because pain can be experienced in many different ways among the SCI population (e.g., neuropathic, musculoskeletal), there may be a need to focus on specific aspects of pain to determine the relationship with community participation. Further, it is possible that experiencing a pressure injury and undergoing treatment involves a variety of different factors beyond pain that contribute to a person's ability to participate in their communities. Despite not being significant in main models, general pain severity and overall community participation were correlated at baseline ($r = -.26; p < .01$). It may be that an individual's pain severity at that time point is related to their community participation concurrently, but that an individual's pain severity in a previous time point does not predict community participation at a later time. Experience sampling methods in which individuals record their pain at random times during the day may be an appropriate future direction for exploring this relationship to account for more accurate readings of pain severity and how it is related to participation in that moment. Some

research has found a significant association between pain and aspects of community participation. One qualitative study that focused on individuals with chronic neuropathic pain highlighted a major theme of pain impacting participation in school, work, and other activities (Henwood & Ellis, 2004). Additionally, participants emphasized how managing chronic pain can affect their social relationships (Henwood & Ellis, 2004). Other research demonstrates that the relationship between pain and participation is less clear. A meta-analysis exploring the psychosocial impacts of persistent pain in spinal cord injury indicated that few studies have explored the effects of pain on participation and that results have been inconsistent (Tran et al., 2016). Pain is also operationalized differently across studies (Ong & Seymour, 2004). While the current study explored participants' report of general severity of pain, pain can be explored in terms of frequency, duration, and interference with activities. There may be benefit to exploring different aspects of pain in relation to participation over time, as well as supplementing quantitative information with qualitative methodology.

Secondary Medical Conditions and Psychosocial Outcomes (Hypothesis 2)

Related to the psychosocial outcomes, general pain severity was significantly related to self-reported depression over time. This finding highlights the important impact of pain on mood symptoms in adults, even years after their injuries. It adds to the current literature by demonstrating that secondary medical conditions such as pain can have longstanding associations with psychosocial functioning. Research has consistently demonstrated an association between chronic pain and depression with those with SCI experiencing chronic pain having a higher likelihood of depressed mood (Craig et al., 2009; Craig et al., 2013). In addition, increased pain has been associated with a greater likelihood of meeting criteria for major depression five years after injury (Hoffman et al., 2011). Some research has highlighted that pain

interference has a stronger association with depression than pain intensity (Cuff et al., 2014).

Pain severity may only be an aspect of pain in the overall relationship between pain and depression. Further, in addition to exploring the relationship of pain on depression, there is also evidence that the relationship is bidirectional, as studies have demonstrated that depression and anxiety can amplify pain in individuals with chronic medical conditions (Bair et al., 2003).

Interestingly, pain was not significantly associated with anxiety symptoms over time. Some research indicates that anxiety in adults with pediatric-onset SCI is related with increased odds of pain that interfered with activity (January et al., 2014a). The current study explores the relationship between pain and anxiety differently, focusing on pain severity versus interference. While pain severity was correlated with anxiety at baseline and was approaching significance in the HLM model, it may be more complicated related to the relationship over time. Because the sample reported overall low levels of anxiety and some anxiety is normative, the relationship between pain and anxiety may be difficult to assess as the sample is generally well-adjusted. Further, compared to depressive symptoms, anxiety symptoms can vary greatly (e.g., generalized versus social anxiety) and it may be that pain severity impacts specific types of anxiety over time. Additionally, many physical symptoms experienced in the context of SCI (e.g., tingling, muscle weakness) are also considered physiological responses to anxiety, which can complicate scores on typical anxiety measures in this population.

Pain severity was also not significantly associated with SWL or PTG. Previous studies have demonstrated correlations between pain and life satisfaction (Norrbrink Budh & Österåker, 2007). However, the current study appears to illustrate that pain severity may worsen negative outcomes such as depression more than improve positive outcomes such as SWL. Because pain is inherently a negative experience, it may be that the absence of pain or lower intensity pain

does not lead to positive psychosocial outcomes in the way that experiencing severe pain affects depression symptoms. Positive psychosocial outcomes such as SWL may be related to the accumulation of positive experiences (e.g., increased opportunities for community participation, social support) rather than the absence of secondary medical conditions (Müller et al., 2012; Putzke et al., 2002). The relationship between pain and PTG may be more complicated, as PTG involves greater retrospection on previous experiences than the other outcomes explored in the study (Tedeschi & Calhoun, 2004). Even though PTG was only measured for participants who were injured after 6 years old, many participants are years removed from their injuries and have been injured for the majority of their lives. This may make it more challenging to reflect on changes or growth since their injuries. In addition, a measure of pain severity may reflect more recent functioning whereas PTG reflects more long-term changes that have taken place over many years.

Further, experiencing a pressure injury in the past year was not associated with any of the psychosocial outcomes in the study. This may be due to there being a wide range in severity across pressure injuries. More severe pressure injuries may lead to increased pain, extensive treatment, and hospitalizations that may uniquely impact outcomes (Gorecki et al., 2011). In addition, the current study, similar to much of the previous research on pressure injuries in SCI, measured occurrence of pressure injuries with a binary variable (i.e., did you experience a pressure injury in the past year – yes or no?). Individuals who experience more frequent pressure injuries (e.g., more than one in a year) or pressure injuries of longer duration may be at higher risk of negative outcomes (Gorecki et al., 2011).

Community Participation and Psychosocial Outcomes (Hypothesis 3)

Increased community participation was associated with decreased depression scores and increased SWL over time. Previous studies have highlighted an association between community participation and depression with lower participation correlated with higher depression (Kraft & Dorstyn, 2015). Considering the use of behavioral activation and positive activity scheduling as an effective intervention for depression (Cuijpers et al., 2007), the connection between increased activity in the community (e.g., volunteering, working, spending time with friends) and lower levels of mood symptoms is reasonable, highlighting key areas of intervention for advancing positive psychosocial outcomes in individuals with SCI. Even though the current study did not identify a relationship over time between pain severity and community participation, another study determined that community participation may also serve as a mediator for the relationship between pain severity and depression, buffering against the negative effects of moderate to severe chronic pain on depressive symptoms (Müller et al., 2017). Additional research has highlighted that individuals' perceived participation is associated with increased life satisfaction (Carpenter et al., 2007; Lund et al., 2007). This research along with the findings from the current study suggest that community participation can increase positive outcomes (e.g., SWL) in addition to decreasing negative outcomes (e.g., depression). The current study builds upon the literature by demonstrating that the relationships between community participation and psychosocial outcomes are present over time and community participation continues to influence depression and SWL specifically with the pediatric-onset population into adulthood. Community participation may be an ideal area of focus for providers in promoting important psychosocial outcomes in the SCI population. Much of this work must also involve addressing barriers on the

individual, community, and societal levels to facilitate opportunities for increased participation (Barclay et al., 2015; Whiteneck et al., 2004).

Community participation was not significantly related to anxiety or PTG over time. Anxiety was negatively correlated with community participation at baseline. Anxiety is often associated with avoidance, which is consistent with higher levels of anxiety being associated with lower levels of participation. However, this relationship may be less significant over time with anxiety in the present not being related to future participation. Given that some level of anxiety is common and normative and that the study sample reported low levels of anxiety overall, it is possible that some anxiety symptoms in individuals already demonstrating appropriate psychosocial functioning does not have a major impact on community participation. Related to PTG, an individual's growth may be influenced by a number of factors over a longer period of time, especially since most participants' injuries occurred years before the time of these interviews. One's community participation in adulthood may be less important to PTG than formative experiences during child and adolescent development.

While the current study did not address differences in community participation across specific racial groups due to a lack of racial diversity in the sample (83.3% White), the dichotomous variable utilized in the models (i.e., White/non-White) demonstrated significantly lower participation scores for non-White participants compared to White participants. Previous research has identified increased barriers to participation for non-White individuals with SCI (Whiteneck et al., 2004). In addition to the challenges of finding employment for individuals with SCI, there are also greater disadvantages for people of color (Krause et al., 1998). In a study exploring the transition to adulthood for individuals with pediatric-onset SCI specifically, non-White participants were less likely to be consistently employed than White participants

(Anderson et al., 2006). These findings altogether underscore the systemic racism and institutional biases related to healthcare, employment opportunities, and accessibility of communities.

Components of Community Participation and Psychosocial Outcomes (Hypothesis 4)

When examining the three subcategories (i.e., mobility, occupational functioning, and social integration) of the community participation composite, increased mobility was significantly associated with lower depression scores over time while increased occupational functioning was significantly associated with higher SWL scores over time. Natural environment (e.g., terrain, climate), transportation, and need for assistance in the home are some of the most common environmental barriers to participation for individuals with SCI (Whiteneck et al., 2004). The mobility domain, which can encompass independence with transportation and time spent outside of one's residence, highlights some of the main barriers that individuals with SCI frequently identify. Despite associations between depression and participation (Kraft & Dorstyn, 2015), few studies have directly determined that mobility specifically is a key predictor in depression. Over time, lower mobility may complicate the ability to schedule activities outside the home contributing to higher levels of depression symptoms, while higher mobility may facilitate increased activity and lower depression symptoms over time.

Occupational functioning was a significant predictor of SWL, which is consistent with research that demonstrates psychosocial benefits of employment in adults with pediatric-onset SCI (e.g., increased life satisfaction and community integration; Anderson & Vogel, 2002). Adults with pediatric SCI are at increased risk for unemployment (Hwang et al., 2015); this finding highlights important benefits for individuals who are engaged in work, school, volunteering, and other activities related to occupational functioning. Participants who are

involved in these types of activities may have more opportunities to demonstrate their autonomy and independence, contributing to positive psychosocial functioning

Social integration was not specifically related to any of the main outcomes in the study. However, access to social support has been identified as a significant factor in how individuals with SCI perceive problems with their participation (Lund et al., 2005). This finding may be due to the generally high levels of social integration among study participants, as the majority of participants scored above 100 (65.1%), indicating no handicap. The variability in scores above 100 may have limited impacts on psychosocial outcomes since these individuals are generally reporting appropriate functioning in the social integration domain even though some are more integrated than others. Interestingly, marital status, which is a specific aspect of the social integration subscale in the CHART was related to multiple outcomes explored in the current study at baseline (e.g., married individuals had higher participation, lower depression, and higher SWL compared to participants who were not married). This is consistent with previous research that demonstrates that individuals with SCI who are single report more barriers to participation than those who are married (Whiteneck et al., 2004) as well as increased depression scores (January et al., 2014b). It is possible that marital status is more important than other aspects of social integration measured in the CHART such as number of friends, relatives, and business associates or frequency of conversations initiated with strangers. The consistent social support from a partner in the home may be more instrumental to psychosocial functioning than outside support and integration.

Coping with SCI (Hypothesis 5)

In the primary models, there were no significant main effects of each of the three coping strategies (e.g., acceptance, religious/spiritual, and emotional support) on participation and no

significant interaction effects exploring coping and secondary medical conditions on participation. It may be that there are other factors that contribute to community participation beyond individual-level coping, as participation is a variable that involves interaction between individual and environmental factors. One's coping strategies may not be helpful if there are limited opportunities for participation in the community and a lack of community supports for facilitating positive adjustment into adulthood. Even though coping itself was not associated with participants' community participation, coping has been shown to be associated with psychological adjustment (Chevalier et al., 2009) and psychosocial outcomes such as depression (Kennedy et al., 2015), anxiety (Kennedy et al., 2003), and PTG (January et al., 2015). This is consistent with baseline correlations in which acceptance coping was related to depression and SWL, religious/spiritual coping was related to SWL and PTG, and emotional support coping was related to PTG. Research with adults with pediatric-onset SCI utilizing the same dataset as the current study, demonstrates correlations between PTG and cognitive coping (i.e., positive reframing and acceptance) and behavioral coping (i.e. active coping and use of instrumental support; January et al., 2015). Exploring the relationship between coping and psychosocial outcomes over time may be an appropriate future direction. Further, it may be beneficial to explore moderation effects of coping on the relationship between community participation and psychosocial outcomes. There is also evidence that coping impacts adjustment to pain in individuals with SCI, such that use of passive coping strategies (e.g., asking for assistance, resting) were associated with greater pain interference (Raichle et al., 2007). While acceptance, religious/spiritual, and emotional support coping were not specifically correlated with pain severity at baseline, individuals use a range of coping strategies that may influence adjustment to

pain that were not captured in this study. Exploring individuals' use of different coping strategies with their experiences with pain over time may be another future direction.

Injury Characteristics

Level of injury (paraplegia versus tetraplegia) and level of impairment (complete versus incomplete) were explored in all primary HLM models. Level of injury was consistently related to community participation while level of impairment was often related to depression across models. Individuals with tetraplegia demonstrated lower levels of community participation than individuals with paraplegia. This was expected given additional medical complications and the wider range of impacts associated with tetraplegia (Barclay et al., 2015; Whiteneck et al., 2004). In the current study, participants with incomplete injuries had higher levels of depressive symptoms than participants with complete injuries, which is a finding aligned with previous research (January et al., 2014b). This may be due to individuals with incomplete injuries having additional challenges related to acceptance around their functioning (e.g., potential for regaining some functioning in incomplete injuries).

A Socioecological Perspective to Disability Research

The current study highlights the importance of using a socioecological disability framework in the context of exploring outcomes for individuals with SCI. This approach differs from a medical model that often focuses on treating deficits and views disability as the consequence of a deficit that limits one's ability to engage in activities and functions (Pledger, 2003). Therefore, the study includes opportunities to explore participants' strengths and positive outcomes. For example, the ceiling effects of the participation measure were removed to accentuate the results of individuals who demonstrate high levels of participation as opposed to only the absence of a handicap. Moreover, in addition to exploring depression and anxiety, there

is a focus on SWL and PTG to emphasize positive outcomes instead of only relying on low scores for undesirable outcomes to explain positive psychosocial experiences.

Further, a socioecological approach recognizes the role of environment in contributing to the experiences of individuals with disabilities (Tate & Pledger, 2003). The current study focuses on community participation as a key variable in exploring psychosocial outcomes for individuals with SCI. While individual characteristics or factors also contribute (e.g., pain level), community participation is a function of the interaction of individual factors and the environment (Fougeyrollas et al., 2002). For example, one's participation may be affected by experiencing a pressure injury in the past year, but there are numerous factors beyond the individual level that may impact whether one can access transportation, obtain a job, or spend time with friends outside of the home. To facilitate community participation, there are needs to address individual factors (e.g., supporting management of a pressure injury), while working to decrease barriers and focus on systemic issues and biases affecting communities.

Community psychology, which espouses a socioecological approach, provides a beneficial perspective for disability research and SCI research more specifically. Community psychology emphasizes the importance of exploring multiple levels of analysis and moving beyond deficits-based research (Kloos et al., 2012). There is benefit to integrating community psychology values into research with individuals with medical complexity, as health research could be augmented by focusing on individuals' strengths and using an ecological approach. Empowerment, prevention, and health promotion are also key aspects of community psychology research (Kloos et al., 2012) that fit within disability research and studies that focus on the experiences of individuals with SCI. The current study highlights the importance of prevention around secondary medical conditions in leading to higher levels of participation. The study also

demonstrates benefits of increased participation, highlighting agency, autonomy, and independence, which are often considered main components of empowerment (Fawcett et al., 1994; van de Ven et al., 2008). In addition, community psychology emphasizes social justice, citizen participation, and diversity. In this sense, community psychology has the ability to move basic research into action and structural change. While the current study does not completely embody all of the tenets of community psychology, it could be a starting point for utilizing research to break down barriers to participation and facilitate positive outcomes in adults with pediatric-onset SCI.

In addition to a socioecological framework, there is evidence that social identity is an important construct when considering disability research (Dirth & Branscombe, 2018). It is necessary to consider how the disability community, or in this case the SCI community, identifies and views disability, as there is a history of research making assumptions about individuals with disabilities and their experiences (Dirth & Branscombe, 2018). There may be diversity in these views and how someone identifies may also impact their psychological experience. Participatory action research (PAR), which has often been used in community psychology, may offer opportunities to invite the voices of individuals with SCI into the research process. Through collaboration with the SCI community, research can be used to answer questions and address concerns that are most important to the community.

Strengths and Limitations

The study has a number of strengths that contribute to the SCI literature. First of all, the study focuses on adults with pediatric-onset SCI, an understudied area within the SCI literature. Because of the unique experiences of individuals with pediatric-onset injuries, it is important to consider long-term outcomes into adulthood. Further, the study explores relationships among

secondary medical conditions, community participation, and psychosocial outcomes over time, utilizing strong statistical methodology through HLM. Participants had up to nine time points, which allowed for relationships to be studied over a 10-year period. Finally, the study uses a community psychology and socioecological lens to examine participants' strengths such as higher levels of participation, SWL, and PTG. This approach also recognizes the interplay between individual and environmental factors in contributing to community participation. The study emphasizes the important role that community participation has in considering secondary medical conditions and psychosocial outcomes.

Although this study contributes to the study of pediatric-onset SCI in a number of ways, there are several limitations to consider. Racial diversity in the sample is a limitation of the study, as participants were largely White (83.3%). Compared to national estimates, which indicate that approximately 58.9% of injuries occur in individuals who are White, there are fewer participants of color in the study than would be expected, particularly Black and Latinx participants (National Spinal Cord Injury Statistics Center, 2020). Research has shown that there is a higher rate of violent etiologies of SCI among Black and Latinx individuals (Chen & DeVivo, 2018), likely caused by historical patterns of inequity and systemic racism. This study has a lower incidence of violent etiology (6.1%) compared to the national rate of 14.0% (National Spinal Cord Injury Statistics Center, 2020). There is a need to consider the barriers and facilitators of research participation in healthcare settings for people of color who have historically been underrepresented in psychology and medical research (George et al., 2014). Furthermore, the study sample was generally well-adjusted as evidenced by low depression and anxiety scores and high participation and SWL scores. Participants with better psychosocial outcomes and higher levels of community participation may be easier to recruit and maintain

involvement over time in the study. Therefore, the study may not be generalizable to the pediatric-onset SCI community at large, which has been shown to be at higher risk for mental health concerns compared to the general population (Migliorini et al., 2008). Future research should investigate the relationship between secondary medical conditions such as pain and pressure injuries and participation in a community sample with a representative mental health presentation. Moreover, the study did not explore whether participants were taking medications to manage pain or mood symptoms. Because antidepressants may also be used for pain management, this would have been a confounding factor as it would have been unclear why a participant was taking a certain medication. Future research could better differentiate the purpose of certain medications.

In addition, many of the participants in the study experienced their injuries years in the past. Relationships among primary variables of interest may differ among individuals who recently experienced their injuries. An additional weakness of the study is recognized in how pain and pressure injuries were measured. For example, this study only explores pain severity as opposed to other aspects of pain such as duration, frequency, and interference. Pressure injuries were also only measured as a dichotomous variable (i.e., In the past year, did a pressure injury occur?). This does not highlight the diversity of experiences among individuals who have experienced a pressure injury (e.g., stage of the injury, hospitalized versus outpatient treatment). Another limitation involves measures of community participation, as the CHART was intended to only determine the presence of handicap, rather than exploring the upper end of functioning in community participation (i.e., those who participate at higher levels than their peers). While the current study removed ceiling effects from the measure to allow for higher scores for those who excel in areas of participation, there is a need for a measure specifically designed to examine

participation across the spectrum of individuals with SCI. Further, geography plays an important role in community participation (e.g., urban versus rural), which can impact accessibility to activities, employment, and transportation. Therefore, an individual's optimal level of participation might differ depending on their community and this should also be considered when measuring community participation.

Implications

The current study offers findings that should ideally contribute to managing secondary medical conditions, facilitating increased community participation, and improving psychosocial outcomes for the pediatric-onset SCI population. There are a multitude of implications for research, practice, and policy considerations.

Research

There are multiple areas in which research within the SCI population and other medically complex individuals can be strengthened through utilizing a community-based socioecological approach. There is a need to include variables that span across multiple levels of analysis (e.g., individual, interpersonal, environmental) to account for the interaction between person and environment and better understand the complex relationships that affect experiences of individuals with disabilities (Tate & Pledger, 2003) For example, individual-level variables such as demographics, injury characteristics, and psychosocial functioning can be explored with interpersonal factors such as social support and family relationships/interactions and environmental factors such as community access and structural barriers. While the current study applied a community-oriented framework to develop research questions around community participation and other positive outcomes such as SWL and PTG, future research can build upon this orientation. Multiple studies have explored the priorities of individuals with SCI, finding a

range of priorities that include health, employment, and social relationships (Simpson et al., 2012). It is necessary to consider how research can elevate the voices of individuals with SCI in the research process. PAR, in which researchers collaborate with the SCI community to gain input on research questions and practical impacts of research, may be one approach (Tate & Pledger, 2003). *My Care My Call*, a program formed through a collaboration between medical professionals, researchers, and members of the SCI community, utilizes a health empowerment framework to focus on prevention of secondary medical conditions (Houlihan et al., 2016). This type of program exemplifies aspects of community psychology and PAR by assigning peer health coaches to participants and allowing participants to choose topics of interest, which can include managing stress, exploring barriers to healthcare, and building a support network (Houlihan et al., 2016).

Specifically related to participation, there is a need to develop norm-referenced measures that can account for the wide range of participation levels across individuals with disabilities. This means that participation measures should be able to appropriately assess individuals whose participation is a strength versus a focus on what individuals are unable to do compared to those without disabilities. Strategies such as collecting data using experience sampling and qualitative methods can provide further insight into participation and individuals lived experiences (Dijkers, 2010). There may also be a need to develop a consensus definition around participation, the domains of participation, and how it should be operationalized in order to develop consistency across research (Dijkers, 2010). Further, individuals with disabilities should play an important role in this conversation, so that definitions are not only developed by researchers and imposed on the community.

While the study demonstrated a significant relationship between experiencing a pressure injury in the past year and community participation over time, it was surprising that the relationship

between pain severity and community participation was not significant over time. Future research should consider exploring different aspects of pain including interference in daily activities and location-specific pain. Location-specific pain (e.g., shoulder pain) may have a stronger affect on participation in certain activities compared to general pain. Because there are concerns related to recall bias around the study of pain (Gendreau et al., 2003), it may be beneficial to have participants recall their pain over shorter time-frames (e.g., pain severity in the last 24 hours or reminders to record pain throughout their daily activities). The experience of pain is multifaceted and this should be considered when exploring the impact of pain in the SCI population.

Practice

A meta-analysis exploring the global impact of pressure injuries on the SCI population demonstrates that approximately one in three individuals with SCI experiences pressure injuries (Shiferaw et al., 2020), while a meta-analysis of neuropathic pain estimates that approximately 53% of SCI patients experience neuropathic pain (Burke et al., 2017). Given the prevalence of these complications and the findings from the study that demonstrate significant relationships over time between pressure injuries and community participation and pain and depression, an emphasis on preventative approaches is warranted. Multidisciplinary care through medical clinic visits and rehabilitation that can focus on prevention of secondary medical conditions and encourage community participation across different domains (e.g., mobility, occupational functioning) and positive psychosocial functioning can be instrumental in supporting patients. Multidisciplinary approaches that involve medical teams, psychologists, physical therapists, occupational therapists, and other professionals have been successful in reducing and managing chronic pain (Heutink et al., 2014) and preventing pressure injuries (Kruger et al., 2013).

Based on the findings that emphasize the impact of community participation on psychosocial functioning (e.g., depression and SWL), multidisciplinary approaches are also appropriate to address barriers and patient needs that can help facilitate community participation (Cox et al., 2001). Barriers and needs may differ across individuals and clinicians should consider patient perspectives in the context of discussing the importance of community participation. There is a need for providers to be flexible and use a variety of approaches to best support patients including case management, motivational interviewing, and exploring potential opportunities for participation in individuals' own community spaces. For example, optimal community participation may vary by individual. While some patients may benefit from resources around education and employment, this may not be the case for others. Peer support and mentorship has also been shown to be associated with aspects of community participation (Sweet et al., 2018) and a mentorship approach may provide added benefit beyond the support from medical teams and other SCI professionals. Encouraging participation and increasing accessibility to physical activity such as recreational sports can also boost independence, quality of life, and social integration in individuals with SCI (Slater et al., 2004). Specifically with the pediatric-onset population, clinicians should consider interventions that allow patients to build skills to support the transition from youth to adulthood, which is a critical period of time that involves significant change (Zebracki et al., 2010).

Policy

In accordance with the principles of community psychology, individuals with disabilities should be involved with the development of policy at all levels. Accessibility in community spaces is critical for well-being and empowerment. There are varying viewpoints among individuals with disabilities and this should be considered in policy development. The World

Health Organization (WHO) advocates for both enabling access to mainstream programs, policies, and services while investing into specific programs for individuals with disabilities (e.g., rehabilitation and job training; WHO, 2011). Given the impact of community participation on psychosocial outcomes over time, policy should consider how to maximize aspects of participation for individuals with disabilities on a local, state, and federal level. The current study emphasizes the significance of occupational functioning for individuals with SCI. Even though research has found that individuals with pediatric-onset SCI have high levels of educational attainment, they have lower levels of employment than their able-bodied peers (Zebracki et al., 2010). This highlights a need for employment reform to ensure equitable access for individuals with SCI into the job market that takes into account the systemic and historical barriers embedded into our society. Further, there may be benefit to specific government programs for vocational training and preparation in this patient population.

Conclusion

Individuals with SCI who are injured in their youth have unique experiences, as they must learn to manage significant life changes during key developmental periods (e.g., adolescence, transition to adulthood). Much can be gained by patients, families, medical providers, and other key stakeholders (e.g., psychologists, social workers) by exploring outcomes in adults with pediatric-onset injuries utilizing a socioecological framework that moves away from a medical model and focuses on person-environment interactions in addition to individual-level factors. By examining variables such as community participation, SWL, and PTG, the study offers implications for building on individuals' strengths. There may be opportunities to manage the effects of secondary medical conditions with interventions that emphasize and support individuals'

assets. Identifying strategies for increasing community participation and overcoming barriers may be an avenue for enhancing positive outcomes and boosting agency and independence.

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