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PREDICTORS OF HEALTH-RELATED QUALITY OF LIFE AMONG YOUTH WITH SPINAL CORD INJURY

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PREDICTORS OF HEALTH-RELATED QUALITY OF LIFE AMONG YOUTH WITH SPINAL CORD INJURY

A Dissertation

To be Presented in Fulfillment of the
Requirements for the Degree of
Doctor of Philosophy in Community Psychology

BY
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May 4, 2017
Department of Psychology
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VITA

The author was born in Dallas, Texas, on April 23, 1985. She graduated from Lake Highlands High School in 2003 and received her Bachelor of Science degree in Psychology from Loyola University Chicago in 2007. She earned her Master's with Distinction in Community Psychology in 2012 at DePaul University.

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CHAPTER I. INTRODUCTION

INTRODUCTION

The purpose of this study is to examine to what extent four different factors impact psychosocial health-related quality of life (HRQOL) of youth (ages 6-18) with Spinal Cord Injury (SCI). These four factors are a) cognitive represented by adolescent and caregiver social problem solving skills and orientation, b) physical represented by bowel/bladder functioning, c) caregiver psychological represented by caregiver anxiety and depression, and d) family represented by family dysfunction.

Although great progress has been made in decreasing mortality and increasing life expectancy for youth with chronic conditions, new issues, such as disease management, preventing secondary complications, improving psychosocial HRQOL, and planning for long-term care, have emerged. Health-related quality of life has been identified as the goal for rehabilitation for people with disabilities (Whiteneck, 1994). HRQOL refers to a "subjective perception of health in emotional, mental, social, and functional domains…in terms of well-being and functioning via patients' self-reporting" (Bullinger et al., 2002, p. 198). Children with disabilities and/or chronic conditions, including youth with SCI, have reported lower overall HRQOL when compared to children without chronic conditions or disabilities (Kelly and Vogel, 2013; Taylor and Newacheck, 1992; Varni, Limbers, and Buriwinkle, 2007).

Therefore, it is important to measure psychosocial HRQOL among children with disabilities and, in particular, examine specific variables that may have a meaningful impact. Additionally, considering the fact that SCI is typically permanent, the appropriate focus of rehabilitation and continued care is preventing secondary complications and improving psychosocial health-related quality of life (HRQOL).

Furthermore, in this present study, youth (ages 6-18) acquired their SCI during childhood or adolescence. The traumatic and pediatric-onset of an injury (particularly while a child/adolescent is still growing and developing) can create significant changes for the child/adolescent, as well as for the caregiver(s) and other family members. According to Family Stress Theory (McCubbin and Patterson, 1993), an unanticipated event can negatively or positively impact family members. This theory examines how an unexpected event can negatively or positively impact family members (the *Adjustment Phase*), and how family members adapt to the event (the *Adaptation Phase*). In the *Adjustment Phase*, this theory looks at a stressor, family vulnerability, functioning before the stressful event, and family members' perception of the stressor. The population (youth with SCI, ages 6-18) in this study have sustained their injury for at least 1 year. Therefore, this dissertation focuses on the *Adaptation Phase* of Family Stress Theory. In the *Adaptation Phase*, family members can utilize positive problem solving and coping both on an individual level, as well as improving the family functioning overall and connecting to resources in the community. Additionally, how a family member copes also has implications for relationships with other family members.

Alternatively, in the *Adaptation Phase*, family members can use maladaptive problem solving and coping strategies on an individual level. If a family member is experiencing mental health problems, (i.e., symptoms of anxiety and/or depression), it may cause additional stress. If one family member is using ineffective coping mechanisms, this may negatively impact other familial relationships. On a larger scale, this can create disharmony and dysfunction within the family and, potentially, the community. In accordance with Family Stress Theory, a traumatic event does not only impact the family member to whom it happens, it also impacts the other family members, especially the primary caregiver, and family dynamics. With SCI, ongoing medical management and preventing secondary complications may also serve as a stressor on both the family overall and each family member. Therefore, in terms of measuring HRQOL, it may be helpful to look at multiple variables reported by both the caregiver and the youth with SCI. This current study aims to consider both caregiver-level and youth self-report variables in order to better understand HRQOL for youth with SCI.

SCI Incidence

Spinal cord injury (SCI) is a very specific disability in that it is usually a) not curable, b) traumatic in onset, and c) a physical disability that does not typically have cognitive complications, unless it also involves a traumatic brain injury. Among all individuals with SCI, less than 15% were injured as youth (National Spine Injury, 2015). SCI is a relatively rare injury in the U.S. with 17,000 new cases (across all ages) happening each year, and approximately 243,000-347,000 persons who are living with SCI in 2016 (https://www.nscisc.uab.edu/Public/Facts%202016.pdf). SCI has serious health complications, including a loss of movement, loss of sensation (including the ability to feel heat, cold and touch), loss of bowel and bladder control, and exaggerated reflex activities or spasms (Mayo Clinic, 2016). SCI may also include changes in sexual functioning, sensitivity and fertility, pain from spinal cord nerve damage, and difficulty breathing, coughing or clearing secretions from the lungs (Mayo Clinic, 2016). Overall, SCI “affects all aspects of a patient’s life, including the physical, behavioral, psychological, and social functioning” (Unalan et al., 2001, p. 318).

Quality of life in children with chronic illness or disability.

Having a chronic illness or disability can be a deeply impactful and traumatic experience. As discussed in Roberts, Kiselica, and Frederickson (2002), anyone who has ever been diagnosed with a serious medical condition “can attest to the pervasive effects, impinging on physical and emotional well-being, work, sexual relationships, and family life….common reactions include anxiety about pain and discomfort, fear and uncertainty about the future and depression with a need for attention to the emotional, social, spiritual and lifestyle adjustment concerns” (p. 422). Individuals with a chronic condition or disability experience not only the complications the condition presents medically, but also the impact on their day-to-day living. For individuals with disabilities, examining different factors that impact health-related quality of life (HRQOL) is particularly important.

Furthermore, in terms of treatment and management from a medical and psychological standpoint, with medical advancement, there has been a huge shift as many diseases have morphed from fatal to chronic. As people with chronic conditions live longer, a deeper exploration into elements that may impact their quality of life is warranted. Pollin (1995) states that individuals with a chronic condition may face serious issues and concerns, including problems with self-image, dependency, control, stigma, abandonment, anger, isolation, and death. Caregivers of a youth with a disability are often involved with the youth's daily routine (which may include activities such as helping them bathe, get dressed, commute to school, etc.). In addition, the caregiver is most likely responsible for scheduling and taking the youth to doctor's appointments, as well as assisting with the medical regimen/maintenance. As an adolescent reaches adulthood, caregivers often must assist with the transition so that the adolescent can become more independent and responsible for his/her own wellbeing.

There also has been a shift towards emphasizing the importance of patient-reported and patient-driven data and measures. Patient-reported data helps facilitate the understanding of the patient's experience, and at times, there may be asymmetry between what the patient and the clinicians/researchers have identified as important. In one example of adolescents with traumatic brain injury (DiBattista, Godfrey, Soo, Catroppa, and Anderson, 2015), researchers facilitated focus groups with adolescents both to discuss the changes they had experienced as a result of the injury and to rank the importance of these changes. The DiBattista et al. (2015) study found priorities varied between subjects and within subjects, suggested that priorities vary by individual, even across one health condition. In another study, focus groups and interviews with youth with a chronic condition and their families identified a variety of priorities impacting their overall HRQOL (Franciosi, Hommel, DeBrosse, Greenberg, Greenler, Abonia, Rothenberg, and Varni, 2012). Panepinto, Torres, and Varni (2012) identified priorities for youth with sickle cell disease (SCD) through interviewing, providers, youth with SCD, and their caregivers. These interviews led to the development of an HRQOL instrument (including psychosocial and physical health domains) that was specific to SCD. There are several other HRQOL instruments for pediatric patients that ope disease-specific (including asthma, diabetes, and cancer), but none developed yet for SCI (Varni et al., 2007).

HRQOL for children is a more recent field of study and measurement, particularly amongst children with disabilities. One of the challenges with measuring health-related quality of life amongst children with disabilities is that many assessments include a physical health component, which will obviously be different for children with different types of disabilities. Additionally, since physical disabilities can vary greatly from one another in terms of how they impact the child, it is difficult to create comparisons across disabilities. Furthermore, quality of life is contextualized by what is important to the individual, making it somewhat difficult to measure, even within a disability. Overall, however, children with chronic conditions experienced lower overall HRQOL when compared to healthy children (Law, Hanna, Anaby, Kertoy, King, & Xu, 2014; Newacheck and Taylor, 1992).

Parents have historically reported lower levels of psychosocial HRQOL as proxy reporters for their youth with SCI when compared to how the youth reported their own levels of psychosocial HRQOL (Garma, Kelly, Daharsh, and Vogel, 2011). Furthermore, although caregivers often have significant insight into their child’s condition, it is important to take a patient-driven approach in seeking to understand what the priorities are for an individual with SCI.

Disease Management and Problem Solving

During the Family Stress Theory’s *Adaptation Phase*, part of the focus is on how family members cope with a stressor (both psychologically and medically.) Examining how both caregivers and adolescents generally perceive challenges (i.e., positively or negatively), as well as what problem-solving techniques or strategies they use, may help researchers to better understand how the family is adapting to the stressor (viz., SCI). Additionally, since SCI is typically permanent and requires ongoing care (e.g., annual wellness visits, hospitalizations due to secondary complications, physical therapy/rehabilitation care, etc.), it is important to consider how youth and/or caregivers are adapting to the SCI for the long-term. Furthermore, as youth with chronic conditions transition into adolescence and become more independent, it is important for them to learn how to manage their health and care regimen. Stepansky et al. (2009) found that for youth with spina bifida, medical regimen responsibility eventually transferred from parent to child over time. Additionally, family conflict was found to be inversely related to medical adherence whereas family cohesion was positively related. These findings suggest that family functioning has an important impact on continued health for youth with SCI, particularly as they transition into adulthood.

In a study of adolescents with diabetes (Helgeson, Reynolds, Siminerio, Escobar, and Becker, 2008), shared responsibility between the parent and adolescents for disease management (as opposed to only having the caregiver responsible for disease management) led to the best psychological and physical health. More specifically, perceptions of shared responsibility (between both the adolescents and caregivers) made adolescents feel less depressed, and yielded higher diabetes self-efficacy and better self-care for both caregivers and youth. In a study of youth (ages 8-15) with spina bifida (Psihogios and Holmbeck, 2013), those with the highest medical adherence were “less likely to be the one responsible for their medical regimen” and had less family conflict. Since youth (in this case, ages 8-15) are still growing cognitively and have not yet developed strong executive functioning skills, it may be more effective for their caregivers to be responsible for their disease management/medical regimen.

In terms of teaching positive problem solving, studies demonstrate that problem solving interventions for parents of youth with chronic conditions were linked to positive outcomes in improving disease-related HRQOL (Berry, Elliott, Grant, Edwards, and Fine, 2012; Eccleston, Palermo, Fisher and Law, 2012.) Moreover, these interventions equipped parents with positive problem solving skills, and improved parents’ psychosocial health (see also Palermo, Law, Essner, Jessen-Fiddick, and Eccleston, 2014; Petranovich, Wade, Taylor, Cassedy, Stancin, Kirkwood, and Maines-Brown, 2015.) Conversely, negative problem-solving strategies were linked to lower psychosocial HRQOL (McCormick, Nezu, Nezu, Sherman, Davey, and Collins, 2014; Wade, Walz, Carey, McMullen, Cass, Mark, and Yeates, 2012, and Wysocki et al.,2006.) For example, in sickle cell patients, parent problem-solving significantly moderated the association between disease complications and child report psychosocial HRQOL (Barakat, Daniel, Smith, Robinson, & Patterson, 2014). These findings suggest that problem-solving skills are an essential piece of child disease-related and psychosocial health.

Although much of the research on improving problem-solving for youth with chronic conditions has been focused on parents and other caregivers, researchers have also examined social problem-solving with children and adolescents. Hill-Briggs (2003) cites effective coping strategies, problem-solving skills, and disease management knowledge as essential for youth (ages 6-18) with chronic conditions. For a chronic condition such as SCI, as adolescents become more independent and prepared for adulthood, identifying problem-solving skills and coping strategies may be particularly salient. Although parent/caregivers remain an important variable to study, for youth with a chronic condition, it becomes increasingly important for clinicians to address issues around developmental changes in adolescence.

Measuring problem solving skills and orientation among individuals who had a chronic condition may also yield meaningful insights into their HRQOL. Newcombe, Dunn, James, and Chang (2012) found that youth (ages 10-17) with asthma who participated in an online problem-solving intervention experienced a decrease in depression and a decrease in employing impulsive/carelessness problem-solving strategies. For adults with chronic pain, Suso-Ribera, Camacho-Guerrero, McCracken, Maydeu-Olivares, and Gallardo-Pujol (2014) found that higher scores on Positive Problem Orientation and Rational Problem-solving were found to be linked to improved mental health. Negative Problem Orientation has also been linked to poor psychological and disease-related outcomes among individuals with disabilities (Suso-Ribera et al., 2014; Dreer et al., 2005).

Maladaptive coping strategies (e.g., self-criticism and wishful thinking) were linked to higher rates of depression, anxiety, and lower psychosocial HRQOL among adolescents with SCI (Smith et al., 2013). Although problem-solving does impact psychosocial HRQOL, it may also serve as a protective measure against disease-related complications for adolescents (ages 13-17) (Smith, Russell, Kelly, Mulcahey, Betz, and Vogel, 2013). More specifically, Elliot et al. (2001) found that maladaptive problem-solving skills, (i.e., impulsivity, carelessness) significantly predicted the number of pressure ulcers an individual with SCI had. For youth with SCI (ages 7-17), caregiver mental health and problem-solving significantly predicted youth-report psychosocial HRQOL (Kelly, Riordan, Zebracki, Thorpe and Vogel, 2016). Therefore, positive problem solving skills may improve youth-report psychosocial HRQOL and potentially, decrease the risk for developing disease-related health complications.

Physical Health Complications and Incontinence

In the *Adaptation Phase* of Family Stress Theory, learning how to make long-term modifications after a stressor (SCI) occurs is also key to family functioning. For the families of youth with SCI, long-term changes include mobility considerations (e.g., making a home wheelchair-accessible) and minimizing secondary complications (e.g., UTIs.) Therefore, managing SCI may also be conceptualized as an ongoing stressor. Due to the limitations in mobility and secondary complications, caregivers (i.e., parents) may have additional responsibilities and considerations as their youth with SCI develops as an adolescent and/or adult. Physical health complications and medical implications of SCI are also essential elements of HRQOL. Adults with SCI reported worse health on several dimensions, including pain, overall and social functioning, physical functioning, and mental health when compared to healthy individuals (Andresen, Fouts, Romeis, and Brownson, 1999). It has been found that adults with SCI who are depressed also have increased secondary physical health complications, particularly pressure ulcers (Kitagawa and Kimura, 2002; Krueger, Pires, Ngann, Sterling, & Rubayi, 2013). Aside from the pain pressure ulcers cause, these secondary complications also led to significantly longer hospital stays and higher medical costs. Longer hospital stays mean that it is much more difficult to participate in community activities, and individuals who are hospitalized may also experience more isolation and a decreased quality of life.

In a prospective study of mortality of individuals with SCI (Krause, Carter, Pickelsimer and Wilson, 2008), pressure ulcers, secondary conditions (e.g., urinary tract infections), irreversible conditions (i.e., amputations and fractures), major depression, and number of days hospitalized were all predictive factors of mortality. Furthermore, overall health was found to be a greater influence over mortality than injury level was. These results indicate that the development of secondary conditions do contribute to and may have a synergistic/cumulative effect on mortality. These findings also have important implications for practitioners involved in the ongoing treatment of individuals with SCI, suggesting that it is important not only to manage SCI and secondary complications, but also to encourage general overall health and well-being.

In terms of secondary conditions in individuals with SCI, bladder incontinence is prevalent and often results in UTIs. UTIs can lead to potentially fatal complications, such as hydronephrosis, renal failure, recurrent infections, and autonomic dysreflexia. Due to the serious nature of these complications, reducing bowel and bladder incontinence is a priority for researchers and clinicians in order to improve overall HRQOL for individuals with SCI. Recently, a new measure specific to adult SCI-HRQOL has been developed and has identified bowel and bladder care management as a significant factor for overall HRQOL (Tulsky et al., 2015). Additionally, bowel and bladder care management almost always involves not only the youth with SCI, but also the caregiver. For some individuals with SCI, one ideal long-term bladder care program is clean intermittent catheterization. It promotes independence, reduces risk of infection, and reduces incontinence if used correctly. For a bowel care program, “diet, exercise/physical activity, oral medications, equipment, rectal medications, and scheduling of bowel care” should be considered (Stiens, Bergman, and Goetz, 1997,p. 93). When looking at incontinence among individuals with SCI, 49% had a UTI a year after hospital discharge (Haisma, van der Woude, Stam, Bergen, Sluis, Post, and Bussman, 2007). Also, aging, weight gain, tetraplegia, and completeness of injury, which impact bladder incontinence, all increased the likelihood of getting a UTI.

A recent study of adults with spina bifida did reveal that urinary incontinence was related to reports of general quality of life as measured by the Short

Form Health Survey, (SF-36, which is a patient-reported survey of health status) (Liu, Dong, Casey, Greiman, Mukherjee, and Kielb, 2015). The Liu et al. (2015) study suggests that urinary incontinence is a problem that impacts overall HRQOL and general psychosocial health. Furthermore, a study of youth with spina bifida demonstrated that increased continence was linked to higher overall HRQOL and spina bifida specific quality of life (Olesen, Kiddoo, and Metcalfe, 2013). Tapia, Khalaf, Berenson, Globe, Chancellor, & Carr (2013) performed a literature review on the impact of urinary incontinence on adults with neurological conditions, including SCI. This review found that SCI patients that were incontinent also reported lower overall HRQOL. Individuals who had daily occurrences of urinary incontinence reported the lowest scores on the mental health component and physical health components of the SF-36 (Short Form Health Survey).

Aside from potential physical complications, incontinence may also lead to embarrassment in social situations (Hicken, Putzke, and Richards, 2001). Experiencing bowel and/or bladder accidents may negatively impact HRQOL and serve as a stressor for youth with SCI. Additionally, if a youth with SCI avoids participating in the community or is afraid to be in certain situations in case they have a bowel or bladder accident, these social concerns may negatively impact their HRQOL. If a child/adolescent with SCI experiences decreased HRQOL, this effect may also negatively impact caregiver psychosocial functioning. Furthermore, if youth with SCI do not adhere to their bowel and bladder care management system, or do not use a method that minimizes incontinence, getting a UTI can result in a hospital stay. A hospital stay may be upsetting to the youth and/or caregiver, and may negatively impact the family (viz., caregivers needing to miss work to take care of youth, relying on other family members to take care of siblings, etc.). Alternatively, if a bowel and bladder care management program minimizes incontinence, it may result in fewer complications and/or hospital stays, which would be less disruptive to both the youth with SCI and their family members. The combination of potential physical (e.g., UTIs) and social (e.g., embarrassment and avoiding participation for fear of bowel/bladder accidents) problems demonstrates the importance of reducing incontinence for individuals with SCI in order to improve their overall HRQOL.

In summary, SCI is a unique disability in that it typically is a result of one traumatic event, and it creates a need for dependence on others for a myriad of personal care issues, particularly bowel and bladder care regimens (Catalano, Chan, Wilson, Chiu, and Muller, 2011). Reducing incontinence was identified as a key component for individuals with SCI, both in terms of reducing secondary health complications, such as UTIs, and also in terms of reducing social embarrassment. At the time of this study, there was no published research on frequency of urinary or fecal incontinence for youth with pediatric-onset SCI (without TBI). Therefore, although it is hypothesized that incontinence would negatively impact psychosocial HRQOL, prior to the present study, the frequency and prevalence of incontinence for youth with SCI is unknown. This study aims to measure both the prevalence of incontinence as well as its potential impact on psychosocial HRQOL.

Caregiver Mental Health

In addition to measuring physical problems, it is also important to consider the psychological factor(s); therefore, in this study the caregiver's mental health is assessed and how it may positively or negatively impact HRQOL for youth with SCI is considered. According to Family Stress Theory (McCubbin and Patterson, 1993), how a caregiver appraises and copes with a stressor during the *Adaptation Phase* can also impact the youth and other family members. If a caregiver has good mental health, he/she may positively influence the psychosocial functioning of their family members. Alternatively, if a caregiver struggles with their mental health, he/she may have negatively influence the psychosocial functioning of their family members. Cadman, Rosenbaum, Boyle and Offord (1991) compared families with a child with a chronic condition/disability vs. those families who had a healthy child; family functioning was not found to differ. Furthermore, parents of a child with a disability or chronic condition were not at a greater risk of substance abuse, or experiencing social isolation. However, parents (both mothers and fathers) of children with chronic conditions/disabilities were found to have higher rates of anxiety and negative affect scores when compared to parents of children without chronic conditions/disabilities.

In a review (Armstrong, Birnie-Lefcovitch and Ungar, 2005) examining different factors influencing resilience among children with a disability, parental characteristics (including locus of control, sense of mastery, and emotional stability) were found to influence parental emotional well-being. Furthermore, stressors such as having a child with a disability may impact both the quality of parenting and emotional wellbeing. Additionally, caregivers of individuals with SCI have also reported feeling overwhelmed by their caregiver responsibilities, and have reported unmet needs for information, economic, emotional, community support, and respite (Arango-Lasprilla, Plaza, Drew, Romero, Pizarro, Francis and Kreutzer, 2010).

Family caregivers of adults with SCI have also reported a lower quality of life (Molazem, Falahati, Jahanbin, Jafari, and Ghadakpour, 2014). For caregivers of adult with SCI, depression has been observed, and dysfunctional problem solving has been associated with a greater likelihood of depression (Dreer, Elliott, Shewchuk, Berry and Rivera, 2007). When measuring mental health outcomes in caregivers of youth (ages 1-18) with SCI, 20% of caregivers experienced moderate to severe anxiety, and 22% experienced moderate to severe depression, (Kelly, Mulcahey, Russell, Anderson and Vogel, 2012). Additionally, caregiver mental health has been found to be predictive of caregiver proxy report of psychosocial HRQOL for youth (ages 5-18) with SCI (Garma et al., 2011).

In a review of 57 studies examining psychosocial health of youth with a chronic condition and family characteristics, 53 contained at least 1 measure of parent or family functioning that was significantly related to child psychosocial health (Drotar, 1997). The prevalence of parent or family functioning studies illustrates the impact of the relationships between family and the child. Many variables, such as barriers to participation, lack of mobility, pain, caregiver functioning, and incontinence impact the overall psychosocial and physical health of a youth with SCI. Moreover, caring for a child with a permanent physical disability can also be a challenge. Mothers of children (ages 0-7) with a disability were found to be more depressed than those mothers of children (ages 0-7) without a disability (Miller, Gordon, Daniele, and Diller, 1992).

As theorized by McCubbin and Patterson (1993), alternatively, certain factors, such as emotional intelligence, problem-solving skills, esteem support, and concrete aid serve as positive variables that improve the quality of parenting and parental emotional well-being (Armstrong, Birnie-Lefcovitch and Ungar, 2005). Given the evidence of caregiver mental health predicting caregiver's own well-being, as well as the proxy report of psychosocial HRQOL for youth with SCI, it is important to examine the relationship between caregiver mental health and both caregiver-report and youth-report of psychosocial HRQOL.

Family Functioning

Although examining individual caregiver functioning is essential to understanding how youth with disabilities are also functioning, family functioning is also a significant predictor of caregiver psychosocial health (King, King, Rosenbaum, and Goffin, 1999). For Family Stress Theory's *Adaptation Phase*, how a family is functioning overall is a key indicator of how the family has adapted to the stressor. In one study of families of youth (ages 6-15) with traumatic brain injury (TBI), family functioning at pre-injury levels was the most predictive of subsequent family functioning, even more so than severity of injury (J'May, Jaffe, Polissar, Fay, Liao, & Martin, 1996). Anttila, Sourander, Metsahonkala, Aromaa, Helenius, and Sillanpa (2004) found that youth (ages 12-14) with chronic conditions reported worse family functioning than families who had youth without chronic conditions. Additionally, according to the Family Stress Theory’s *Adaptation Phase* (McCubbin and Patterson, 1993), each family member's psychosocial health, problem-solving and coping ultimately impacts the family as a whole. Therefore, if a family member is not coping well with the youth's SCI, a family may experience more dysfunction than a family who is comprised of members coping well. Additionally, if a youth/adolescent with SCI is experiencing secondary complications (such as UTIs from ineffective catheterization method(s)), this may also create stress on the caregiver, including the financial cost for hospitalizing their child. Having to take the child/adolescent to the hospital may also take away time and resources (both emotional and financial) from siblings, which may also negatively impact a sibling’s psychosocial health. If the youth with SCI, caregiver(s), and sibling(s) are experiencing negative disruptions to their routine(s), it may adversely impact the family as a whole.

However, there is also research that demonstrates relatively comparable family functioning in families who do have children with chronic health conditions. In a review of 15 studies measuring family functioning for youth with a chronic condition, most of the studies demonstrated that there was not a significant difference between the functioning of families of youth without a chronic condition and that of families of youth with a chronic condition (McClellan and Cohen, 2007). Kabacoff, Miller, Bishop, Epstein, and Keitner, (1990) compared family functioning using the McMaster Family Assessment Device across three samples, one nonclinical, one psychiatric, and one for families of youth with medical (non-psychiatric) problems. Although the medical (non-psychiatric) families reported more dysfunction than the nonclinical sample, the difference was not statistically significant. This finding suggests that functioning may be similar in families that have a child with a chronic physical health condition versus families with a physically healthy child. Family functioning is an important element to understanding the psychosocial health of a child with SCI. Although SCI is a traumatic event for a family, it is important to note that healthy family functioning serves as a positive factor for family members, including the child with SCI. Understanding family functioning gives us a wider lens into understanding a child's psychosocial health.

Rationale

This study is also the first to look at how four specific factors, individually and cumulatively impact both youth-report psychosocial HRQOL and caregiver proxy-report psychosocial HRQOL for youth with SCI. The four specific factors include 1) adolescent and caregiver social problem solving skills and orientation, 2) bowel/bladder functioning, 3) overall family dysfunction, and, 4) caregiver mental health. Additionally, this dissertation study is unique, because it looks at the same predictors of HRQOL as HRQOL is seen by both the caregiver and youth from the same families. Discrepancies have been documented between the caregiver and youth-report psychosocial HRQOL (Garma et al., 2011), so it may be important to consider both perspectives in identifying psychosocial HRQOL.

Children and adolescents affected by SCI may experience unique barriers to participating and enjoying activities that individuals without SCI may not experience. Additionally, SCI usually occurs as the result of an immediate episode of trauma with permanent effects as opposed to resulting from a congenital condition. Unlike some conditions, SCI is almost always permanent. Youth may have had no health or mobility limitations prior to SCI and may experience a complete and total change immediately after SCI. Therefore, SCI presents a host of challenges and potential changes for both youth with SCI and their families.

Additionally, with positive medical advancements, individuals with pediatric-onset SCI are living longer lives than before. However, living longer also presents new challenges and considerations in terms of long-term care for their physical health and potentially a new set of complications that develop with aging. Researchers and clinicians are identifying disease-specific HRQOL issues and developing HRQOL instruments from speaking with individuals who are impacted by the condition (Franciosi et al., 2012; Panepinto et al., 2012).

More recently, Tulsky et al. (2015) developed an SCI-HRQOL for adults with SCI, called SCI-QOL. Although there is clearly overlap between HRQOL for adults with SCI and youth with SCI, developmental differences may make some issues particularly salient for youth that are not as salient for adults, and vice versa. This particular study uses an instrument that is youth-specific (i.e., psychosocial subscales of the PEDS-QL, Varni et al., 2001) and has been well-tested and validated among youth with disabilities, including youth with SCI. The effectiveness of problem-solving interventions, and relevance for adolescents with SCI who are transitioning into adulthood, merits an exploration of problem-solving skills and how they may predict psychosocial HRQOL.

Family Stress Theory's *Adaptation Phase* (McCubbin and Patterson, 1993) examines how family members are coping with a stressor in the long-term. If adolescents and caregivers are adapting in a negative way (e.g., perceiving challenges as insurmountable) with ineffective strategies (e.g., avoiding solving a problem), then a family is not adjusting well to the stressor (i.e., the SCI). Alternatively, if adolescents and caregiver are adapting in a positive way (e.g., seeing problems as challenges) with effective strategies (i.e., thinking through potential solutions to a problem), then a family is adjusting well to the stressor.

For adolescents with SCI, coping research suggests that social support, emotional regulation (calming) and cognitive restructuring are effective coping strategies (Smith, Russell, Kelly, Mulcahey, Betz and Vogel, 2013). Alternatively, using escape-oriented and avoidant coping strategies was linked to a lower psychosocial HRQOL and higher anxiety and depression scores. Although coping has been studied for youth with SCI, to this author's knowledge, adolescent social problem-solving skills and orientation have not. Understanding problem-solving in adolescents may give us insight into how the adolescent is handling their SCI. Considering that positive problem solving skills and orientation have been linked to better psychosocial HRQOL and improved disease-related outcomes in other conditions, they may also be linked to psychosocial HRQOL for adolescents with SCI (Barakat, et al., 2014; Berry et al., 2012; Eccleston et al., 2012). Additionally, negative problem-solving skills and orientation have also been linked to negative overall HRQOL outcomes and disease-related symptoms in adolescents (Dreer et al., 2005). Therefore, it is also important to see how the negative problem solving may adversely impact psychosocial HRQOL. It may also be interesting to see to what extent problem-solving skills and orientation uniquely contribute to psychosocial HRQOL for adolescents as opposed to all individuals with SCI. Although this current study does not contain a social problem-solving intervention, it is still beneficial to see how both the caregiver and youth with SCI perceive problems in a positive or negative way. Furthermore, problem-solving skills and orientation are teachable and have been shown to be effective for both caregivers and youth with chronic conditions (Law et al., 2016.) Therefore, it is a point for intervention for parents and youth who may need to develop more positive problem-solving abilities.

When asked the most important priority that affects their quality of life, adults with SCI have reported that it is improving their bowel and bladder functioning (Anderson, 2004). Incontinence is an issue that is relevant for individuals with SCI in terms of understanding potential physical health complications, such as UTI. Furthermore, it is also crucial to understand how incontinence may impact participation and cause social embarrassment (Hicken, Putzke, and Richards, 2001). Considering that reducing incontinence and improving bowel and bladder care regimens are specific sub-domains that have been identified for SCI-HRQOL research, these may also be important and salient issues for youth with SCI (Tulsky et al., 2015).

However, it should be noted that among youth with spina bifida, clean intermittent catheterization is considered the best bladder care method, but this method has also been linked to higher levels of caregiver stress (Kanaheswari, Razak, Chandra, & Ong, 2011). Clean intermittent catheterization provides a reduced risk of causing a UTI, but is also labor-intensive for the caregiver, who needs to change the catheter as frequently as every 4-6 hours. Borzyskowski, Cox, Edwards, and Owen (2004) examined how bowel and bladder management for youth with urinary incontinence (including SCI, spina bifida, and other neurogenic bladder conditions) impacted families. Borzyskowski et al. (2004) found that a simply needing a bladder care program is a psychosocial stressor for not only the caregiver and youth, but for the family as a whole. Therefore, both effective disease management (preventing bowel and bladder accidents), and complications resulting from ineffective bowel/bladder care can negatively impact caregiver psychosocial health. Therefore, according to Family Stress Theory's *Adaptation Phase*, it is important to note that minimizing bowel and bladder accidents may reduce potential stressor(s) (i.e., avoiding a youth with SCI being hospitalized due to a UTI) while also creating more caregiver stress (viz, caregiver needing to catheterize the youth with SCI every 4-6 hours to avoid a UTI).

Additionally, if youth with SCI are worried about a bowel and/or bladder accident, they may not participate in certain situations and/or activities. If youth with SCI are not participating in activities, this may also negatively impact caregivers and other family members who may worry about the youth with SCI (McCubbin and Patterson, 1993). Although incontinence has been found to be predictive of HRQOL for adults with SCI and for youth with spina bifida, which is perhaps the closest related health condition to SCI, its relation to psychosocial HRQOL has yet to be studied among youth with SCI (Olesen, Kiddoo, and

Metcalfe, 2013.) To this author's knowledge, this is the first study examining how incontinence impacts psychosocial HRQOL for youth with SCI. Furthermore, it is the first study to examine the frequency of both fecal and urinary incontinence among youth with SCI without TBI. This study will help glean some insight into the prevalence of incontinence among youth with SCI, as well as measuring its potential impact on psychosocial HRQOL.

Furthermore, previous research has found relationships between caregiver psychosocial health and the psychosocial health of youth with SCI, as well as relationships between family functioning and disease-related outcomes for youth with chronic conditions other than SCI (Garma et al., 2011;King, King, Rosenbaum, and Goffin, 1999). These findings suggest that for youth with SCI, there may be relationships between family functioning and youth psychosocial HRQOL. Family functioning has been found to be related to the psychosocial health of youth with a chronic condition (Drotar, 1997). Additionally, SCI is a condition that requires constant ongoing management specific to SCI (such as bowel and bladder care, concerns around mobility, addressing pain issues, etc.). Therefore, how the family functions may be a contributing factor for how SCI is managed in the home. Measuring how the family is functioning may also give insight into how much support the child with SCI is receiving. It is possible that a family that demonstrates greater dysfunction may not have adequate resources or may be experiencing family dynamics that are not conducive to the child's overall HRQOL (McCubbin and Patterson, 1983). To the author's knowledge, the relation of family functioning and the health-related quality of life of children and youth with SCI has not been studied previously.

This dissertation study looks at psychosocial HRQOL for youth with SCI by considering different levels of variables in the family in accordance with Family Stress Theory (McCubbin and Patterson, 1993). This dissertation study includes four different factors, including adolescent and caregiver social problem solving skills/orientation, incontinence, overall family functioning, and, caregiver mental health (measured by anxiety and depression). These four factors were selected in order to understand whether and how multiple, diverse factors (viz., ability to solve problems, physical health, mental health, how the family is functioning) may impact psychosocial HRQOL.

For youth with spina bifida, Holmbeck (2007), notes that adjusting to a chronic condition is multi-faceted and multi-directional. For youth with spina bifida, biological, social, neuropsychological and family functioning components all influence one another. Although spina bifida has some similar implications as SCI for youth, including problems with mobility and incontinence, the implications of the disorder are not the same. Spina bifida typically includes neurocognitive implications, whereas the youth with SCI in this present study do not have neurological impairments.

Although an SCI-specific HRQOL instrument has recently been published, it was developed for adults with SCI (Tulsky et al. 2015). Some factors are relevant for youth with SCI, although there are some areas that are not identified due to developmental differences (i.e., school-related HRQOL, parent psychosocial functioning and how it may impact the child or adolescent with SCI, etc.) Thus, looking at different predictors may give insight into which factor(s) are most impactful in terms of psychosocial HRQOL for youth (ages 6-18) with SCI.

Research Hypotheses and Questions

Hypotheses: PREDICTING YOUTH PERCEPTIONS OF QUALITY OF LIFE

The following hypotheses (I.A, I.B, and I.C) use the youth-report psychosocial HRQOL scores as the dependent variable. The subsequent hypotheses (II.A, II.B, and II.C) use the caregiver proxy report of the youth psychosocial HRQOL scores as the dependent variable.

Hypothesis I.A.1: Adolescent having a greater Positive Problem Orientation and using more rational problem-solving (i.e., positive problem-solving strategies) will report higher psychosocial health-related quality of life

I.A.2: Adolescents having a greater Negative Problem Orientation and using Impulsivity/Carelessness and Avoidance (i.e., negative problem solving strategies) will report lower psychosocial HRQOL.

Hypothesis I.B. Fecal and urinary incontinence predicts lower psychosocial quality of life for youth with SCI.

Hypothesis I.C.: Caregiver mental health problems (i.e., anxiety and depression) and family dysfunction predict lower youth-report psychosocial quality of life.

Hypotheses: PREDICTING CAREGIVER PERCEPTIONS OF YOUTH QUALITY OF LIFE

The following hypotheses (II.A, II.B, and III.C) use the caregiver proxy report of the youth psychosocial HRQOL scores as the dependent variable. The hypotheses from the previous section (I.A, I.B, and I.C) use the youth-report psychosocial HRQOL scores as the dependent variable.

Hypothesis II.A.1. Caregivers having a greater Positive Problem Orientation and using more Rational Problem Solving (i.e., positive problem-solving strategies) will report higher proxy psychosocial HRQOL.

II.A.2: Caregivers having a greater Negative Problem Orientation and using Impulsivity/Carelessness and Avoidance (i.e., negative problem solving strategies) will report lower proxy psychosocial HRQOL.

Hypothesis II.B. Fecal and urinary incontinence predicts lower psychosocial quality of life for youth with SCI as perceived by the primary caregiver.

Hypothesis II.C: Caregiver mental health problems (i.e., anxiety and depression) and family dysfunction predict lower caregiver-report psychosocial quality of life for youth with SCI.

Research Question:

III. If multiple variables predict youth health-related psychosocial quality of life, are there parsimonious models of a) youth-report and/or b) caregiver-report factors that explain variance in quality of life scores?

Methods

Participants.

Youth with SCI:

Participants (*n* = 158) were recruited at three orthopedic hospitals (one in the Midwest, one on the East Coast, and one on the West Coast) within the same hospital system. Youth from ages 1-18 were recruited for the overall study and had sustained their SCI for at least 1 year. However, the 158 youth in this study included only patients 6-18 years old and also had data available from the primary caregiver. Youth ages 6-18 were selected because developmentally, they should be toilet trained, and are also old enough to be in school. If a bowel or bladder accident occurs, it is more likely to be due to a complication of SCI as opposed to bowel/bladder accidents that may occur as a part of toilet training.

For this particular study, participants and their primary caregivers (*n* = 158) were included. Participants with SCI were, on average, 12.66 years old (*SD* =3.97), and were, on average, 6.28 (*SD* = 5.19 years) years old at the time of injury. There were 90 males with SCI and 68 females with SCI in the study. In terms of race, 94 participants are Caucasian, 8 are African-American, 1 is Native American, 27 are of Hispanic origin, 4 are Asian, 6 are other, and 18 participants did not provide responses. In terms of DeVivo ASIA (American Spinal Injury Association) score/level of injury, 30 participants are categorized as tetraplegic/ABC, 75 participants are categorized as paraplegic/ABC, 19 participants are categorized as D (more than 50 percent of the muscles below the level of injury are strong enough to move against gravity), and 34 participants did not provide responses (https://www.travisroyfoundation.org/sci/resources/spinal-cord-injury-levels-classification/). 110 participants primarily speak English at home, 24 primarily spoke Spanish, 1 spoke both, 1 spoke a different language than English or Spanish, and 22 participants did not provide responses.

Primary Caregivers of Youth with SCI:

Primary caregivers were, on average, 42.53 years old (*SD* = 7.9 years) at the time of data collection. There were 142 primary female caregivers and 16 primary male caregivers. 111 of the primary caregivers are mothers, 1 is a step-mother, 6 are grandmothers, 16 are fathers, 4 self-identified as “Other,” and 20 did not provide responses. 92 primary caregivers are Caucasian, 10 are African-American, 1 is Native American, 27 are of Spanish Origin, 5 are Asian, 2 self-identified as Other/Unclassified, and 21 participants did not provide responses.

Table 1. Demographics of Youth (Ages 6-18) with SCI

Variable	
Race	*n*
Caucasian	94
African-American	8
Native American	1
Spanish origin	27
Asian	4
Other	6
Missing	18
Gender	
Male	90
Female	68

DeVivo/ASIA Score (Level of Injury)	
Tetraplegic/ABC	30
Paraplegic/ABC	70
D	19
Missing	39

Table 2. Demographics of Caregivers

Variable	
Race	*n*
Caucasian	92
African-American	10
Native American	1
Spanish origin	27
Asian	5
Other	2
Missing	21
Gender	
Male	16
Female	142
Caregiver Role	
Mother	111
Stepmother	1

Grandmother	6
Father	16
Missing	24

Measures

Youth with SCI (Ages 6-18): Youth Self-Report and Caregiver Proxy Report

Pediatric Quality of Life Inventory (Peds-QL). The Peds-QL (Varni, Seid, and Kurtin, 2001) measures health-related quality of life of and was tested among youth with a chronic condition and healthy youth (See Appendix C.) The Peds-QL contains 23 items and 4 subscales, including Physical Functioning (8 items), School Functioning (5 items), Social Functioning (5 items), and Emotional Functioning (5 items). The survey items ask how much certain things (i.e., socializing, focusing at school, etc.) have been a problem in the past month. The raw item scores include 0 (Never a problem), 1 (Almost never a problem), 2 (Sometimes a problem), 3 (Often a problem), and 4 (Almost always a problem). The items are then reverse scored and linearly transformed so that higher scores indicated better HRQOL. The scores are converted to a 100-point scale, so that 0 =100, 1= 75, 2= 50, 3= 25, and 4=0. Only the psychosocial subscales, including School Functioning (5 items), Emotional Functioning (5 items), and Social Functioning (5 items) were analyzed, and the psychosocial PEDS-QL will be referred to as psychosocial HRQOL for this study. Sample items from School Functioning include, “It is hard to pay attention in class” and “I forget things.” Sample items for Emotional Functioning include “I have trouble sleeping” and “I feel angry.”

Sample items for Social Functioning include, “It is hard to keep up with my peers,” and “Other kids tease me.” In a previous study of youth with SCI (Garma, Kelly, Daharsh and Vogel, 2010), youth reported the following means and standard deviations for each subscale: School Functioning, *M* = 66.0 (*SD* = 19.6), Emotional Functioning, *M* = 68.60 (*SD* = 19.6), and Social Functioning, *M* = 74.4 (*SD* = 19.0). For this dissertation study, the following alpha scores were reported, School Functioning (0.70), and Emotional Functioning (0.71), indicating average to good reliability in terms of measuring dimensions of health-related quality of life. Social Functioning reported a lower alpha scale (0.61), indicating that for this population, this subscale may lack some internal consistency. However, the Social Functioning sub scale has previously been reported to have a lower alpha score when compared to the School Functioning and Emotional Functioning sub scales of the psychosocial PEDS-QL/psychosocial HRQOL, so the 0.61 alpha level in this dissertation study is not surprising (Garma et al., 2011). In terms of validity, the PEDS-QL has been tested in several populations and has demonstrated the ability to distinguish differences between youth with a chronic condition and healthy youth (Varni et al., 2003). Additionally, using the known groups method and by comparing item correlations with morbidity indicators (e.g., school missed, care needed), the psychosocial HRQOL (psychosocial PEDS-QL) demonstrated good construct validity.

Adolescents with SCI (Youth Ages 13-18) and Caregiver

Social Problem Solving Inventory-Revised (SPSI-R). The Social Problem Solving Inventory-Revised (D'Zurilla and Chang, 1995) is a 52-item self-report measure that measures a person's ability to problem solve in the real world (See Appendix E for measure). This measure includes 5 subscales, which are Positive Problem Orientation (5 items: constructive attitudes and thoughts, such as perceiving problems as challenges to overcome), Negative Problem Orientation (10 items: dysfunctional thoughts and feelings, such as low self-efficacy), Rational Problem Solving (20 items: systematically using effective problem solving skills), Impulsivity/Carelessness Style (10 items: dysfunctional problem-solving that is not well-planned), and Avoidance Style (7 items: dysfunctional behavior, such as procrastination and passivity).

Sample items for Positive Problem Orientation include "When my first efforts to solve a problem fail, I know if I persist and do not give up too easily, I will be able to eventually find a good solution" and "When I am faced with a difficult problem, I believe that I will be able to solve it on my own if I try hard enough." Sample items for Negative Problem Orientation include "I feel threatened and afraid when I have an important problem to solve" and "I feel nervous and unsure of myself when I have an important decision to make." Sample items for Rational Problem Solving include "When I have a decision to make, I try to predict the positive and negative consequences of each option" and "When I am trying to solve a problem, I think of as many options as possible until I cannot come up with any more ideas." Sample items for Impulsivity/Carelessness style include "When making decisions, I do not evaluate all my options carefully enough” and “I am too impulsive when it comes to making decisions.” Sample items for Avoidance style include “I put off solving problems until it is too late to do anything about them” and “I wait to see if a problem will resolve itself first, before trying to solve it myself.”

For each dimension, alpha scores were reported, Positive Problem Orientation (alpha = 0.85), Negative Problem Orientation (alpha = 0.81), Rational Problem Solving (alpha = 0.85), and Avoidance Style (alpha = 0.75). These alphas indicate good internal consistency reliability in terms of measuring problem-solving orientation and approaches. However, Impulsivity/Carelessness Style (alpha =0.60) had a lower alpha score, indicating that this subscale has lower internal consistency. However, it may be that the items from the Impulsivity/Carelessness subscale are more distinct from one another, and less likely to co-occur. The SPSI-R has demonstrated good test-retest reliability, Negative Problem Orientation being the most stable subscale over time (D'Zurilla et al., 2002 Hawkins, Sofronoff, and Sheffield, 2008). In addition, all of the SPSI-R subscales have also demonstrated good construct validity when compared to other mental health measures (D’Zurilla et al 2002). The SPSI-R subscales also demonstrated good divergent validity when compared to unrelated measures (e.g., the SPSI-R subscales were able to distinguish problem-solving from academic achievement scores, Hawkins, Sofronoff, and Sheffield, 2008).

Incontinence (Youth Ages 6-18)

Incontinence was measured using the following questions:

1. Patient frequency of fecal incontinence (within the last three months): 0 = never, 1 = less than once per month, 2 = once every month, 3 = not every week, but at least once per month, 4=not every day but at least once per week, 5 = 1 episode per day, and 6 = 2 or more episodes a day.
2. Patient frequency of urinary incontinence (within the last three months): 0 = none, 1 = yes, unspecified, 2 = average monthly, 3 = average weekly, 4 = average daily

Incontinence data was provided by parent or child-report to a clinician, who filled out a physical health chart. This is not an assessment that has previously had its psychometrics (i.e., validity and reliability) assessed.

Caregiver of youth with SCI

McMaster Family Functioning. The McMaster Assessment Device (Epstein, Baldwin, and Bishop, 1983) is a 53-item scale that measures family functioning and has 7 subscales. For this study, only the General Functioning (12 items) measure was included (see Appendix D for measure).

Item responses are scored from strongly agree (1) to strongly disagree (4), with higher scores indicating more dysfunction. To eliminate confusion, in this particular dissertation, item responses were still be scored the same, and this subscale is referred to as the General Dysfunction subscale. This way, higher scores will indicate more of the variable in the name of the scale. For the General Dysfunction subscale, alpha scores of (.83-.86) were previously reported, indicating good reliability, and good concurrent validity has also been reported (Byles, Byrne, Boyle, & Offord, 1988; Kabacoff et al., 1990; Mansfield, Keitner, & Dealy, 2015). For this dissertation study, good reliability (alpha = 0.88) was reported).

Caregiver Report

Beck Depression Inventory II. The Beck Depression Inventory II (Beck, Steer and Brown, 1996) is a 21-item scale that measures depressive symptomatology among adults. Item responses are scored from 0 to 3, with higher scores indicating more depression. One sample item includes “Feel like a failure” with the response options of “I do not feel like a failure” (0), “I have failed more than I should have” (1), “As I look back, I see a lot of failures” (2), and “I feel I am a total failure as a person” (3). Another item includes “Feelings of sadness” with the response options of “I do not feel sad” (0), “I feel sad much of the time” (1), “I am sad all of the time” (2), and “I am so sad or unhappy that I can’t stand it” (3). High internal consistency and construct validity have been reported (Beck et al., 1996; Storch, Roberti and Roth, 2004). For the Beck Depression Inventory, excellent reliability was reported in this study (alpha = 0.91).

Beck Anxiety Inventory. The Beck Anxiety Inventory (Steer and Beck, 1997) is a 21-item scale that measures anxiety symptomatology among adults. Item responses are scored from 0 to 3, with higher scores indicating more anxiety. One sample item includes “Fear of losing control” with the response options of “Not at all” (0), “Mildly” (1), “Moderately” (2), and “Severely” (3). Another item includes “Shaky” with the response options of “Not at all” (0), “Mildly” (1), “Moderately” (2), and “Severely” (3). Internal consistency, test-retest reliability, convergent and discriminant validity have also been reported (Fydrich, Dowdall, and Chambless, 1992). For the Beck Anxiety scale, excellent reliability was reported in this study (alpha = 0.92).

Data Collection Procedure

IRB approval for this study was obtained before collecting data. The adolescents and caregivers had the options to fill out the measures a) on paper or through an online platform, and b) at home or in-person. Families were recruited during inpatient stays or outpatient (clinic) visits. Data was collected either during the patient's first visit or shortly after their first visit (if the caregivers preferred to answer questions at home, due to time constraints. Caregivers completed the following measures: Social Problem Solving Inventory-Revised Inventory (including 5 subscales), a proxy-report of the PEDS-QL, McMaster Family Functioning - General Functioning scale, Beck Anxiety Inventory, and Beck Depression Inventory II. Youth ages 6-18 completed the following measure: PEDS-QL (HRQOL). Incontinence (both urinary and fecal) was reported by the caregiver and was recorded in the patient's medical records. In addition to the aforementioned scales, adolescents (ages 13-18) completed the Social Problem Solving Inventory-Revised Inventory (including 5 subscales). Only data from the patient’s first data collection point at Shriner’s available in this particular database were used for this study.

RESULTS

Data Preparation

In terms of missing data, participants who were missing more than 1 item for each psychosocial subscale of the youth-report psychosocial quality of life (HRQOL) scales were excluded from all analyses, in accordance with the guidelines of the respective author(s) of each scale. Additionally, participants who were missing more than 1 item for each of the three psychosocial subscales of the caregiver proxy-report of the youth's psychosocial quality of life were excluded from all analyses. For example, a participant could be missing 1 item from each of the psychosocial subscales (i.e., missing 3 items in total), but would not be included if he/she was missing 2 items from one subscale. Individuals who were missing more than 1 item from each of the problem-solving subscales were excluded from the problem-solving analyses. For the subsequent problem-solving analyses, the resulting *n* included between 82-85 adolescents and between 113-114 caregivers. Individuals who were missing responses for the urinary incontinence frequency variable were excluded from the linear regression analyses. For the subsequent incontinence analyses, the resulting *n* included between 94-137 respondents for urinary and between 80-101 respondents for fecal. Individuals who were missing more than 1 response from the caregiver-report family dysfunction scale were excluded from the linear regression analyses. For the family dysfunction analyses, the resulting *n* included between 120-128 respondents. Individuals who were missing more than 1 item from the caregiver depression and more than 1 item from the caregiver anxiety scales were also excluded from the linear regression analyses. For the subsequent caregiver depression and anxiety analyses, the resulting *n* included between 78-92 respondents for caregiver depression and between 119-127 respondents for caregiver anxiety.

Preliminary analyses were conducted to examine both the skewness and kurtosis of the data. Most of the variables, including youth-report psychosocial HRQOL, caregiver-report psychosocial HRQOL, frequency of urinary incontinence, youth-report problem-solving total scale and subscales (including PPO, RPS, NPO, AV, and I/C), caregiver-report problem-solving total scale and subscales (including PPO, RPS, NPO, AV, and I/C), caregiver mental health (i.e., anxiety and depression), family dysfunction, were found to have no significant skewness or kurtosis (within +-2 standard errors). However, frequency of fecal incontinence was found to be significantly positively skewed (+1.35). In order to address skewness and create normalized data, fecal incontinence data was transformed using a square root transformation. Once the fecal incontinence data was transformed, the skewness was reduced to 1.10, with a standard error of .24. Outliers were inspected using normality probability plots. One outlier was discovered for youth-report psychosocial HRQOL, and was excluded from subsequent analyses.

To ensure that the appropriate assumptions for a multiple regression were not violated before analysis, data was also checked for homoscedasticity and multicollinearity. Homoscedasticity was examined for each regression that was conducted by looking at the scatterplots of the residuals. The scatterplots appeared to be randomly distributed and did not exhibit homoscedasticity. Multicollinearity was examined by looking at the Variance Inflation Factor (VIF) for each variable of interest, and all variables, except for caregiver depression and anxiety, had a VIF that exceeded 10 (Hair, Anderson, Tatham and Block, 1995). This means that multicollinearity was not an issue between variables, except for caregiver depression and anxiety. The correlation matrix was examined for all variables. In this matrix, only caregiver anxiety and depression had a correlation that was large enough (r=.58, p <.01) to potentially present a multicollinearity problem for a multiple regression. This significant correlation is not surprising, considering that a high correlation and co-morbidity between anxiety and depression is well documented within the literature (Lovibond and Lovibond, 1995). Furthermore, a previous study (Garma et al., 2011) that looked at the relationship between HRQOL and mental health among youth with SCI and their caregivers, combined depression and anxiety scores into one mental health measure for multiple regression analyses. Therefore, in subsequent multiple regressions where both caregiver depression and anxiety were examined as predictors of HRQOL, both scales were combined and named as one predictor called caregiver mental health.

The location and completeness of an SCI often has different implications in terms of mobility and participation. Therefore, many previous studies (Anderson et al., 2009; Garma et al., 2011) have examined the relationship between level of injury and HRQOL for both adults and children with SCI. Therefore, this present study examined the relationship between the ASIA score/DeVivo category (level of injury) Additionally, ASIA score/DeVivo category(level of injury) was not found to be significantly correlated with either caregiver-report HRQOL or youth-report HRQOL. As noted in Table 3, age was not significantly correlated with the ASIA score/DeVivo category (level of injury), $r(137) = -.14$, *ns*. ASIA score/DeVivo category (level of injury) was also not found to explain a significant proportion of variance in youth-report health-related quality of life, adjusted $R^2 = .01$, $F(1, 110) = .63$, $p = .30$. Age was found to be significantly if modestly correlated with youth-report psychosocial HRQOL ($r = .18$, $p < .05$). However, age did not significantly predict youth-report health-related quality of life, $\beta = t(137) = 1.88$, *ns*, or explain a significant proportion of variance in psychosocial HRQOL scores, adjusted $R^2 = .01$, $F(1, 136) = 3.40$, *ns* (see attached for Correlation Matrix/Table 3).

Table 4 includes means and standard deviations for the following youth-report variables: Psychosocial HRQOL, Total Social Problem-Solving Scale, Positive Problem Orientation, Rational Problem Solving, Negative Problem Orientation, Impulsivity/Carelessness, and Avoidance. Table 5 also includes means and standard deviations for the following caregiver-report variables: Psychosocial HRQOL, Total Social Problem-Solving Scale, Positive Problem Orientation, Rational Problem Solving, Negative Problem Orientation, Impulsivity/Carelessness, Avoidance and Family Dysfunction, Caregiver Anxiety and Caregiver Depression. Table 6 contains data about participants' type(s) of bowel and bladder care management. Table 7 contains frequency of urinary incontinence data, and Table 8 contains frequency of fecal incontinence data.

Both youth-report and caregiver-report psychosocial HRQOL averages in this study were similar to those found in other studies for youth with SCI (Russell et al., 2015). Additionally, caregiver proxy report of psychosocial HRQOL tends to be lower than youth-report psychosocial HRQOL for youth with SCI, which is also consistent with the Garma et al. (2011) study. Although most studies that include social problem-solving inventory scales focus on the change before and after an intervention, total problem-solving scales were similar in this study compared to others at pre-test levels (Law et al., 2016). Unfortunately, to the author's knowledge, there is no published data on rates of fecal and/or urinary incontinence among youth with SCI, so it is not possible to compare these particular variables to other youth with SCI studies. However, there is published research on urinary incontinence rates in adults with SCI (Liu, Attar, Gall, Shah and Craggs, 2010). Almost 12% of adults with SCI reported daily incontinence, over 22% reported weekly incontinence, almost 21% reported monthly incontinence, and slightly over 44% reported no incontinence. In another study (Krogh, Christensen, Sabroe and Laurberg, 2006), fecal incontinence and constipation was measured using a neurogenic bowel dysfunction scale in adults with SCI. 28% of adults had minor bowel dysfunction, 15% had minor dysfunction, 28% had moderate dysfunction, and 29% had severe dysfunction. While these studies do not provide normative rates for youth with SCI, they do indicate that fecal and urinary incontinence are common problems for adults with SCI.

In a study that compared families who have a youth who has a chronic illness/disability with those who do not, family dysfunction scores for families who have healthy youth have been found to have an average of 1.58 (*SD*=.05) on the McMaster Family Functioning Device (Herzer et al., 2010). In this same study, for families of youth with chronic conditions (5 chronic conditions in total), average responses range from the lowest score of 1.60 (*SE* =.05) for youth with epilepsy to the highest score of 1.77 (*SE* =.08) for youth with sickle cell disease. However, even though there were differences found in family dysfunction, they were not statistically significant in the Herzer et al. (2010) study.

Additionally, another study (Schuman et al., 2013) demonstrated that families who had youth with inflammatory bowel disease had even more family dysfunction with averages scores around 1.87 (*SD* = 0.37). Since there was not a control group in this study, it is not possible to see if families of youth with SCI were statistically different. However, when comparing the youth with SCI to the other Herzer et al. (2010) study of youth with various chronic conditions, the average family dysfunction appears to be comparable. In a previous psychosocial health study of the caregivers of youth with SCI, caregiver anxiety was reported as *M*=8.45 (*SD*=8.43) and caregiver depression was *M*=11.37 (*SD*=10.07) (Kelly et al., 2011). However, in this dissertation study, caregivers reported lower levels of anxiety, (*M*=6.67, *SD* =7.80), but the difference was not statistically significant, *t*(265) =1.92, *ns*. Caregivers in this dissertation study also reported lower levels of depression (*M*=8.27, *SD* =7.70) although not statistically significant, *t*(210) =12.84, *ns*, from the Kelly et al. (2011) study.

Overall, although there are no published rates for fecal and urinary incontinence for youth with SCI, the sample in this study is relatively comparable to published rates on measures of psychosocial HRQOL, and social problem-solving scales for youth with SCI (Kelly et al, 2016), and family dysfunction for other youth with chronic health conditions (Herzer et al., 2011).

Table 4. Means and Standard Deviations for Youth-Report Variables:

Variable (Youth)	Mean (SD)
Youth Report Psychosocial HRQOL	70.53 (16.00)
Youth Total Social Problem-solving	13.58 (2.59)
Youth Positive Problem Orientation	2.70 (0.97)
Youth Rational Problem-Solving	2.18 (0.96)
Youth Negative Problem Orientation	3.00 (0.85)
Youth Avoidance	2.88 (0.84)
Youth Impulsivity/Carelessness	2.76 (0.72)

Table 5. Means and Standard Deviations for Caregiver-Report Variables:

Variable (Caregiver)	Mean (SD)
Caregiver Report Psychosocial HRQOL	64.58 (16.52)
Caregiver Total Social Problem-solving	14.45 (2.58)
Caregiver Positive Problem Orientation	2.63 (0.83)
Caregiver Rational Problem-Solving	2.36 (0.84)
Caregiver Negative Problem Orientation	3.09 (0.75)
Caregiver Avoidance	3.22 (0.64)
Caregiver Impulsivity/Carelessness	3.09 (0.76)
Family Dysfunction	1.77 (0.46)
Caregiver Anxiety	6.67 (7.80)
Caregiver Depression	8.27 (7.70)

I. Hypotheses: PREDICTING YOUTH PERCEPTIONS OF HEALTH-RELATED QUALITY OF LIFE

The following hypotheses (I.A, I.B, and I.C) use the youth-report psychosocial HRQOL scores as the dependent variable. The subsequent hypotheses (II.A, II.B, and II.C) use the caregiver proxy report of the youth psychosocial HRQOL scores as the dependent variable.

Hypothesis I.A.1: Adolescent having a greater Positive Problem Orientation and using more Rational Problem Solving (i.e., positive problem-solving strategies) will report higher psychosocial health-related quality of life

I.A.2: Adolescents having a greater Negative Problem Orientation and using Impulsivity/Carelessness and Avoidance (i.e., negative problem solving strategies) will report lower psychosocial HRQOL.

Adolescents with SCI (youth ages 13-18 and excluding youth ages 6-12) and caregivers completed the SPSI (social problem-solving scale). For Hypothesis I.A, five separate linear regressions were conducted to determine which adolescent report subscales predicted youth-report psychosocial HRQOL. Each regression was conducted separately to examine how each problem-solving subscale impacted youth-report psychosocial HRQOL.

The first linear regression found that youth Positive Problem Orientation significantly predicted youth-report psychosocial HRQOL, $\beta=.24$, $t(83) = 2.27$, $p < .05$, and also explained a significant proportion of variance in psychosocial HRQOL scores, adjusted $R^2 = .06$, $F(1, 82) = 5.17$, $p < .05$. Therefore, youth who utilized greater Positive Problem Orientation experienced higher psychosocial HRQOL. The second linear regression found that youth Rational Problem solving was found to significantly predict youth-report psychosocial HRQOL, $\beta = .24$, $t(83) = 5.84$, $p < .05$, and was also found to explain a significant proportion of variance in psychosocial HRQOL scores, adjusted $R^2 = .06$, $F(1, 82) = 4.93$, $p < .05$. Therefore, youth who utilized more rational problem solving skills experienced higher psychosocial HRQOL.

The third linear regression found that youth Negative Problem Orientation (NPO) significantly predicted youth-report psychosocial HRQOL, $\beta = -.55$, $t(85) = -6.08$, $p < .01$, and also explained a significant proportion of variance in psychosocial HRQOL scores, adjusted $R^2 = .31$, $F(1, 84) = 36.92$, $p < .01$. Therefore, youth who utilized a more Negative Problem Orientation experienced lower psychosocial HRQOL. The fourth linear regression found that youth Impulsivity/Carelessness (I/C) significantly predicted youth-report psychosocial HRQOL scores, $\beta = -.28$, $t(83) = -2.60$, $p < .05$, and also explained a significant proportion of variance in psychosocial HRQOL scores, adjusted $R^2 = .08$, $F(1 ,82) = 6.75$, $p <. 05$. Therefore, youth who utilized more impulsivity/carelessness in their problem-solving experienced lower psychosocial HRQOL. The fifth linear regression found that youth Avoidance (AV) significantly predicted youth-report psychosocial HRQOL scores, $\beta = -.38$, $t(82) = -3.65$, $p < .01$, and also were found to explain a significant proportion of variance in psychosocial HRQOL scores, adjusted $R^2 = .14$, $F(1, 81) = 13.33$, $p < .01$. Therefore, youth who utilized more avoidant problem-solving experienced lower psychosocial HRQOL.

Considering that each of the five individual subscales of the problem-solving inventory was a significant predictor of youth-report psychosocial HRQOL, the total problem-solving scale (which included all 5 subscales) was entered as a predictor. In a linear regression, overall youth total problem-solving scores (including all 5 subscales) were found to be a significant predictor of youth-report psychosocial HRQOL, $\beta = .54$, $t(82) = 2.60$, $p < .01$, and also explain a significant proportion of variance in psychosocial HRQOL scores, adjusted $R^2 = 0.30$, $F(1, 81) = 34.06$, $p < .01$. It is important to note that youth NPO explained a similar amount of variance (adjusted $R^2 =.31$, $\beta =.55$) when compared to total youth problem-solving (adjusted $R^2 =.30$, $\beta =.54$), suggesting that NPO alone may be a more parsimonious way to examine the impact of problem-solving skills on youth-report psychosocial HRQOL. Alternatively, when 4 of the 5 subscales (including PPO, RPS, I/C and AV - excluding NPO) were entered as predictors for youth-report psychosocial HRQOL in a multiple linear regression, only AV remained a significant predictor, $\beta = -.41$, $t(82) = -3.06$, $p < .05$ and explained a significant proportion of variance in youth-report psychosocial HRQOL scores, adjusted $R^2 = 0.24$, $F(4, 57) = 5.69$, $p < .01$. Considering that including the 4 out of 5 subscales yielded a smaller amount of variance explained than using only the NPO subscale for predicting youth-report psychosocial HRQOL, NPO still seems to be the best predictor for youth-report psychosocial HRQOL.

Hypothesis I.B. Fecal and urinary incontinence predicts lower psychosocial quality of life for youth with SCI.

Table 6: Bowel and Bladder Care Management

Wearing Diapers (*n*=158)	Main Catheterization Method (*n*=158)
No = 83	Intermittent self-catheterization = 72
Yes, overnight only =8	Catheterization by attendant = 40
Yes, other = 3	Multiple Methods = 9
Yes, unspecified = 3	Other = 1
Yes, 24 hours a day = 44	Diapers = 4
Missing = 17	Transurethral = 3
	Mitranoff = 5
	Missing = 24

Table 7: Urinary Incontinence within last 3 months

Frequency	**N (Total = 158)**
None	**63 (39.87%)**
Yes, unspecified	10 (6.33%)
Yes, average daily	41 (25.95%)
Yes, average weekly	25 (15.82%)
Yes, average monthly	8 (5.06%)
Missing	11 (6.97%)

For urinary incontinence within last 3 months, 63 youth (39.87%) reported “None,” (see additional details in Urinary Incontinence table), whereas 84

(53.16%) youth reported at least some urinary incontinence. Unspecified urinary incontinence was excluded from the following regression to better interpret the findings. Frequency (as a continuous variable) of urinary incontinence within the last 3 months was not found to be a significant predictor of youth-report psychosocial HRQOL scores, β =-.14, $t(118) = -1.55$, p=.13, and did not explain a significant proportion of variance in psychosocial HRQOL scores, adjusted $R^2 = .01$, $F(1, 117) = 2.39$, p=.13. This means that urinary incontinence was not found to significantly predict youth-report psychosocial HRQOL.

Table 8: Fecal Incontinence within last 3 months

Frequency	**n (Total = 158)**
Never	51 (32.28%)
Daily	4 (2.53%)
Not every day, but at least once a week	12 (7.60%)
1-3 times a month	1 (0.63%)
Monthly	5 (3.16%)
Less than once a month	28 (17.72%)
Missing Responses	57 (36.08%)

For fecal incontinence within the last three months, 57 youth were missing responses, and 51 reported no fecal incontinence. Before analyses, the fecal incontinence data was normalized with a square root transformation. Frequency of fecal incontinence was found to be a significant predictor of youth-report psychosocial HRQOL, $\beta = -.22$, $t(99) = -2.92$, $p < .05$, and also explain a significant proportion of variance in psychosocial HRQOL scores, adjusted $R^2 = 0.05$, $F(1, 98) = 4.82$, $p < .05$.

A Little's test (Little, 1988) was conducted to see if urinary and fecal data were missing completely at random (MCAR), or if there was a pattern to the missing data. The Little's test was significant for both urinary and fecal incontinence, $\chi^2 = 9.56$, df = 2, $p < .01$, suggesting that both measures were not missing completely at random. This finding means that there was a pattern to which urinary and fecal incontinence data were missing.

Hypothesis I.C.: Caregiver mental health problems (i.e., anxiety and depression) and family dysfunction predict lower youth-report psychosocial quality of life.

In terms of mental health problems, caregivers reported an average score of 6.67 (*SD* =7.80) on the Beck Anxiety measure (*n*=120) and an average score of 8.27 (*SD* =7.27) on the Beck Depression measure (*n*=87). Caregiver anxiety was not found to significantly predict youth-report psychosocial HRQOL, β =-.06, $t(127)$=-.05, p =.96, or explain a significant proportion of variance in youth-report psychosocial HRQOL scores, adjusted R^2 =.00, $F(1,126) = .63$, $p = .96$. This finding indicates that caregiver anxiety did not necessarily have an impact on youth-report psychosocial HRQOL. Caregiver depression trended significantly towards predict youth-report psychosocial HRQOL, $\beta = -.21$, $t(78) = -1.78$, p =.08, and explained a proportion of variance in youth-report psychosocial HRQOL scores at the trend level, adjusted $R^2 = .04$, $F(1,77) = 3.15$, $p = .08$.

Caregivers reported an average score of 1.77 (*SD* = 0.46) on the McMaster Family Assessment/Dysfunction Device. Family dysfunction scores were not found to be a significant predictor of youth-report psychosocial HRQOL scores, $\beta = -.06$, $t(128) = -.66$, $p = .51$, or explain a significant proportion of variance in youth-report psychosocial HRQOL scores, adjusted $R^2 = .00$, $F(1, 127) = 0.44$, $p = .51$. This finding indicates that family dysfunction, reported by caregiver, did not necessarily impact youth-report psychosocial HRQOL.

II. Hypotheses: PREDICTING CAREGIVER PERCEPTIONS OF YOUTH QUALITY OF LIFE

The following hypotheses (II.A, II.B, and III.C) use the caregiver proxy report of the youth psychosocial HRQOL scores as the dependent variable. The hypotheses from the previous section (I.A, I.B, and I.C) use the youth-report psychosocial HRQOL scores as the dependent variable.

Hypothesis II.A.1. Caregivers having a greater Positive Problem Orientation and using more rational problem-solving (i.e., positive problem-solving strategies) will report higher proxy psychosocial HRQOL.

II.A.2: Caregivers having a greater Negative Problem Orientation and using Impulsivity/Carelessness and Avoidance (i.e., negative problem solving strategies) will report lower proxy psychosocial HRQOL.

Caregiver-report psychosocial HRQOL scores (i.e., the caregiver's perceptions towards the youth's psychosocial quality of life) were also analyzed. Each social problem-solving subscale (total of 5 linear regressions, 1 for each subscale) was entered in individually as a predictor for caregiver proxy-report of youth psychosocial HRQOL. In terms of significant correlations, caregiver Avoidance was significantly correlated with caregiver Impulsivity/Carelessness, $r(137) = 0.48$, p

$<.01$ and caregiver Negative Problem Orientation, $r(137) = .50$, $p <.01$. Caregiver Negative Problem Orientation was also found to be significantly correlated with caregiver Impulsivity/Carelessness, $r(137) = 0.48$, $p <.01$.

The first linear regression found that caregiver Positive Problem Orientation was not predictive of caregiver-report youth psychosocial HRQOL, $\beta = .06$, $t(114) = 0.61$, $p =.55$, and did not explain a significant proportion of the variance, adjusted $R^2 = .00$, $F(1,113) = 0.37$, $p =.55$. The second linear regression found that caregiver Rational Problem Solving was not predictive of caregiver-report youth psychosocial HRQOL, $\beta = .11$, $t(113) = 1.15$, $p =.26$, and did not explain a significant proportion of the variance, adjusted $R^2 = .01$, $F(1,112) = 1.31$, $p = .26$. These findings indicate that a caregiver's Positive Problem Orientation and Rational Problem Solving did not impact their proxy report of psychosocial HRQOL. This finding is dissimilar to the earlier findings for Hypothesis I.A. The H.I.A findings demonstrated that both youth Positive Problem Orientation and youth Rational Problem Solving positively and significantly impacted youth-report psychosocial HRQOL.

The third linear regression found that caregiver Negative Problem Orientation was predictive of caregiver-report psychosocial youth HRQOL, $\beta = -.29$, $t(114) = -3.24$, $p < .01$, and explained a significant proportion of the variance, adjusted $R^2 = .09$, $F(1,113) = 10.49$, $p < .01$. These findings are significant, and suggest that caregivers who have a more Negative Problem Orientation also report lower psychosocial HRQOL for their child/adolescent. The fourth linear regression found that caregiver Impulsivity/Carelessness was also predictive of caregiver-report youth psychosocial HRQOL, $\beta = -.19$, $t(114) = -2.08$, $p < .05$, and explained a significant proportion of the variance, adjusted $R^2 = .04$, $F(1,113) = 4.33$, $p < .05$. Similar to the previous regression, greater caregiver impulsivity/carelessness also predicts lower proxy-report of psychosocial HRQOL for their youth. The fifth linear regression found that caregiver Avoidance was not predictive of caregiver-report youth psychosocial HRQOL, $\beta =-.14$, $t(113) = -1.47$, $p =.14$, and did not explain a significant proportion of the variance, adjusted $R^2 = .02$, $F(1,112) = 2.17$, $p = .14$. Similar to the findings in Hypothesis I.A, higher caregiver Negative Problem Orientation and Impulsivity/Carelessness significantly predicted lower caregiver proxy report of youth psychosocial HRQOL; however, unlike the youth-report psychosocial HRQOL findings, caregiver Avoidance was not a significant predictor of caregiver proxy report of youth psychosocial HRQOL.

Primary caregiver social problem-solving total scores (i.e., how a caregiver perceives his/her own problems and problem-orientation) were also found to significantly predict caregiver-report psychosocial HRQOL scores, $\beta = .23$, $t(111) = 2.43$, $p < .05$, and explained a significant proportion of the variance, adjusted $R^2 = .05$, $F(1,127) = 7.29$, $p < .05$. This finding suggests that caregivers who utilize more positive problem solving skills and fewer maladaptive problem-solving skills report higher proxy psychosocial HRQOL for their youth. However, the total variance of psychosocial HRQOL scores explained by the total social problem-solving scale (adjusted $R^2 = .05$) is less than the variance explained by 1 subscale, NPO, (adjusted $R^2 = .09$), suggesting that using only the NPO subscale may be a more parsimonious model.

A multiple regression was used to see if there was a more parsimonious model by using only the significant caregiver social problem-solving subscales (NPO and I/C) that were predictive of caregiver-report youth psychosocial HRQOL. Negative Problem Orientation (NPO) significantly predicted caregiver-report psychosocial HRQOL scores, $\beta = -.26$, $t(113) = -2.51$, $p < .01$. This means that higher impulsivity/carelessness predicted lower HRQOL. Impulsivity/Carelessness (I/C) did not significantly predict caregiver-report psychosocial HRQOL scores, $\beta =-.07$, $t(113) = -0.67$, $p = .51$. In this multiple regression, NPO explained a significant proportion of the variance in caregiver-report youth psychosocial HRQOL scores, adjusted $R^2= .07$, $F(1, 112) = 5.40$, $p <.01$. The amount of variance explained by Negative Problem Orientation suggests that only using this subscale may be a more parsimonious way to explore caregiver proxy report of psychosocial HRQOL.

Hypothesis II.B. Fecal and urinary incontinence predicts lower psychosocial quality of life for youth with SCI as perceived by the primary caregiver.

Frequency of urinary incontinence in the past three months (excluding unspecified) was found to significantly predict caregiver-report psychosocial HRQOL scores, $\beta = -.21$, $t(93) = -2,03$, $p < .05$, and explained a significant proportion of the variance, adjusted $R^2 = .03$, $F(1,92) = 4.10$, $p < .05$. This finding indicates that greater frequency of urinary incontinence predicts a reduced psychosocial HRQOL. Frequency of fecal incontinence in the past three months was not found to significantly predict caregiver-report psychosocial HRQOL scores, β =-.14, $t(80)$ =-1.26, p = .21 and did not explain a significant proportion of variance in caregiver-report psychosocial HRQOL scores, adjusted R^2 = 0.00, $F(1, 79)$ = 1.58 , p = .21. Although the previous finding in Hypothesis I.B found that fecal incontinence was a negative predictor of psychosocial HRQOL for youth and that urinary incontinence was not a significant predictor, the findings were reversed for the caregiver report of psychosocial HRQOL. For caregiver report psychosocial HRQOL, fecal incontinence was not a significant predictor and urinary incontinence was a significant predictor.

Hypothesis II.C: Caregiver mental health problems (i.e., anxiety and depression) and family dysfunction predict lower caregiver-report psychosocial quality of life.

Family Dysfunction was found to significantly predict caregiver-report psychosocial HRQOL scores, β = -.29, $t(120)$ = -3.26, p < .01, and explained a significant amount of variance, adjusted R^2 = .08, $F(1,119)$ = 10.61, p < .01. This finding suggests that greater family dysfunction significantly predicts a reduced caregiver-report psychosocial HRQOL.

Caregiver anxiety was found to be predictive of caregiver-report psychosocial quality of life for youth, β = -.31, $t(119)$ = -3.58, p < .01, and explained a significant proportion of the variance, adjusted R^2= .10, $F(1,118)$ = 12.84, p <.01. Caregiver depression was also found to be predictive of caregiver-report psychosocial HRQOL, β = -.49, $t(92)$ = -4.39, p < .01, and explained a significant proportion of the variance, adjusted R^2= .16, $F(1,91)$ = 17.35, p <.01. As mentioned earlier, because caregiver anxiety and depression demonstrated a high correlation with one another (r=.58, p < .01), they were combined as one predictor in a linear regression called caregiver mental health problems. Caregiver mental health problems were found to be predictive of caregiver-report psychosocial HRQOL, β = -.37, t(74) = -3.43, p <.01, and explained a significant proportion of the variance, adjusted R^2= .14, F(1,73) = 11.78, p <.01. This finding suggests that caregiver mental health problems (i.e., higher caregiver anxiety and depression) predict lower caregiver proxy report of psychosocial HRQOL. However, since caregiver depression explained a greater proportion of variance in HRQOL scores (adjusted R^2= .16) when compared to the combination of caregiver anxiety and depression (adjusted R^2= .14), using only caregiver depression appears to be more parsimonious.

Research Question:

III. If multiple variables significantly predict youth psychosocial health-related quality of life, is there a parsimonious model of youth-report and of caregiver-report factors that explains variance in psychosocial health quality of life scores for youth?

Youth-Report HRQOL

Multiple regressions were conducted to see if a more parsimonious model could be created to significantly predict variance in youth-report psychosocial HRQOL scores for adolescents. To determine which predictors should be entered, the adjusted R^2 values from the previous linear regressions for youth-report psychosocial HRQOL in Hypothesis I.A, I.B, and I.C were examined. For Hypothesis I.A, youth-report NPO explained more variance (adjusted R^2 =.31, β =.55) than any of the other problem-solving subscales or the youth total social problem-solving scale, (adjusted R^2 =.30, β =.54). Therefore, NPO was selected as the only subscale predictor from the youth total social problem-solving scale. In Hypothesis I.B, frequency of fecal incontinence was found to be a significant predictor of youth-report psychosocial HRQOL whereas frequency of urinary incontinence was not. In Hypothesis I.C, neither family dysfunction nor caregiver anxiety were found to significantly predict youth-report psychosocial HRQOL, so they were not entered into the multiple regression. However, caregiver depression was found to be a significant predictor at the trend level, so it was included in the second regression.

Youth-report NPO and frequency of fecal incontinence were entered as predictors of youth-report psychosocial HRQOL in a multiple linear regression. Youth-report NPO was predictive of youth-report psychosocial HRQOL, β =-.65, $t(56)$ =-6.55, p <.01 Fecal incontinence was also predictive of youth-report psychosocial HRQOL, β =-.34, $t(56)$ =-3.46, p <.01. In this multiple regression, youth report NPO and fecal incontinence explained a significant proportion of the variance in youth-report psychosocial HRQOL scores, adjusted R^2=.46, $F(2,54)$ =24.82, p <.01. Therefore, utilizing NPO (i.e., having a pessimistic view towards the future, worrying about problems, etc.) and experiencing fecal incontinence predicted lower youth-report HRQOL.

Youth-report NPO, frequency of fecal incontinence, and caregiver depression were entered as predictors of youth-report psychosocial HRQOL in a multiple linear regression. Youth-report NPO was predictive of youth-report psychosocial HRQOL, $\beta = -.63$, $t(28) = -3.98$, $p <.01$. Fecal incontinence did not significantly predict youth-report psychosocial HRQOL, $\beta = -.27$, $t(28) = -1.74$, $p =.10$. Caregiver depression did not significantly predict youth-report psychosocial HRQOL, $\beta = -.09$, $t(28) = -0.55$, $p =.59$. In this multiple regression, youth-report NPO explained a significant proportion of the variance in youth-report psychosocial HRQOL sores, adjusted $R^2 = .34$, $F(3,25) = 5.88$, $p <.01$. Overall, it appears that the best consistent predictor of youth-report psychosocial HRQOL was youth NPO in this study, and that fecal incontinence was the second best predictor.

Caregiver-Report HRQOL

Additionally, five multiple regressions were conducted to see if there was a more parsimonious model that significantly predicted variance in caregiver-report psychosocial HRQOL scores. The adjusted R^2 values that were significant predictors for caregiver-report psychosocial HRQOL were, from highest to lowest: caregiver depression (adjusted $R^2 = .16$), caregiver mental health problems (i.e., combined caregiver anxiety and depression) (adjusted $R^2 = .14$), caregiver anxiety (adjusted $R^2 = .10$), caregiver NPO (adjusted $R^2 =.09$), caregiver-report family dysfunction (adjusted $R^2 = .08$), and frequency of urinary incontinence (adjusted $R^2 =.03$). Different iterations of multiple regressions were conducted in order to find the best predictor(s) of caregiver-report psychosocial HRQOL in terms of a) being the most consistent predictor in each regression equation, and b) explaining the most variance.

Caregiver mental health problems (i.e., combined caregiver anxiety and depression), caregiver NPO, caregiver-report family dysfunction, and frequency of urinary incontinence were entered as predictors of caregiver-report psychosocial HRQOL in a multiple linear regression. Caregiver mental health problems did significantly predict caregiver-report psychosocial HRQOL, $\beta = -.15$, $t(65) = -2.06$, $p < .05$. Caregiver mental health problems explained a significant proportion of the variance in caregiver-report psychosocial HRQOL scores, adjusted $R^2 = .21$, $F(4,58) = 4.16$, $p < .01$. Negative Problem Orientation did not significantly predict caregiver-report psychosocial HRQOL, $\beta = -.13$, $t(62) = -0.90$, $p = .37$. Family dysfunction did not significantly predict caregiver-report psychosocial HRQOL, $\beta = -.15$, $t(62) = -1.13$, $p = .26$. Urinary incontinence did not significantly predict caregiver-report psychosocial HRQOL, $\beta = -.06$, $t(62) = -0.54$, $p = .59$.

Caregiver depression, caregiver NPO, caregiver-report family dysfunction, and frequency of urinary incontinence were entered as predictors of caregiver-report psychosocial HRQOL in a multiple linear regression. Caregiver depression did significantly predict caregiver-report psychosocial HRQOL, $\beta = -.35$, $t(76) = -2.06$, $p < .05$. Caregiver depression explained a significant proportion of the variance in caregiver-report psychosocial HRQOL scores, adjusted $R^2 = .21$, $F(4,72) = 5.77$, $p < .01$. Negative Problem Orientation did not significantly predict caregiver-report psychosocial HRQOL, $\beta = -.12$, $t(76) = -0.93$, $p = .36$. Family dysfunction did not significantly predict caregiver-report psychosocial HRQOL, $\beta = -.08$, $t(76) = -0.71$, $p = .48$. Urinary incontinence did not significantly predict caregiver-report psychosocial HRQOL, $\beta = -.14$, $t(76) = -1.36$, $p = .18$.

Caregiver anxiety, caregiver NPO, caregiver-report family dysfunction, and frequency of urinary incontinence were entered as predictors of caregiver-report psychosocial HRQOL in a multiple linear regression. Caregiver anxiety did significantly predict caregiver-report psychosocial HRQOL, β = -.27, $t(76) = -2.61$, $p < .05$. Caregiver anxiety explained a significant proportion of the variance in caregiver-report psychosocial HRQOL scores, adjusted $R^2 = .17$, $F(4,98) = 6.21$, $p < .01$. Negative Problem Orientation did not significantly predict caregiver-report psychosocial HRQOL, β = -.16, $t(76) = -1.58$, $p = .12$. Family dysfunction did not significantly predict caregiver-report psychosocial HRQOL, β = -.14, $t(76) = -1.44$, $p = .15$. Urinary incontinence did not significantly predict caregiver-report psychosocial HRQOL, β = -.14, $t(76) = -1.36$, $p = .18$.

Caregiver NPO, family dysfunction, and caregiver depression were entered as predictors of caregiver-report psychosocial HRQOL in a multiple linear regression. Caregiver NPO did not significantly predict caregiver-report psychosocial HRQOL, β = -.10, $t(74) = -0.80$, $p = .43$. Family dysfunction did not significantly predict caregiver-report psychosocial HRQOL, β = -.16, $t(74) = -1.38$, $p = .17$. Caregiver depression did significantly predict caregiver-report psychosocial HRQOL scores, β = -.37, $t(74) = -2.76$, $p < .01$ and explained a significant proportion of the variance, adjusted $R^2 = .24$, $F(3,71) = 8.85$, $p < .01$.

Caregiver mental health problems (i.e., anxiety and depression), caregiver NPO, and family dysfunction were entered as predictors of caregiver-report psychosocial HRQOL in a multiple linear regression. Caregiver mental health problems did significantly predict caregiver-report psychosocial HRQOL, β = -.29, $t(65) = -2.06$, $p < .05$. Caregiver mental health problems explained a significant proportion of the variance in caregiver-report psychosocial HRQOL scores, adjusted $R^2 = .21$, $F(3,62) = 6.58$, $p < .01$. Caregiver NPO did not significantly predict caregiver-report psychosocial HRQOL, $\beta = -.14$, $t(65) = -1.06$, $p = .30$. Family dysfunction did not significantly predict caregiver-report psychosocial HRQOL, $\beta = -.19$, $t(65) = -1.54$, $p = .13$. Overall, it appears that the best consistent predictor of caregiver report psychosocial HRQOL was caregiver depression in this study.

Discussion

This dissertation examined a set of predictors and their relationship(s) to both youth and caregiver-report HRQOL. For Hypothesis I.A.1, greater youth positive problem-solving orientation and rational problem-solving were found to significantly predict higher youth-report psychosocial HRQOL. For Hypothesis I.A.2, youth negative problem-solving orientation, impulsivity, carelessness and avoidance negatively impacted youth-report psychosocial HRQOL. More specifically, the negative/maladaptive problem-solving was more predictive of youth-report psychosocial HRQOL than positive problem-solving. Taken together, these findings indicate that while positive problem-solving was important for determining youth-report psychosocial HRQOL, avoiding maladaptive problem-solving is even more important for youth. Additionally, looking at a four-factor model for measuring HRQOL is also supported by the problem-solving findings.

The finding that negative problem-solving orientation and strategies predict lower psychosocial HRQOL, whereas positive problem-solving orientation and strategies predict higher psychosocial HRQOL, is also supported by the Family Stress (McCubbin and Patterson, 1993) Theory. If an adolescent is positively coping with the stressor of their SCI, then it may also positively influence their HRQOL and, potentially, other family members. Conversely, if a youth is negatively coping with their SCI, the opposite may be true. The importance of positive problem-solving for children/adolescents with chronic conditions is consistent with the literature (Hills-Briggs, 2003). Moreover, the impact negative problem-solving strategies can have on a child or adolescent with a chronic condition's mental health has also been documented (Dreer et al., 2005; Newcombe et al., 2012; Suso-Ribera et al., 2014). Additionally, when looking at all problem-solving subscales (including negative and positive problem-solving strategies) across various health conditions, NPO specifically has been found to be the most and the only significant predictor of psychosocial HRQOL (Barakat et al., 2014; Blucker, 2011; Dreer, Elliott and Tucker, 2004). Similarly, for youth with SCI, maladaptive coping has also been found to negatively impact psychosocial HRQOL (Smith et al., 2013). Using the Family Stress Theory, NPO may also be conceptualized as a maladaptive method of coping that could also negatively impact family dynamics and the way in which other family members cope.

For hypothesis I.B, frequency of urinary incontinence was not predictive of youth-report psychosocial HRQOL. However, frequency of fecal incontinence predicted youth-report psychosocial HRQOL. Minimizing bowel and bladder incontinence is often a crucial component of SCI management. Bowel and bladder functioning also vary by both the level and completeness of injury. As noted in Table 6, there is a variety of urinary and bowel care management options employed by youth with SCI. Due to the fact that bowel and bladder function can vary from person to person, there is no universally recommended method of bowel and bladder care management, but the best methods are those that work for the patient while also minimizing the risk of developing secondary complications (i.e., UTIs, autonomic dysreflexia, and/or bowel/bladder accidents) (Bladder Management for Adults with Spinal Cord Injury, 2006).

For 63 (39.87%) youth who are experiencing no urinary incontinence, their current urinary catheterization method is effectively preventing bladder accidents. However, the majority of youth in this sample (53.16%, *n*=84) reported at least some urinary incontinence, and (25.95%, *n*=41) youth reported experiencing urinary incontinence daily. Fecal incontinence seemed much less frequent than urinary incontinence, with 51 (32.28%) youth reporting no fecal incontinence and only 4 youth reporting fecal incontinence daily. However, 50 (31.63%) youth still reported some fecal incontinence, and 57 (36.08%) youth were missing responses for this variable. Given the number of missing responses for fecal incontinence, it is difficult to ascertain the prevalence among youth with SCI. It may be that there was simply not enough urinary and fecal data collected to demonstrate the degree to which both types of incontinence impact youth and caregiver report HRQOL. Furthermore, by performing a Little's test, the urinary and fecal incontinence data were found to be not missing completely at random. Therefore, there was a pattern between hospitals that yielded missing data. Since the data was not missing at random, it is important to heed take caution in terms of interpreting and generalizing the findings.

Additionally, although urinary incontinence did not significantly predict youth-report psychosocial HRQOL, fecal incontinence did, suggesting that it may negatively impact youth's psychosocial health. Incontinence (both urinary and fecal) has been identified as a distinct predictor of psychosocial HRQOL (Tulsky et al., 2015) among adults with SCI, as well as youth with spina bifida, and adults with neurological conditions, including SCI (Olesen, Kiddo, and Metcalfe, 2003;

Tapia et al., 2003). Additionally, there is research for youth with fecal incontinence that demonstrates a bowel management program positively increased psychosocial HRQOL reported by youth and caregivers (Colares, Purcaru, da Silva, Frota, da Silva, Melo-Filo, Bischoff, and Pena, 2016).

For hypothesis I.C, caregiver-report family dysfunction was not found to significantly predict youth-report psychosocial HRQOL. Family dysfunction, to this author's knowledge, has been studied amongst youth with chronic conditions, but not SCI. It is possible that family dysfunction does not have as large of an impact on youth psychosocial HRQOL as one might expect, or that youth are less aware of family dysfunction than caregivers are. Family functioning has, in some cases, been found to be significantly worse in families with a youth who has a chronic condition (Anttila et al., 2004). However, when comparing families with a healthy child to families with a youth with a chronic condition, family functioning also has been found to be similar (Cadman et al., 1991; Herzer et al., 2010; J'May et al., 1996; Kabacoff et al., 1990; and McClellan and Cohen, 2007).

For Hypothesis II.A, caregiver Negative Problem Orientation significantly impacted caregiver-report psychosocial HRQOL. In this dissertation study, only Impulsivity/Carelessness and Negative Problem Orientation were found to significantly predict caregiver report psychosocial HRQOL. It should also be noted that Negative Problem Orientation and Impulsivity/Carelessness were significant predictors in both the caregiver report and youth-report of psychosocial HRQOL. Using negative appraisals and maladaptive problem solving leads to worse psychosocial HRQOL, which is consistent with the McCubbin and Patterson (1993) theory. McCubbin and Patterson posit that family members can either adapt positively or negatively given certain stressors. If a caregiver thinks negatively about the future and/or does not solve problems in a healthy way, they may be more likely to also see their youth's HRQOL in a negative light. This same theory also applies to how an adolescent may perceive his/her own HRQOL. Additionally, if an adolescent does not know how to appropriately cope with the challenges that come with SCI (for example, preventing bladder accidents, learning to be more independent to prepare for adulthood, etc.), this may negatively impact not only their perceptions of HRQOL, but also potential future SCI-related complications (i.e., UTIs, pressure ulcers, etc.)

For Hypothesis II.B., frequency of urinary incontinence was found to significantly predict caregiver-report psychosocial HRQOL, which is contrary to the finding that it does not significantly impact youth-report psychosocial HRQOL. Frequency of fecal incontinence was not found to significantly predict caregiver-report psychosocial HRQOL; however, it was found to be predictive of youth-report psychosocial HRQOL. Although incontinence was hypothesized to impact psychosocial HRQOL for youth with SCI, this is the first study to examine either the prevalence of incontinence or its potential impact on psychosocial HRQOL for youth with SCI. However, as mentioned earlier, a Little’s test was performed and found that both the urinary and fecal incontinence data were found to not be missing completely at random. Therefore, the fecal and urinary incontinence data was missing in a systematic way, suggesting that each hospital site may have handled or collected the data differently. Perhaps the most noteworthy pattern here is that incontinence in some form predicts health-related quality of life of youth with SCI from both youth and caregiver perspectives. In addition, it appears counterintuitive that the frequency of urinary incontinence would impact only caregiver-report psychosocial HRQOL and that frequency of fecal incontinence would impact only youth-report psychosocial HRQOL. It may be that youth grow more accustomed to urinary incontinence since it occurs at a higher frequency, whereas caregivers are more concerned with continual urinary incontinence because it does happen at a higher frequency. Additionally, fecal incontinence may have a greater impact on youth because it may be more embarrassing (i.e., more noticeable) for youth than urinary incontinence is. Notably, a significant portion of the data for fecal and urinary incontinence measure was missing. The missing data could have minimized the relationship between both types of incontinence and HRQOL. However, it is important to note that incontinence (either urinary or fecal) negatively impacted HRQOL from either the caregiver or youth perspective. These findings, along with the literature that supports reducing incontinence as an important priority for individuals with SCI (i.e., adults with SCI, youth with spina bifida), suggest that it remains an important consideration for future research and intervention.

For Hypothesis II.C., family dysfunction was found to significantly predict caregiver-report psychosocial HRQOL, suggesting that family discord may negatively impact a youth's psychosocial HRQOL from the caregiver’s perspective. However, since this was not found to be significant in the youth-report psychosocial HRQOL, it could be (similar to Hypothesis I.C), that youth are less impacted by family dysfunction or are less aware of family dysfunction than caregivers think they are. Additionally, caregivers may perceive any family problems they have (e.g., problems with their significant other, issues among siblings, extended family dynamics, etc.) in a different light. It is also possible that positive family functioning has more of an impact on how the caregiver perceives the youth's psychosocial HRQOL than the youth feels it does. It may also be a significant predictor simply because it is the same reporter providing the information, leading to same source effects.

Both caregiver depression and anxiety were found to significantly predict caregiver report HRQOL, which supports the McCubbin and Patterson (1983) Family Stress theory. If caregivers are struggling with anxiety and/or depression, it may negatively impact their perceptions of their youth’s psychosocial HRQOL, or it may directly impact their youth’s psychosocial HRQOL.

Although the correlation is significant in this study (r=.53, $p < .01$), there is still a discrepancy between caregiver-report psychosocial HRQOL and youth-report psychosocial HRQOL. This discrepancy is also consistent with the literature (Garma et al., 2011), and demonstrates the importance of looking at multiple reporters for psychosocial HRQOL. To this author’s knowledge, there has only been one previous study about youth problem-solving and/or coping and youth/child-report psychosocial HRQOL (i.e., ages 18 and under) with SCI (Russell et al., 2015). The Russell et al. (2015) study categorized youth as ineffective copers, cognitive copers, active copers, and avoidant copers. Ineffective copers employed the highest amount of coping strategies, but these coping strategies also included maladaptive strategies, such as blame, wishful thinking, and social withdrawal. In contrast, cognitive copers used fewer coping strategies, but the ones they did use more frequently included cognitive reframing and acceptance, which were linked to higher psychosocial HRQOL. The present dissertation study suggested that problem-solving does impact youth/child-report psychosocial HRQOL positively.

Overall, the most salient predictors of psychosocial HRQOL across both youth and caregivers were Negative Problem Orientation and caregiver depression. Negative Problem Orientation is essentially a negative appraisal of a situation, and perceiving a problem instead of a challenge. Caregivers who are depressed may be more likely to use maladaptive problem orientation and/or strategies, or individuals who use maladaptive problem orientation and/or strategies are more likely to be depressed. Furthermore, greater Negative Problem Orientation among both youth with SCI and their caregivers demonstrated youth and caregiver-reports of decreased psychosocial HRQOL. McCormack, Nezu, Nezu, Sherman, Davey, and Collins (2014) found that for adults with asthma, employing maladaptive problem solving predicted a lower overall HRQOL and lower control over asthma attacks.

Strengths

One of the strengths of the study is that this data was collected across three hospitals across the U.S.A. (California, Illinois, and Pennsylvania). Additionally, all of the youth in this study has sustained their injury for at least one year and had not sustained a traumatic brain injury. Being able to include youth with SCI who are all in the same Shriner's hospital network also means that data can be shared across the network/sites with relative ease. Having a national sample of youth with SCI is a strength because SCI in youth is still rare, and having youth taking part from across the country increases the generalizability of the study.

Including youth who have sustained their injury for at least one year also ensures that families are in the Family Stress Theory's *Adaptation Phase* as opposed to the *Adjustment Phase*. While adjusting to SCI may be an ongoing and evolving challenge, the first year is typically the most impactful and dynamic in terms of adjustment for both the youth and family. Additionally, including youth who do not have TBI is also important in terms of being able to compare youth with SCI to one another for both the psychosocial HRQOL and problem-solving measures. SCI without traumatic brain injury typically does not present cognitive impairments, whereas TBI is variable in terms of how it impacts the youth's psychosocial and intellectual functioning.

Additionally, to this author's knowledge, this is the first study that examines the relationship between psychosocial HRQOL (both youth-report and proxy caregiver report) and incontinence (both fecal and urinary). Fecal incontinence was found to impact youth-report psychosocial HRQOL, and urinary incontinence was found to impact caregiver proxy report of psychosocial HRQOL. These findings may merit further investigation into methods of reducing incontinence for youth with SCI.

Furthermore, by determining that there is a relationship between psychosocial HRQOL and incontinence for youth with SCI, this study lays a foundation for valuable future research that addresses the questions:

1) Why does bowel and bladder incontinence occurs in youth with SCI?
2) Should a different catheterization method occur?
3) Do caregivers or youth with SCI need additional bowel and bladder care training?
4) How they impact youth psychosocial HRQOL?
5) Does it reduce participation and/or lead to a higher incidence of UTIs?

Another strength of the study is it identified common factors (Negative Problem Orientation and caregiver depression) that predicted both youth-report psychosocial HRQOL and caregiver-proxy report youth psychosocial HRQOL. Finding a commonality between two different reporters of psychosocial HRQOL definitely strengthens the connection between caregiver depression and both youth and caregiver Negative Problem Orientation with psychosocial HRQOL. Finding a commonality between two reports of HRQOL strengthens the concept that caregiver depression and Negative Problem Orientation should be addressed in practice and research. Additionally, the Family Stress Theory posits that if a stressor happens to a family member, it does not just affect the family member, it also impacts the family as individuals, their relationships with one another, and, potentially their relationship(s) with the community.

Limitations:

One potential limitation of this study is that the sample size might be considered relatively modest (*n*=158), and was smaller for some analyses due to missing data and/or variables (*n* ranging from 80 to 158). In particular, the missing urinary and fecal incontinence data, which the Little's test identified as not MCAR, was problematic for analyzing a potential relationship to HRQOL. If more data was available, it may be that both urinary and fecal incontinence data negatively impact both youth and caregiver report HRQOL. The modest sample size might limit the generalizability of the results to youth with other chronic health conditions. However, a sample size of 158 is relatively large given the rarity of pediatric-onset SCI (1.99 cases per 100,000 children in the United States (http://asia-spinalinjury.org/committees/pediatric/pediatric-committee-news-and-resources/pediatric-spinal-cord-injury-facts/.)

Furthermore, problem-solving was only measured in caregivers and adolescents (youth that were 13 and older). Therefore, it is unclear if the impact of problem-solving orientation and skills would also be found in youth that are younger than 13. For future research, it would be important to look at problem-solving orientation and skills in youth that are younger than 13.

Additionally, as mentioned previously, both the fecal and urinary incontinence data were found to not be missing completely at random. Due to the systematic missingness of the incontinence data, the findings should be interpreted with caution. Furthermore, in terms of the fecal incontinence measure, 30% of the data was missing for frequency and thus could not be included in the analyses. It may be that other measures of urinary and fecal incontinence than the ones used in this study may be more accurate and complete and thus may yield more meaningful insight into how incontinence impacts psychosocial HRQOL for youth with SCI. In terms of measuring how incontinence impacts psychosocial HRQOL, one example among adults with spina bifida includes measuring the a) length of time spent dry/without an accident, and measuring b) quantity of urinary leakage, not frequency, for urinary incontinence (Szymanski, Misseri, Whittam, Kaefer, Rink and Cain, 2016). Additionally, as adolescents become adults, the amount of independence someone has in regards to their bowel and bladder routine may also be an important measure for psychosocial HRQOL (Frimberger, Cheng, and Kropp, 2012).

This study did not examine a causal relationship between negative problem-solving strategies and psychosocial HRQOL, so it is unclear as to whether a lower psychosocial HRQOL leads to using negative problem-solving strategies, or whether using negative problem-solving strategies negatively impacts a youth’s psychosocial HRQOL or both. Additionally, since this study was cross-sectional, it was not possible to ascertain if problem orientation or problem-solving skills changed over time, although Negative Problem Orientation has been found to be relatively stable over time (D'Zurilla et al., 2002; Hawkins, Sofronoff, and Sheffield, 2008). It was also not possible to determine whether caregiver depression leads to decreased psychosocial HRQOL, if decreased psychosocial HRQOL leads to caregiver depression or both.

Implications for Practice

Problem-solving interventions have demonstrated promise in terms of improving coping for both caregivers and youth with chronic conditions, and have demonstrated positive gains in both disease-related outcomes and psychosocial health (Barakat et al., 2014; Berry et al., 2012; Eccleston et al., 2012, and Kelly et al., 2016). Minimizing Negative Problem Orientation in both youth and caregivers may be an important component of an intervention for youth with SCI. In particular, youth-report Negative Problem Orientation seemed to have the biggest impact on youth-report psychosocial HRQOL. Therefore, deterring Negative Problem Orientation, (i.e., perceiving SCI as a problem and having a negative outlook on the future) may be a good strategy for improving psychosocial HRQOL.

However, given that Negative Problem Orientation is the most stable of predictors of the SPSI-R subscales (D’Zurilla et al., 2002), it may also be indicative of a deeper problem, such as depression. Considering that caregiver depression was such a salient predictor, it is important to also address treating depression amongst caregivers and not only employing problem-solving strategies. By equipping caregivers with rational problem solving skills (viz., an intervention, support group, and/or cognitive behavioral therapy), reframing SCI and its related challenges in a positive light, practitioners (i.e., doctors, clinicians, etc.) can target caregiver mental health. As evidenced by the variance explained by caregiver depression on both youth and caregiver-report HRQOL scores, it is also important to measure caregiver mental health.

Fecal incontinence was found to significantly predict youth-report psychosocial HRQOL, and urinary incontinence was found to significantly predict caregiver-report psychosocial HRQOL. As noted earlier in this study (Catalano et al., 2011; Hicken, Putzke, and Richards, 2001), individuals with SCI who are experiencing incontinence may also experience a decrease in overall HRQOL, and may also be less likely to participate in activities because they are afraid they will have a bowel or bladder accident. Additionally, participation is a key element to improved/general overall HRQOL (Gorzkowski et al., 2010; Kelly et al., 2012; Klaas et al., 2010). Although it was not measured in this study, it is recommended to measure how incontinence may impact participation. If incontinence decreases the likelihood of participation, and participation is linked to psychosocial HRQOL, incontinence may also partially explain a relationship between participation and psychosocial HRQOL.

In terms of practice, interventions that address caregiver depression may also be important to improve youth HRQOL. Also, since it is uncertain as to whether decreased youth psychosocial HRQOL leads to higher caregiver depression or vice versa, it is also important to provide psychosocial services for youth who have depressed caregivers. Caregivers may need psychosocial services as well, and may also benefit from a support group with fellow caregivers. Additionally, since both adolescent and caregiver Negative Problem Orientation were found to negatively impact HRQOL, employing problem solving interventions that also include a mental health assessment and component would also be an excellent area for future practice.

Implications for Theory

McCubbin and Patterson's Family Stress Theory (1993) emphasizes how a stressful event can impact a family. This theory examines how an unexpected event can negatively or positively impact family members (the *Adjustment Phase*), and how family adapts (the *Adaptation Phase*). This theory looks at a stressor, family vulnerability, functioning before the stressful event, and how family members perceive a stressor. In this dissertation study, the unexpected event/stressor would be the SCI and related complications (i.e., incontinence). Appraisal(s) and coping are measured by problem-solving orientation and skills, caregiver mental health, and family dysfunction. Unfortunately, in this dissertation study, there was no measure of family strength/vulnerability before the SCI occurred. Therefore, this dissertation study only focuses on family functioning after the SCI. Using not only the youth-report psychosocial HRQOL, but also the caregiver-report psychosocial HRQOL, indicated that Negative Problem Orientation and caregiver depression were the most predictive for both measures. Additionally, using both the youth and caregiver’s perspectives of psychosocial HRQOL also demonstrates the importance of looking at multiple dimensions. Using both the caregiver and youth reports for psychosocial HRQOL yield richer pictures in terms of understanding how a youth is functioning, particularly a youth with a disability (Kelly et al., 2016).

Caregiver mental health significantly predicted caregiver-report psychosocial HRQOL, consistent with the McCubbin and Patterson (1993) Family Stress Theory and previous research for youth with SCI (Kelly, Klaas, Mulcahey, Russell, Andersen, and Vogel, 2012). A more recent study (Kelly, Riordan, Zebracki, Thorpe and Vogel, 2016) found that caregiver mental health also significantly predicted youth-report psychosocial HRQOL for youth (ages 7-17) with SCI. For the Kelly et al. (2016) study, caregiver anxiety and depression were measured using the HADS (Hospital Anxiety and Depression Scale) as opposed to the BAI and BDI scales used in the current study. Surprisingly, caregiver anxiety was not found to be a significant predictor of youth-report psychosocial HRQOL in this dissertation. Although caregiver anxiety was not a significant predictor of youth-report psychosocial HRQOL in this study, caregiver depression was a significant predictor at the p =.08 or trend level. Additionally, caregiver mental health problems were a significant predictor of caregiver-report psychosocial HRQOL. Considering that caregiver depression was a significant predictor of both the youth (at the p=.08 level) and caregiver report of psychosocial HRQOL, it is a salient factor that impacts psychosocial HRQOL for youth with SCI. This finding is consistent with the literature and Family Stress Theory (McCubbin and Patterson, 1993) that supports that caregiver depression can negatively impact youth HRQOL. It may be that caregiver depression can cause youth to experience a decrease in psychosocial HRQOL, or it may be that a decrease in psychosocial HRQOL leads to depression, or both. However, it was not possible to determine causation in this dissertation study.

Although there definitely needs to be more research in determining what strategies can help a youth with SCI avoid Negative Problem Orientation, incontinence, and secondary health conditions, more recent research explores the positive components for both youth with SCI and their caregivers. For example, post-traumatic growth has been demonstrated among adults with SCI who were injured in their youth (January, Zebracki, Chlan & Vogel, 2015). Additionally, when comparing adults who acquired their SCI during childhood vs. adulthood, individuals with pediatric-onset SCI actually reported better overall HRQOL than their adult counterparts (Ma, Post, Gorter, and Ginis, 2016). A mixed methods study (Morrison, Kelly, Russell and Vogel, 2016) demonstrated that caregivers were able to identify benefits from raising a youth with SCI, including resilience and connecting with others. In terms of theory, measuring psychosocial HRQOL in terms of both needs and strengths would also yield a more full picture of the experience of youth with SCI and their families.

Also, in accordance with the McCubbin and Patterson (1993)'s Family Stress Theory's *Adaptation Phase*, a family can either adapt negatively or positively to change. If a family builds resilience, this leads to better psychosocial outcomes for family members. Learning more about the positive growth, wisdom, and resilience a family experiences while raising a youth with SCI is also an important element of using a strengths-based approach for both researchers and practitioners. Although Family Stress Theory (1993) is still widely cited, a more recent (Patterson, 2002) article posits that family resilience can be understood as both a process and an outcome. McCubbin and McCubbin (2013) have developed a new theory called "Relational and Resilience Theory of Ethnic Family Systems" (R&RTEFS; as cited in Henry, Morris, and Harrist, 2015). The McCubbin and McCubbin 2013 theory looks at how culture can impact family dynamics and foster a sense of resilience. However, this dissertation study does not focus on cultural factors that may impact caregiver or youth variables. There may be potential indicators of youth with SCI, caregiver, and family cultural resilience that were not measured in this dissertation study.

Future Research Directions

In terms of research, it would be helpful to better understand the relationship between negative problem-solving strategies and orientation (i.e., Impulsivity/Carelessness, Avoidance, and Negative Problem Orientation) and psychosocial HRQOL. Considering that other studies focused on a problem-solving intervention, it may be possible that an intervention for youth with SCI and their caregivers may positively impact their problem-solving skills and orientation, but it may also be most difficult to change Negative Problem Orientation.

Additionally, caregiver depression was a significant predictor in both youth-report and caregiver-report of psychosocial HRQOL. Looking at the relationship between psychosocial HRQOL, caregiver depression, and caregiver and adolescent Negative Problem Orientation would be an excellent area for future research. In particular, using structural equation modeling (SEM) may yield a richer picture of psychosocial HRQOL from both the caregiver and youth perspectives. For example, a latent construct such as family resilience could be conceptualized using both caregiver and youth PPO and RPS. Family resilience could also be measured looking at social support, community engagement, and sibling (of youth with SCI) mental health. Family vulnerability could be conceptualized using caregiver and youth NPO, I/C, AV, incontinence, and family dysfunction.

Family vulnerability could also be measured by access to resources, caregiver employment status, and other measures of family functioning (i.e., what is the relationship like between the sibling(s) and caregivers? what are the relationship(s) between immediate and extended family members? etc.).

Considering that incontinence is an important issue for individuals with SCI, practitioners may want to look at other measures of reporting urinary and fecal incontinence. Asking a child to think about incontinence to self-report at a check-up that is only semi-annual or annual may not be frequent enough to get an accurate report of urinary incontinence. Furthermore, youth may under-report if they are embarrassed (particularly older youth), or may simply not remember the frequency accurately. It might be helpful to potentially measure fecal and urinary incontinence using another method aside from an annual/semi-annual check-up. For example, keeping a log of frequency of fecal and urinary incontinence, and/or checking in with patients (or caregivers) more frequently via phone or email may yield more accurate responses.

Overall, although significant multiple regressions were found for youth-report psychosocial HRQOL and for caregiver proxy-report psychosocial HRQOL, there was still a considerable amount of variance that was not explained in either model. These findings suggest that there is still more research needed in determining what contributes to psychosocial HRQOL for youth with SCI. In this particular study of psychosocial HRQOL, a youth with SCI is contextualized by multiple factors. These factors include how well the family is functioning, youth and caregiver problem-solving skills, caregiver mental health, and physical problems (i.e., incontinence). Additionally, Family Stress Theory (McCubbin and Patterson, 1993) emphasizes that how family members cope with a stressor can either build resilience or create disharmony in the family or both among different family members, at different times and/or for different issues. A youth with SCI's experience is multi-faceted, and these findings suggest the need to unpack the various components. Measuring resilience and strengths among youth who have a pediatric-onset SCI is an important element of future psychosocial HRQOL research. As medicine steers towards patient-driven outcomes, it also important that youth with SCI's experiences are measured using a strengths-based framework instead of a deficit-based one.

Another future direction would be to look at how pain influences psychosocial HRQOL. It is documented in the SCI literature (Andresen et al., 1999) that pain can have a negative impact on health, including psychosocial health. This is especially important because SCI is a chronic condition. Adults who acquire SCI in adulthood, most likely, can remember how they felt before the injury. However, pain memory research suggests that infants/toddlers who acquire an injury may be less able or likely to recall how they felt before their injury (van Baeyer, Marche, Rocha and Salmon, 2004). Youth may become used to being in pain so that it becomes “normal" and may not consider it as pain that needs to be ameliorated (Castle, Imms, and Howie, 2007).

Furthermore, medicine and disability studies are moving in the direction of participant and/or patient-driven outcomes. There was a recently published special edition journal (Tulsky et al., 2015) that identified several dimensions of

HRQOL for adults with SCI through participatory methods. However, this adult framework does not mean that the same factors will also be important for youth with SCI. There may be certain factors (such as caregiver problem-solving, school climate for people with disabilities, and education and practice around bowel and bladder care) that are differentially important for youth with SCI. Additionally, combined interventions with components for both caregiver and individual with SCI have demonstrated positive psychological and physical health benefits (Schulz, Czaja, Lustig, Zdaniuk, Martire, and Perdomo, 2009). It is recommended that future researchers engage with both children and adolescents with SCI to determine what is most important to them to improve psychosocial HRQOL.

Summary:

Understanding the different dimensions of psychosocial HRQOL for youth with SCI is still a relatively new research focus in medical and disability studies. Community psychology and disability studies emphasize the importance of looking at context in terms of understanding an individual’s experience. Additionally, Family Stress Theory (McCubbin and Patterson, 1993) posits that a stressor disrupts not only the individual it immediately impacts, but also the family members, and their relationships with one another. This study aimed to look at new factors, including cognitive approaches to challenges, physical health indicators (i.e., incontinence), caregiver mental health problems (i.e., anxiety and depression), and general family dysfunction that may impact psychosocial HRQOL for youth with SCI, in terms of the perspectives of both the youth and the caregiver. More specifically, the present study examined how problem-solving orientation and strategies, incontinence, caregiver mental health, and family dysfunction impact both the youth-report psychosocial HRQOL and the caregiver-report psychosocial HRQOL.

This dissertation study used several linear regressions to determine each variable’s impact on each reporter’s psychosocial HRQOL. To this author's knowledge, this was the first study that examined the frequency of incontinence and how fecal and urinary incontinence impacted psychosocial HRQOL for youth with pediatric-onset SCI (without TBI). Additionally, this was also the first study that looked at how family dysfunction impacts both youth and caregiver proxy report of psychosocial HRQOL for youth (ages 6-18) with SCI. The finding that Negative Problem Orientation is significant in both caregiver proxy report and youth-report psychosocial HRQOL is also unique. For adolescent-report psychosocial HRQOL participants also completed the total problem-solving scale, Negative Problem Orientation and fecal incontinence were found to significantly impact psychosocial HRQOL. For the caregiver proxy-report psychosocial HRQOL, caregiver depression was found to be the most predictive. The findings of this study suggest that more research is needed to determine which variables impact both caregiver and youth-report psychosocial HRQOL for youth with SCI. Additionally, problem-solving and mental health interventions, as well as interventions/education about reducing incontinence may improve psychosocial HRQOL for youth with SCI.

References

American Spinal Injury Association.Retrieved from http://asiaspinalinjury.org/committees/pediatric/pediatric-committee-news-and-resources/pediatric-spinal-cord-injury-facts/ on 04-01-2017

Arango-Lasprilla, J. C., Plaza, S. L. O., Drew, A., Romero, J. L. P., Pizarro, J. A. A., Francis, K., & Kreutzer, J. (2010). Family needs and psychosocial functioning of caregivers of individuals with spinal cord injury from Colombia, South America. *NeuroRehabilitation*, *27*(1), 83-93.

Anderson, K. D. (2004). Targeting recovery: priorities of the spinal cord-injured population. *Journal of Neurotrauma*, *21*(10), 1371-1383.

Andresen, E. M., Fouts, B. S., Romeis, J. C., & Brownson, C. A. (1999). Performance of health-related quality-of-life instruments in a spinal cord injured population. *Archives of physical medicine and rehabilitation*, *80*(8), 877-884.

Anttila, P., Sourander, A., Metsahonkala, L., Aromaa, M., Helenius, H., & Sillanpaa, M., (2004). Psychiatric symptoms in children with primary Headache. *Journal of the American Academy of Child & Adolescent Psychiatry*, 43, 412-419.

Armstrong, M. I., Birnie-Lefcovitch, S., & Ungar, M. T. (2005). Pathways between social support, family well being, quality of parenting, and child resilience: What we know. *Journal of child and family studies*, *14*(2), 269-281.

Barakat, L. P., Daniel, L. C., Smith, K., Robinson, M. R., & Patterson, C. A.

(2014). Parental Problem-Solving Abilities and the Association of Sickle Cell Disease Complications with Health-Related Quality of Life for School-Age Children. *Journal of clinical psychology in medical settings*, *21*(1), 56-65.

Beck, A. T., Steer, R. A., & Brown, G. K. (1996). Beck depression inventory-II. *San Antonio, TX*, 78204-2498.

Bendixen, R. M., Senesac, C., Lott, D. J., & Vandenborne, K. (2012). Participation and quality of life in children with Duchenne muscular dystrophy using the International Classification of Functioning, Disability, and Health.*Health Qual Life Outcomes*, *10*(1), 43.

Berry, J. W., Elliott, T. R., Grant, J. S., Edwards, G., & Fine, P. R. (2012). Does problem-solving training for family caregivers benefit their care recipients with severe disabilities? A latent growth model of the Project CLUES randomized clinical trial. *Rehabilitation Psychology*, *57*(2), 98–112. doi:10.1037/a0028229

Blucker, R. T. (2011). *Psychological characteristics and adjustment in caregivers of children with severe neurodisability with chronic pulmonary symptoms* (Doctoral dissertation, Texas A&M University).

Borzyskowski, M., Cox, A., Edwards, M., & Owen, A. (2004). Neuropathic bladder and intermittent catheterization: social and psychological impact on families. *Developmental medicine and child neurology*, *46(*3), 160-167.

Byles, J., Byrne, C., Boyle, M. H., & Offord, D. R. (1988). Ontario Child Health Study: reliability and validity of the general functioning subscale of the

McMaster Family Assessment Device. *Family process*, *27*(1), 97-104.

Bullinger, M., Schmidt, S., Petersen, C., & DISABKIDS GROUP. (2002). Assessing quality of life of children with chronic health conditions and disabilities: a European approach. *International Journal of Rehabilitation Research, 25*(3), 197-206.

Cadman, D., Rosenbaum, P., Boyle, M., & Offord, D. R. (1991). Children with chronic illness: family and parent demographic characteristics and psycho-social adjustment. *Pediatrics*, *87*(6), 884-889.

Psychology, 31(9), 928-938.

Castle, K., Imms, C., & Howie, L. (2007). Being in pain: a phenomenological study of young people with cerebral palsy. *Developmental Medicine & Child Neurology*, *49*(6), 445-449.

Catalano, D., Chan, F., Wilson, L., Chiu, C. Y., & Muller, V. R. (2011). The buffering effect of resilience on depression among individuals with spinal cord injury: a structural equation model. *Rehabilitation Psychology, 56*(3), 200.

Colares, J. H., Purcaru, M., da Silva, G. P., Frota, M. A., da Silva, C. A., Melo-Filho, A. A. Bischoff, C., & Peña, A. (2016). Impact of the Bowel Management Program on the quality of life in children with fecal incontinence. *Pediatric surgery international*, *32*(5), 471-476.

Consortium for Spinal Cord Medicine. (2006). *Bladder management for adults with spinal cord injury: a clinical practice guideline for health-care providers*. Consortium for Spinal Cord Medicine.

Di Battista, A., Godfrey, C., Soo, C., Catroppa, C., & Anderson, V. (2015). Does what we measure matter? Quality-of-life defined by adolescents with brain injury. *Brain injury*, *29*(5), 573-582.

Dreer, L. E., Elliott, T. R., Shewchuk, R., Berry, J. W., & Rivera, P. (2007). Family caregivers of persons with Spinal Cord Injury: Predicting caregivers at risk for probable depression. *Rehabilitation Psychology*, *52*(3), 351–357. http://doi.org/10.1037/0090-5550.52.3.351

Dreer, L. E., Elliott, T. R., Fletcher, D. C., & Swanson, M. (2005). Social Problem-solving abilities and psychological adjustment of persons in low-vision rehabilitation. *Rehabilitation Psychology*, *50*(3), 232.

Dreer, L. E., Elliott, T. R., & Tucker, E. (2004). Social problem-solving abilities and health behaviors among persons with recent-onset spinal cord injury. *Journal of Clinical Psychology in Medical Settings*, *11*(1), 7-13.

Drotar, D. (1997). Relating parent and family functioning to the psychological adjustment of children with chronic health conditions: What have we learned? What do we need to know? *Journal of Pediatric Psychology*, *22*(2), 149-165.

D'Zurilla, T. J., & Chang, E. C. (1995). The relations between social problem solving and coping. *Cognitive therapy and research*, *19*(5), 547-562.

Eccleston, C., Palermo, T. M., Fisher, E., & Law, E. (2012). Psychological interventions for parents of children and adolescents with chronic illness. *Cochrane Database of Systematic Reviews (Online)*, *8*, CD009660. doi:10.1002/14651858.CD009660.pub2

Eiser, C., & Varni, J. W. (2013). Health-related quality of life and symptom reporting: Similarities and differences between children and their parents. *European Journal of Pediatrics, 172*(10), 1299-304. doi:http://dx.doi.org/10.1007/s00431-013-2049-9

Elliott, T. R., Shewchuk, R. M., & Richards, J. S. (1999). Caregiver social problem-solving abilities and family member adjustment to recent-onset physical disability. *Rehabilitation Psychology*, *44*(1), 104.

Elliott, T. R., Shewchuk, R. M., & Richards, J. S. (2001). Family caregiver social problem-solving abilities and adjustment during the initial year of the caregiving role. *Journal of Counseling Psychology*, *48*(2), 223.

Epstein, N. B., Baldwin, L. M., & Bishop, D. S. (1983). The McMaster family assessment device*. *Journal of marital and family therapy*, *9*(2), 171-180.

Flanagan, A., Kelly, E. H., & Vogel, L. C. (2013). Psychosocial outcomes of children and adolescents with early-onset spinal cord injury and those with spina bifida. *Pediatric Physical Therapy*, *25*(4), 452-459.

Franciosi, J.P., Hommel, K.A., DeBrosse, C.W., Greenberg, A.B., Greenler, A.J., Abonia, J.P., Rothenberg, M.E., & Varni, J.W. (2012). Quality of life in Pediatric Eosinophilic Esophagitis: What is important to patients? *Child: Care, Health and Development*, *38*(4), 477–483. doi:10.1111/j.1365-2214.2011.01265.x

Frimberger, D., Cheng, E., & Kropp, B. P. (2012). The current management of the neurogenic bladder in children with spina bifida. *Pediatric Clinics of North America*, *59*(4), 757-767.

Fydrich, T., Dowdall, D., & Chambless, D. L. (1992). Reliability and validity of the Beck Anxiety Inventory. Journal of Anxiety Disorders, 6(1), 55-61.

Gorzkowski, J. A., Kelly, E. H., Klaas, S. J., & Vogel, L. C. (2010). Girls with spinal cord injury: Social and job-related participation and psychosocial outcomes. *Rehabilitation psychology*, *55*(1), 58.

Hair, J. F., Black, B., Anderson, R., & Tatham, R. (1995). Multivariate Data Analysis: Text and Readings.

Haisma, J. A., Van Der Woude, L. H., Stam, H. J., Bergen, M. P., Sluis, T. A., Post, M. W., & Bussmann, J. B. (2007). Complications following spinal cord injury: occurrence and risk factors in a longitudinal study during and after inpatient rehabilitation. *Journal of rehabilitation medicine, 39*(5), 393-398.

Helgeson, V. S., Reynolds, K. A., Siminerio, L., Escobar, O., & Becker, D. (2008). Parent and adolescent distribution of responsibility for diabetes self-care: Links to health outcomes. *Journal of Pediatric Psychology*, *33*(5), 497-508.

Henry, C. S., Sheffield Morris, A., & Harrist, A. W. (2015). Family resilience: Moving into the third wave. *Family Relations*, *64*(1). 22-43.

Herzer, M., Godiwala, N., Hommel, K. A., Driscoll, K., Mitchell, M., Crosby, L. E., Piazza-Waggoner, C., Zeller, M., and Modi, A. C. (2010). Family Functioning in the Context of Pediatric Chronic Conditions. *Journal of Developmental and Behavioral Pediatrics : JDBP*, *31*(1), 26. doi:10.1097/DBP.0b013e3181c7226b

Hicken, B. L., Putzke, J. D., & Richards, J. S. (2001). Bladder management and quality of life after spinal cord injury. *American journal of physical medicine & rehabilitation*, *80*(12), 916-922.

Hill-Briggs, F. (2003). Problem solving in diabetes self-management: a model of chronic illness self-management behavior. *Annals of Behavioral Medicine*,*25*(3), 182-193.

Holmbeck, G. N., Greenley, R. N., Coakley, R. M., Greco, J., & Hagstrom, J. (2006). Family functioning in children and adolescents with spina bifida: An evidence-based review of research and interventions. *Journal of Developmental & Behavioral Pediatrics*, *27*(3), 249-277.ß

Holmbeck, G. N., Johnson, S. Z., Wills, K. E., McKernon, W., Rose, B., Erklin, S., & Kemper, T. (2002). Observed and perceived parental overprotection in relation to psychosocial adjustment in preadolescents with a physical disability: the mediational role of behavioral autonomy. *Journal of consulting and clinical psychology*, *70*(1), 96.

January, A. M., Zebracki, K., Chlan, K. M., & Vogel, L. C. (2015). Understanding post-traumatic growth following pediatric-onset spinal cord injury: the critical role of coping strategies for facilitating positive psychological outcomes. *Developmental Medicine & Child Neurology*, *57*(12), 1143-1149.

J'May, B. R., Jaffe, K. M., Polissar, N. L., Fay, G. C., Liao, S., & Martin, K. M.

(1996). Predictors of family functioning and change 3 years after traumatic brain injury in children. *Archives of physical medicine and rehabilitation*, *77*(8), 754-764.

Kabacoff, R. I., Miller, I. W., Bishop, D. S., Epstein, N. B., & Keitner, G. I. (1990). A psychometric study of the McMaster Family Assessment Device in psychiatric, medical, and nonclinical samples. *Journal of family psychology*,*3*(4), 431.

Kanaheswari, Y., Razak, N., Chandra, V., & Ong, L. C. (2011). Predictors of pa renting stress in mothers of children with spina bifida. *Spinal Cord*, 49, 376-380.

Kelly, E. H., Klaas, S. J., Garma, S., Russell, H. F., & Vogel, L. C. (2012). Participation and quality of life among youth with spinal cord injury. *Journal of pediatric rehabilitation medicine*, *5*(4), 315-325.

Kelly, E. H., Mulcahey, M. J., Klaas, S. J., Russell, H. F., Anderson, C. J., & Vogel, L. C. (2012). Psychosocial Outcomes Among Youth with Spinal Cord Injury and Their Primary Caregivers. *Topics in Spinal Cord Injury Rehabilitation*, *18*(1), 67–72. doi:10.1310/sci1801-67

Kelly, E. H., Riordan, A. L., Zebracki, K., Thorpe, S., & Vogel, L. C. (2016). Relationships between caregiver characteristics and health-related quality of life among youth with Spinal Cord Injury. *Topics in Spinal Cord Injury Rehabilitation*, *22*(2), 149-157.

Kelly, E. H., & Vogel, L. C. (2013). Overview of psychosocial health among youth with spinal cord injury. *Topics in spinal cord injury rehabilitation*, *19*(2), 129.

King, G., King, S., Rosenbaum, P., & Goffin, R. (1999). Family-centered caregiving and well-being of parents of children with disabilities: linking process with outcome. *Journal of pediatric psychology, 24*(1), 41-53.

Kitagawa and Kimura. (2002). The Influence of Complications on Rehabilitation of Spinal Cord Injuries: Economical Minus Effects and Physical Disadvantages Caused by Urinary Tract Infection and Decubitus Ulcer. *Journal of Nippon Medical School*, *69*(3), 268-277.

Klaas, S. J., Kelly, E. H., Gorzkowski, J., Homko, E., & Vogel, L. C. (2010). Assessing patterns of participation and enjoyment in children with spinal cord injury. *Developmental Medicine & Child Neurology*, *52*(5), 468-474.

Krause, J. S., Carter, R. E., Pickelsimer, E. E., & Wilson, D. (2008). A prospective study of health and risk of mortality after spinal cord injury.*Archives of physical medicine and rehabilitation*, *89*(8), 1482-1491.

Krogh, K., Christensen, P., Sabroe, S., & Laurberg, S. (2006). Neurogenic bowel dysfunction score. *Spinal cord*, *44*(10), 625-631.

Kruger, E. A., Pires, M., Ngann, Y., Sterling, M., & Rubayi, S. (2013). Comprehensive management of pressure ulcers in spinal cord injury: current concepts and future trends. *The journal of spinal cord medicine*, *36*(6), 572-585.

Law, E. F., Fales, J. L., Beals-Erickson, S. E., Failo, A., Logan, D., Randall, E., ... & Palermo, T. M. (2016). A Single-Arm Feasibility Trial of Problem-

Solving Skills Training for Parents of Children with Idiopathic Chronic Pain Conditions Receiving Intensive Pain Rehabilitation. *Journal of Pediatric Psychology*, jsw087.

Law, M., Hanna, S., Anaby, D., Kertoy, M., King, G., & Xu, L. (2014). Health-related quality of life of children with physical disabilities: a longitudinal study.*BMC pediatrics*, *14*(1), 26.

Leduc, B. E., & Lepage, Y. (2002). Health-related quality of life after spinal cord injury. *Disability and rehabilitation*, *24*(4), 196-202.

Little, R. J. (1988). A test of missing completely at random for multivariate data with missing values. *Journal of the American Statistical Association. 83*(404), 1198-1202.

Liu, C. W., Attar, K. H., Gall, A., Shah, J., & Craggs, M. (2010). The relationship between bladder management and health-related quality of life in patients with spinal cord injury in the UK. *Spinal Cord*, *48*(4), 319-324.

Liu, J. S., Dong, C., Casey, J. T., Greiman, A., Mukherjee, S., & Kielb, S. J. (2015). Quality of life related to urinary continence in adult spina bif ida patients.*Central European journal of urology*, *68*(1), 61.

Lovibond, P. F., & Lovibond, S. H. (1995). The structure of negative emotional states: Comparison of the Depression Anxiety Stress Scales (DASS) with the Beck Depression and Anxiety Inventories. *Behaviour research and therapy*, *33*(3), 335-343.

Ma, J. K., Post, M. W. M., Gorter, J. W., & Ginis, K. M. (2016). Differences in health, participation and life satisfaction outcomes in adults following pediatric-versus adult-sustained spinal cord injury. *Spinal cord*.

Mansfield, A. K., Keitner, G. I. and Dealy, J. (2015), The Family Assessment Device: An Update. Fam. Proc., 54: 82–93. doi:10.1111/famp.12080

McClellan, C. B., & Cohen, L. L. (2007). Family functioning in children with chronic illness compared with healthy controls: a critical review. *The Journal of pediatrics*, *150*(3), 221-223.

McCormick, S. P., Nezu, C. M., Nezu, A. M., Sherman, M., Davey, A., & Collins, B. N. (2014). Coping and social problem solving correlates of asthma control and quality of life. *Chronic respiratory disease*, *11*(1), 15-21.

McCubbin, L. D., & McCubbin, H. I. (2013). Resilience in ethnic family systems: A relational theory for research and practice. In D. Becvar (Ed.), Handbook of family resilience (pp. 175–195). New York, NY: Springer.

McDonald, C. M., McDonald, D. A., Bagley, A., Thomas, S. S., Buckon, C. E., Henricson, E., Nicorici, A., & Sussman, M. D. (2010). Relationship between clinical outcome measures and parent proxy reports of health-related quality of life in ambulatory children with Duchenne muscular dystrophy. *Journal of child neurology*, *2 5*(9), 1130-1144

McKinley, W. O., Jackson, A. B., Cardenas, D. D., & Michael, J. (1999). Long-term medical complications after traumatic spinal cord injury: a regional model systems analysis. *Archives of physical medicine and rehabilitation*, *80*(11), 1402-1410.

Miller, A. C., Gordon, R. M., Daniele, R. J., & Diller, L. (1992). Stress, appraisal, and coping in mothers of disabled and nondisabled children. *Journal of Pediatric Psychology*, *17*(5), 587-605.

Molazem, Z., Falahati, T., Jahanbin, I., Jafari, P., & Ghadakpour, S. (2014). The effect of psycho-educational interventions on the quality of life of the family caregivers of the patients with Spinal Cord Injury: A randomized controlled trial. *International Journal of Community Based Nursing and Midwifery, 2*(1), 31–39.

Morrison, M., Kelly, E. H., Russell, H. F., & Vogel, L. C. (2016). Rewards of parenting children and adolescents with spinal cord injuries. *Spinal Cord*.

Newcombe, P. A., Dunn, T. L., Casey, L. M., Sheffield, J. K., Petsky, H., Anderson-James, S., & Chang, A. B. (2012). Breathe Easier Online: Evaluation of a Randomized Controlled Pilot Trial of an Internet-Based Intervention to Improve Well-being in Children and Adolescents With a Chronic Respiratory Condition. *Journal of Medical Internet Research, 14*(1), e23. doi:10.2196/jmir.1997

Olesen, J. D., Kiddoo, D. A., & Metcalfe, P. D. (2013). The association between urinary continence and quality of life in paediatric patients with spina bifida and tethered cord. *Paediatrics & Child Health*, *18*(7), e32–e38.

Palermo, T. M., Law, E. F., Essner, B., Jessen-Fiddick, T., & Eccleston, C. (2014). Adaptation of problem-solving skills training (PSST) for parent caregivers of youth with chronic pain. *Clinical practice in pediatric psychology*, *2*(3), 212.

Panepinto, J. A., Torres, S., & Varni, J. W. (2012). Development of the PedsQL™ sickle cell disease module items: qualitative methods. *Quality of Life Research*, *21*(2), 341-357.

Petranovich, C. L., Wade, S. L., Taylor, H. G., Cassedy, A., Stancin, T., Kirkwood, M. W., & Brown, T. M. (2015). Long-term caregiver mental health outcomes following a predominately online intervention for adolescents with complicated mild to severe traumatic brain injury. *Journal of pediatric psychology*, jsv001.

Pollin, I., & Kanaan, S. B. (1995). *Medical crisis counseling: Short-term therapy for long-term illness*. WW Norton & Co.

Psihogios, A. M., & Holmbeck, G. N. (2013). Discrepancies in mother and child perceptions of spina bifida medical responsibilities during the transition to adolescence: Associations with family conflict and medical adherence. *Journal of pediatric psychology, 38*(8), 859-870.

Roberts, S. A., Kiselica, M. S., & Fredrickson, S. A. (2002). Quality of Life of Persons with Medical Illnesses: Counseling's Holistic Contributions. *Journal of counseling & development*, *80*(4), 422.

Russell, H. F., January, A. M., Kelly, E. H., Mulcahey, M. J., Betz, R. R., & Vogel, L. C. (2015). Patterns of coping strategy use and relationships with psychosocial health in adolescents with spinal cord injury. *Journal of pediatric psychology*, jsu159.

Schulz, R., Czaja, S. J., Lustig, A., Zdaniuk, B., Martire, L. M., & Perdomo, D. (2009). Improving the quality of life of caregivers of persons with Spinal

Cord Injury: A randomized controlled trial. *Rehabilitation Psychology*, *54*(1), 1–15. http://doi.org/10.1037/a0014932

Schuman, S. L., Graef, D. M., Janicke, D. M., Gray, W. N., & Hommel, K. A. (2013). An exploration of family problem-solving and affective involvement as moderators between disease severity and depressive symptoms in adolescents with inflammatory bowel disease. *Journal of clinical psychology in medical settings*, *20*(4), 488-496.

Seltzer, M. M., Greenberg, J. S., Floyd, F. J., Pettee, Y., & Hong, J. (2001). Life course impacts of parenting a child with a disability. *Journal Information*,*106*(3).

Shavelle, R. M., DeVivo, M. J., Paculdo, D. R., Vogel, L. C., & Strauss, D. J. (2007). Long-Term Survival After Childhood Spinal Cord Injury. *The Journal of Spinal Cord Medicine*, *30*(Suppl 1), S48–S54.

Smith, T. F., Russell, H. F., Kelly, E. H., Mulcahey, M. J., Betz, R. R., & Vogel, L. C. (2013). Examination and measurement of coping among adolescents with spinal cord injury. *Spinal cord*, *51*(9), 710-714.

Spinal Cord Injury (SCI) Facts and Figures at a Glance. (2015, February 1). Retrieved March 15, 2015, from https://www.nscisc.uab.edu/Public/Facts2015.pdf

Spinal cord injury. (2014, October 8.) Retrieved June 2, 2015, from http://www.mayoclinic.org/diseases-conditions/spinal-cord-injury/basics/symtpoms/con-20023837

Steer, R. A., & Beck, A. T. (1997). Beck Anxiety Inventory.

Stepansky, M. A., Roache, C. R., Holmbeck, G. N., & Schultz, K. (2009). Medical adherence in young adolescents with spina bifida: Longitudinal associations with family functioning. *Journal of pediatric psychology*, jsp054.

Stiens, S. A., Bergman, S. B., & Goetz, L. L. (1997). Neurogenic bowel dysfunction after spinal cord injury: clinical evaluation and rehabilitative management. *Archives of physical medicine and rehabilitation*, *78*(3), S86-S102.

Storch, E. A., Roberti, J. W., & Roth, D. A. (2004). Factor structure, concurrent validity, and internal consistency of the beck depression inventory—second edition in a sample of college students. *Depression and anxiety*, *19*(3), 187-189.

Stubberud, J., Langenbahn, D., Levine, B., Stanghelle, J., & Schanke, A. (2015). Emotional health and coping in spina bifida after goal management training: A randomized controlled trial. *Rehabilitation Psychology*, *60*(1), 1-16. doi:10.1037/rep0000018

Suso-Ribera, C., Camacho-Guerrero, L., McCracken, L. M., Maydeu-Olivares, A., & Gallardo-Pujol, D. (2014). Social problem solving in chronic pain: An integrative model of coping predicts mental health in chronic pain patients.*Journal of health psychology*, 1359105314544133.

Szymanski, K. M., Misseri, R., Whittam, B., Kaefer, M., Rink, R. C., & Cain, M. P. (2016). Quantity, not frequency, predicts bother with urinary incontinence and its impact on quality of life in adults with Spina

Bifida. *The Journal of urology, 195*(4), 1263-1269.

Tapia, C. I., Khalaf, K., Berenson, K., Globe, D., Chancellor, M., & Carr, L. K. (2013). Health-related quality of life and economic impact of urinary incontinence due to detrusor overactivity associated with a neurologic condition: a systematic review. *Health and Quality of Life Outcomes, 11*, 13. doi:10.1186/1477-7525-11-13

Taylor, W. R., & Newacheck, P. W. (1992). Impact of childhood asthma on health. *Pediatrics, 90*(5), 657-662.

Tulsky, D. S., Kisala, P. A., Tate, D. G., Spungen, A. M., & Kirshblum, S. C. (2015). Development and psychometric characteristics of the SCI-QOL Bladder Management Difficulties and Bowel Management Difficulties item banks and short forms and the SCI-QOL Bladder Complications scale. *The journal of spinal cord medicine*, *38*(3), 288-302.

Tulsky, D. S., Kisala, P. A., Victorson, D., Tate, D. G., Heinemann, A. W., Charlifue, S., Kirshblum, S., Fyffe, D., Gershon, R., Spungen, A., Bombardier, C., Dyson-Hudson, T., Amtmann, D. Kalpakjian, C, Choi, S., Jette, A., Forcheimmer, M. & Cella, D. (2015). Overview of the Spinal Cord Injury–Quality of Life (SCI-QOL) measurement system. *The journal of spinal cord medicine,38*(3), 257-269.

Unalan, H., Gençosmanoğlu, B., Akgün, K., Karamehmetoğlu, S., Tuna, H., Ones, K., Rahimpenah, A., Uzun, E., & Tüzün, F. (2001). Quality of life of primary caregivers of spinal cord injury survivors living in the community: controlled study with short form-36 questionnaire. *Spinal cord*, *39*(6), 318-322.

von Baeyer, C. L., Marche, T. A., Rocha, E. M., & Salmon, K. (2004). Children's memory for pain: overview and implications for practice. *The journal of Pain*, *5*(5), 241-249.

Varni, J. W., Limbers, C. A., & Burwinkle, T. M. (2007). Impaired health-related quality of life in children and adolescents with chronic conditions: a comparative analysis of 10 disease clusters and 33 disease categories/severities utilizing the PedsQL™ 4.0 Generic Core Scales. *Health and quality of life outcomes*, *5*(1), 43.

Varni, J. W., Seid, M., & Kurtin, P. S. (2001). PedsQL™ 4.0: Reliability and validity of the Pediatric Quality of Life Inventory™ Version 4.0 Generic Core Scales in healthy and patient populations. *Medical care*, *39*(8), 800-812.

Vogel, L. C., Klaas, S. J., Lubicky, J. P., & Anderson, C. J. (1998). Long-term outcomes and life satisfaction of adults who had pediatric spinal cord injuries.*Archives of physical medicine and rehabilitation*, *79*(12), 1496-1503.

Wade, S. L., Walz, N. C., Carey, J., McMullen, K. M., Cass, J., Mark, E., & Yeates, K. O. (2012). A randomized trial of teen online problem solving: Efficacy in improving caregiver outcomes after brain injury. *Health psychology*,*31*(6), 767.

Wang, M. Y., Hoh, D. J., Leary, S. P., Griffith, P., & McComb, J. G. (2004). High rates of neurological improvement following severe traumatic pediatric spinal cord injury. *Spine*, *29*(13), 1493-1497.

Whiteneck, G. G. (1994). Measuring what matters: key rehabilitation outcomes. *Archives of Physical Medicine and Rehabilitation*, *75*(10), 1073-1076.

World Health Organization. International classification of functioning, disability and health: ICF short version. Geneva: World Health Organization; 2001.

Wysocki, T., Harris, M. A., Buckloh, L. M., Mertlich, D., Lochrie, A. S., Taylor, A., Sadler, M., Mauras, N., & White, N. H. (2006). Effects of behavioral family systems therapy for diabetes on adolescents’ family relationships, treatment adherence, and metabolic control. *Journal of Pediatric Psychology*, *31*(9), 928-938

Appendix A: Chart review form

SCI Participation Study
Chart Review Form

Project ID number: Date of first project interview:

Chart review date: Staff reviewing:

On the day of the interview, this patient was seen at Shriners as an:

- _____ Inpatient
- _____ Outpatient (clinic visit/rehabilitation)
- _____ Intensive outpatient
- _____ Research participant only

Participation of primary caregiver:

- _____ Primary caregiver participated in the study
- _____ Primary caregiver agreed to participate and brought packet home for completion
- _____ Primary caregiver declined participation in the study

Participation of secondary caregiver:

- _____ Secondary caregiver participated in the study
- _____ Packet was sent home for secondary caregiver to participate
- _____ Child has a secondary caregiver but that person declined participation
- _____ Child does not have a secondary caregiver

<u>Patient Information</u>

1. Sex: Female Male

2. Date of birth:

3. Country of primary residence:

4. Date of injury:

5. Cause of injury:

6. Level of injury:

7. ASIA Impairment: A B C D

8. Does child currently have health insurance coverage? Yes No

If yes, what type? (check all that apply)
- Medicaid/Medicare
- Private Company
- Other:

Appendix B: Physical Health Form

SCI Participation Study
Physical Health Form

Project ID number: Staff:

Date:

BMI

1. What is the patient's body mass index (BMI)?

Bowel and Bladder Functioning

2. Does child wear diapers?

____ No
____ Yes

3. If yes, how often?
    ____ 24 hours/day
    ____ Overnight only
    ____ Other:

4. In the past 3 months, have child's defecation method and bowel care procedures fallen in the range of "normal defecation?" ____ No
____ Yes

5. Frequency of fecal incontinence (within the last three months):

____ Two or more episodes per day
____ One episode per day
____ Not every day but at least once per week
____ Not every week but at least once per month
____ Once every month
____ Less than once per month
____ Never
____ Unknown

6. Bladder emptying:

Normal voiding
____ No
____ Yes

7. If no, what methods are used:

____ Bladder reflex triggering: Voluntary (tapping, scratching, anal stretch, etc.)

____ Bladder expression: Straining (abdominal straining, Valsalva's manoeuvre)
____ Bladder expression: External compression (Credé manoeuvre)
____ Intermittent catheterization: Self-catheterisation
____ Intermittent catheterization: Catheterisation by attendant

____ Indwelling catheter: Transurethral
____ Indwelling catheter: Suprapubic
____ Continent catheterizable stoma (Mitrofanoff)
____ Diapers
____ Other method, specify________________________

8. Any involuntary urine leakage (incontinence) within the last three months:
____ No
____ Yes: ____ Average daily ____ Average weekly ____ Average monthly

9. Surgical procedures on the urinary tract:
____ No
____ Yes: ____ Bladder augmentation ____ Botulinum toxin injection
____ Mitrofanoff

Pressure Ulcers

10. In the past year, have you had a pressure ulcer?
____ No
____ Yes

11. If yes, how many pressure ulcers have you had in the last year? _______

12. If yes, have these pressure ulcers interfered with your activities of daily living or limited your participation in other activities?
____ No
____ Yes

13. Have these pressure ulcers required hospitalization/surgery?
____ No
____ Yes: Days hospitalized: _______

Appendix C: PEDS-QL (Varni et al., 2001)

In the past 1 month, how much of a problem has this been for you…

ABOUT MY FEELINGS (problems with…)

Never	Almost Never	Sometimes	Often	Almost always
0	1	2	3	4

1. I feel afraid or scared
2. I feel sad or blue
3. I feel angry
4. I have trouble sleeping
5. I worry about what will happen to me

HOW I GET ALONG WITH OTHERS (problems with…)

Never	Almost Never	Sometimes	Often	Almost always
0	1	2	3	4

1. I have trouble getting along with other teens/kids
2. Other teens/kids do not want to be my friend
3. Other teens/kids tease me
4. I cannot do things that other teens/kids my age can do
5. It is hard to keep up with my peers

ABOUT SCHOOL (problems with….)

Never	Almost Never	Sometimes	Often	Almost always
0	1	2	3	4

1. It is hard to pay attention in class
2. I forget things
3. I have trouble keeping up with my schoolwork
4. I miss school because of not feeling well
5. I miss school to go to the doctor or hospital

Appendix D: McMaster Family Assessment Device - General Functioning Subscale

1. Planning family activities is difficult because we misunderstand each other.

Strongly agree Agree Disagree Strongly disagree

2. In times of crisis we can turn to each other for support.

Strongly agree Agree Disagree Strongly disagree

3. We cannot talk to each other about the sadness we feel.

Strongly agree Agree Disagree Strongly disagree

4. Individuals are accepted for what they are.

Strongly agree Agree Disagree Strongly disagree

5. We avoid discussing our fears and concerns.

Strongly agree Agree Disagree Strongly disagree

6. We can express feelings to each other.

Strongly agree Agree Disagree Strongly disagree

7. There are lots of bad feelings in the family.

Strongly agree Agree Disagree Strongly disagree

8. We feel accepted for what we are.

Strongly agree Agree Disagree Strongly disagree

9. Making decisions is a problem for our family.

Strongly agree Agree Disagree Strongly disagree

10. We are able to make decisions about how to solve problems.

Strongly agree Agree Disagree Strongly disagree

11. We don’t get along well together.

Strongly agree Agree Disagree Strongly disagree

12. We confide in each other.

Strongly agree Agree Disagree Strongly disagree

Appendix E: Social Problem Solving Inventory: SPSI-R:S

Thomas J. D'Zurilla, Ph.D., Arthur M. Nezu, Ph.D., & Albert Maydeu-Olivares, Ph.D.

Client ID: Age: Gender: M or F

Date of Birth: Today's Date

Instructions: Below are some ways that you might think, feel, and act when faced with problems in everyday living. We are not talking about the ordinary hassles and pressures that you handle successfully every day. In this questionnaire, a problem is something important in your life that bothers you a lot, but you don't immediately know how to make it better or stop it from bothering you so much. The problem could be something about yourself (such as your thoughts, feelings, behavior, health, or appearance), your relationships with other people (such as your family, friends, teachers, or boss), or your environment and the things you own (such as your house, car, property, or money). Please read each statement carefully and choose one of the numbers below that best shows how much the statement is true of you. See yourself as you usually think, feel, and act when you are faced with important problems in your life these days. Circle the number that is most true of you. Do not erase if you want to change an answer, instead, put an "X" through the answer you wish to change. Try to answer all of the questions.

	Not at All True of Me	Slightly True of Me	Moderately True of Me	Very True of Me	Extremely True of Me
	0	1	2	3	4
1. I feel threatened and afraid when I have an important problem to solve.	0	1	2	3	4
2. When making decisions, I do not evaluate all my options carefully enough.	0	1	2	3	4
3. I feel nervous and unsure of myself when I have an important decision to make.	0	1	2	3	4
4. When my first efforts to solve a problem fail, I know if I persist and do not give up too easily, I will be able to eventually find a good solution.	0	1	2	3	4
5. When I have a problem, I try to see it as a challenge, or opportunity to benefit in some positive way from having the problem.	0	1	2	3	4
6. I wait to see if a problem will resolve itself first, before trying to solve it myself.	0	1	2	3	4

7. When my first efforts to solve a problem fail, I get very frustrated.	0	1	2	3	4
8. When I am faced with a difficult problem, I doubt that I will be able to solve it on my own no matter how hard I try.	0	1	2	3	4
9. Whenever I have a problem, I believe it can be solved.	0	1	2	3	4
10. I go out of my way to avoid having to deal with problems in my life.	0	1	2	3	4
11. Difficult problems make me very upset.	0	1	2	3	4
12. When I have a decision to make, I try to predict the positive and negative consequences of each option.	0	1	2	3	4
13. When problems occur in my life, I like to deal with them as soon as possible.	0	1	2	3	4
14. When I am trying to solve a problem, I go with the first good idea that comes to mind.	0	1	2	3	4
15. When I am faced with a difficult problem, I believe that I will be able to solve it on my own if I try hard enough.	0	1	2	3	4
16. When I have a problem to solve, one of the first things I do is get as many facts about the problem as possible.	0	1	2	3	4
17. When a problem occurs in my life, I put off trying to solve it for as long as possible.	0	1	2	3	4
18. I spend more time avoiding my problems than solving them.	0	1	2	3	4
19. Before I try to solve a problem, I set a specific goal so that I know exactly what I want to accomplish.	0	1	2	3	4
20. Before I try to solve a problem, I set a specific goal so that I know exactly what I want to accomplish.	0	1	2	3	4
21. After carrying out a solution to a problem, I try to evaluate as carefully as possible how much the situation has changed for the better.	0	1	2	3	4
22. I put off solving problems until it is too late to do anything about them.	0	1	2	3	4
23. When I am trying to solve a problem, I think of as many options as possible until I cannot come up with any more ideas.	0	1	2	3	4

24. When making decisions, I go with my “gut feeling” without thinking too much about the consequences of each option.	0	1	2	3	4
25. I am too impulsive when it comes to making decisions.	0	1	2	3	4

Appendix F. Pearson r *Intercorrelation Coefficients*

	1 Y PQL	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21
1. Y. PQL	1	.49**	.15	.18*	.55**	-.09	-.24**	-.21*	-.25*	-.44**	-.52**	.30*	.24	-.02	-.05	.00	-.04	-.12	-.02	-.08	-.15
2. C. P-QL	.49**	1	.11	.02	.40**	-.29**	-.20*	-.14	-.26*	-.35**	-.21	.21	.21	.23*	-.19*	-.14	-.29**	.06	.11	-.31**	-.40**
3.ASIA / DeVivo	.15	.11	1	-.14	.19	.06	.06	.02	-.14	-.32*	-.36**	.00	-.08	-0.06	.14	.07	.01	-.02	-.03	.04	.12
4. AGE	.18*	.02	-.14	1	-.10	.07	-.16	-.22*	.16	.04	.15	.05	-.02	-.01	-.02	-.10	-.02	-.06	-.02	-.01	-.10
5. Y. P.S.	.55**	.40**	.19	-.10	1	.01	-.08	-.07	-.47**	-.63**	-.71**	.73**	.52**	.12	-.04	-.15	-.09	-.01	.16	0.15	-.06
6. FAM DYS.	-.09	-.29**	.06	.07	.01	1	.14	.02	.08	.02	-.03	-.02	.03	-.38**	.15	0.12	.25**	-.32**	-.43**	.19*	.42**

*p<.05 is denoted by **

*p< .01 is denoted by ***

7. U. I.	-.24**	-.20*	.06	-.16	-.08	.14	1	.23*	.08	.19	-.10	.06	-.05	.00	.04	.11	.07	.07	.03	-.09	.01
8. F. I.	-.21*	-.14	.02	-.22*	-.07	.02	.23*	1	.07	.08	-.14	-.01	-.19	-.10	.16	-.20	.12	.07	.03	-.13	.02
9. Y. I/C	-.25*	-.26*	-.14	.16	-.47**	.08	.08	.07	1	.39**	.34**	0.10	0.12	.00	-.05	.02	-.10	.01	-.14	.09	.12
10. Y AV	-.44**	-.35**	-.32*	.04	-.63**	.02	.19	.08	.39**	1	.52**	-0.24	.13	.10	-.07	.06	-.15	.11	.03	-.21	.00
11. Y NPO.	-.52**	-.21	-.36**	.15	-.71**	-.03	-.10	-.14	.34**	.52**	1	-.31*	-.05	.14	-.14	-.19	-.14	.05	-.02	-.12	-.13
12. Y. PPO	.30*	.21	.00	.05	.73**	-.02	.06	-.01	.10	-.24	-.31*	1	.62**	.20	-.06	-.18	-.26*	.05	.15	.09	-.12
13. Y. RPS	.24	.21	-.08	-.02	.52**	.03	-.05	-.19	.12	.13	-.05	.62**	1	.33**	-.26*	-.36**	-.36**	.03	.13	.12	-.01
14. CG PS	-.02	.23*	-.06	-.01	.12	-.38**	.00	-.10	0.00	.10	.14	.20	.33**	1	-.61**	-.67**	-.72**	.73**	.71**	-.10	-.40**

$p<.05$ *is denoted by* *

$p< .01$ *is denoted by* **

15. CG. I/ C	-.05	-.19*	.14	-.02	-.04	.15	.04	.16	-0.05	-.07	-.14	-.06	-.26*	-.61**	1	.48**	.48**	-.10	-.13	.03	.18
16. CG AV	.00	-.14	.07	-.10	-.15	.12	.11	-.20	.02	.06	-.19	-.18	-.36**	-.67**	.48**	1	.50**	-.25**	-.24**	-.01	0.13
17. CG NPO	-.04	-.29**	.01	-.02	-.09	.25**	.07	.12	-.10	-.15	-.14	-.26*	-.36**	-.72**	.48**	.50**	1	-.34**	-.24**	.36**	.54**
18. CG PPO	-.12	.06	-.02	-.06	-.01	-.32**	.07	.07	.01	.11	.05	.05	.03	.73**	-.10	-.25**	-.34**	1	.68**	-.02	-.27*
19. CG RPS	-.02	.11	-.03	-.02	.16	-.43**	.03	.03	-.14	.03	-.02	.15	.13	.71**	-.13	-.24**	-.24**	.68**	1	-.02	-.23*
20. CG ANX	-.08	-.31**	.04	-.01	.15	.19*	-.09	-.13	.09	-.21	-.12	.09	.12	-.10	.03	-.01	.36**	-.02	-.02	1	.59**
21. CG DEP	-.15	-.40**	.12	-.10	-.06	.43**	.01	.02	.12	.00	-.13	-.12	-.01	-.40**	.18	.13	.54**	-.27*	-.23*	.59**	1

$p<.05$ is denoted by *

$p < .01$ is denoted by **

Correlation Table Key

1. Youth HRQOL
2. Caregiver HRQOL
3. ASIA/DeVivo/Level of Injury
4. Age
5. Youth Total Social Problem Solving
6. Family Dysfunction
7. Urinary Incontinence
8. Fecal Incontinence
9. Youth Impulsivity/Carelessness
10. Youth Avoidance
11. Youth Negative Problem Orientation
12. Youth Positive Problem Orientation
13. Youth Rational Problem Solving
14. Caregiver Total Social Problem Solving
15. Caregiver Impulsivity/Carelessness
16. Caregiver Avoidance
17. Caregiver Negative Problem Orientation
18. Caregiver Positive Problem Orientation
19. Caregiver Rational Problem Solving
20. Caregiver Anxiety
21. Caregiver Depression