



2012

The Direct and Indirect Impact of Pain Intensity, Weight Status, and Activity Involvement on Social Competence Outcomes in Children and Adolescents with Spina Bifida

Bonnie S. Essner
Loyola University Chicago

Follow this and additional works at: https://ecommons.luc.edu/luc_diss



Part of the [Clinical Psychology Commons](#)

Recommended Citation

Essner, Bonnie S., "The Direct and Indirect Impact of Pain Intensity, Weight Status, and Activity Involvement on Social Competence Outcomes in Children and Adolescents with Spina Bifida" (2012). *Dissertations*. 347.

https://ecommons.luc.edu/luc_diss/347

This Dissertation is brought to you for free and open access by the Theses and Dissertations at Loyola eCommons. It has been accepted for inclusion in Dissertations by an authorized administrator of Loyola eCommons. For more information, please contact ecommons@luc.edu.



This work is licensed under a [Creative Commons Attribution-NonCommercial-No Derivative Works 3.0 License](#).
Copyright © 2012 Bonnie S. Essner

LOYOLA UNIVERSITY CHICAGO

THE DIRECT AND INDIRECT IMPACT OF PAIN INTENSITY, WEIGHT STATUS,
AND ACTIVITY INVOLVEMENT ON SOCIAL COMPETENCE OUTCOMES IN
CHILDREN AND ADOLESCENTS WITH SPINA BIFIDA

A DISSERTATION SUBMITTED TO
THE FACULTY OF THE GRADUATE SCHOOL
IN CANDIDACY FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY

PROGRAM IN CLINICAL PSYCHOLOGY

BY

BONNIE SUE ESSNER

CHICAGO, ILLINOIS

AUGUST 2012

Copyright by Bonnie S. Essner, 2012
All rights reserved.

ACKNOWLEDGEMENTS

I am deeply grateful for the many family, friends, professional colleagues, and advisors who have contributed to the completion of this dissertation in so many ways. I would like to thank Dr. Grayson N. Holmbeck, who has been an exemplary mentor for my professional development and who has been an inspiration in life outside of academia, as well. I admire his dedication to his research, to the Loyola University Clinical Psychology Graduate program, and to each of the graduate students with whom he works. Along with Dr. Holmbeck, I have had the distinct privilege of receiving mentorship, both formally and informally, from so many other talented and creative clinical supervisors, researchers, and fellow students during my graduate studies. They have all enriched my life and challenged me to be a better clinician, researcher, and person. I cannot begin to name each of the many people who have impacted my life during the course of writing this dissertation, so I hope they will all accept my sincerely heartfelt, collective thanks.

My parents, Robert and Karla Essner, have instilled in me a strong love of education, encouraged the qualities of curiosity and creativity, and rooted for me through every stage of life. They have given me the confidence to daringly go in the direction of my dreams, wherever those many lead. I am grateful for their guidance and their love. I would also like to thank my brothers, my friends, and many family members, including

my husbands' parents, who reminded me of the importance to pursue other interests while working on this dissertation.

Most importantly, I would like to thank my husband, Jim Maurer. This journey through graduate school has been a team effort and I am so proud of what we have accomplished together. I have continually been awed by his unwavering support, deep love and affection, enthusiastic encouragement, and genuine commitment to me, to our marriage, and to our professional successes. I am truly fortunate. He is forever my friend, forever my love. I look forward to continuing to discover the adventures that await us.

For my husband, Jim. Forever my friend, forever my love.

TABLE OF CONTENTS

ACKNOWLEDGEMENTS	iii
LIST OF TABLES	viii
LIST OF FIGURES	ix
CHAPTER ONE: INTRODUCTION	1
General Overview	1
Overview of Spina Bifida	5
Independent Variables: Condition Parameters	10
Limitations of Previous Work	10
Pain Symptoms	13
Motor Function	16
Weight Status	19
Mediator Variables: Activity Participation	22
Moderator Variables: Demographic, Individual, and Family Factors	24
Demographic Characteristics: Age	24
Individual Characteristics: Internalizing Symptoms	26
Family Characteristics: Parental Intrusiveness	27
Dependent Variables: Indicators of Social Competence	29
Study Hypotheses	31
Hypothesis Ia	32
Hypothesis Ib	32
Hypothesis II	32
Hypothesis III	33
Hypothesis IV	33
CHAPTER TWO: METHOD	34
Participants	34
Sample Recruitment	34
Current Study: Reduced Sample	36
Design and Procedure	38
Measures	43
Condition Severity Independent Variables	43
Pain Intensity	45
Motor Function	45
Weight Status	46
Activity Involvement Mediator Variables	47
Activities	47
Social Organization Involvement	48
Activity Limitations	49

Demographic, Individual, and Family Moderator Variables	50
Age	50
Internalizing Symptoms	50
Parental Intrusiveness	51
Social Competence Dependent Variables	53
Perceived Social Acceptance	53
Number of Friends	53
Quality of Social Interactions	54
Additional Measures	55
Intellectual Functioning	55
Demographic Information and Spina Bifida Characteristics	55
Proposed Data Analyses	56
Hypotheses Ia and Ib	57
Hypothesis II	59
Hypotheses III and IV	60
Power Analysis	61
CHAPTER THREE: RESULTS	63
Preliminary Analyses	63
Outliers	63
Skewness	64
Scale Descriptives	66
Results for Study Main Hypotheses	71
Hypotheses Ia and Ib	71
Hypothesis II	74
Hypotheses III and IV	79
Illustrated Summary of Regression Analyses Findings	84
Exploratory Analyses	84
CHAPTER FOUR: DISCUSSION	90
Conclusions	90
Implications for Clinical Practice	106
Study Strengths	109
Study Limitations	110
REFERENCES	114
VITA	127

LIST OF TABLES

Table	Page
1. Youth demographics and spina bifida characteristics	37
2. Measured Used in the Current Study	44
3. Skewness Z-score values and Transformations Used for Variables in Regression Analyses	65
4. Scale Means, Standard Deviations, Alphas, and Ranges	67
5. Results of Hierarchical Multiple Regressions Testing Hypotheses Ia and Ib: Psychosocial Variables Moderating the Association Between Condition Severity Variables and Activity Involvement	75
6. Results of Hierarchical Multiple Regressions Testing Hypotheses II: Condition Severity Variables Predicting Five Social Competence Outcomes	78
7. Results of Hierarchical Multiple Regressions Testing Hypotheses III and IV: Condition Severity Variables and the Activity Involvement Mediator Variable Predicting the Five Social Competence Outcomes	81
8. Results of Exploratory Hierarchical Multiple Regressions: Activity Involvement Mediator Variable Predicting the Five Social Competence Outcomes	89

LIST OF FIGURES

Figure	Page
1. Proposed model examining associations among physical status, activity limitations, and social competence outcomes in youth with spina bifida	4
2. Revised model examining associations among physical status, activity Limitations, and social competence outcomes in youth with spina bifida	72
3. Illustrated Summary of Regression Analyses Findings	85
4. Findings From Exploratory Analyses	89

CHAPTER ONE

INTRODUCTION

General Overview

The attainment of developmentally-appropriate social competence is a major task of childhood and adolescence that has significant consequences for achievement in other domains of functioning (Holmbeck, 2002). Peer acceptance, positive interactions with peers, and strong social skills have both immediate and long-term benefits to youths' psychosocial health. As children and adolescents transition through early developmental stages, peers can serve as valuable sources of social and emotional support that are qualitatively distinct from the support provided by adults. For example, peers and close friends offer emotional support to one another, whereas caregivers and other adults provide support that is more instrumental in nature (La Greca, Bearman, & Moore, 2002). Peer acceptance during childhood and adolescence has also been associated with numerous indices of psychosocial adjustment, including academic success, moral development, and other positive outcomes into adulthood (Cicchetti & Bukowski, 1995; Birch & Ladd, 1996; Newcomb & Bagwell, 1998; Parker & Asher, 1987). Conversely, difficulties with social adjustment are related to long-term negative consequences, such as school drop-out, and mental illness (Parker & Asher, 1987; Kupersmidt, Coie, & Dodge, 1990). Thus, social competence has emerged as a central focus of the child and

adolescent psychology literature, due to its demonstrated relation with general psychosocial adaptation (La Greca, Prinstein, & Fetter, 2001).

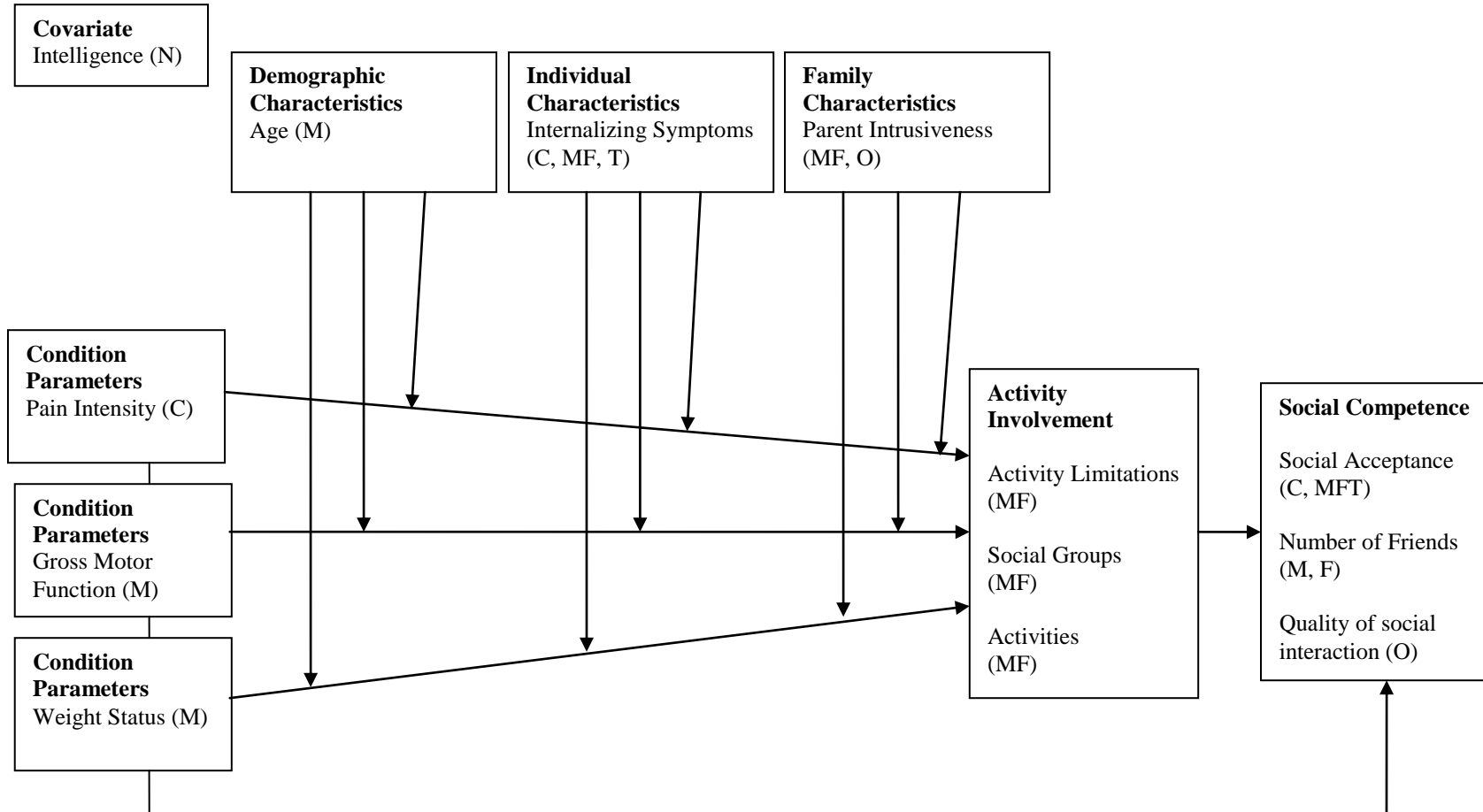
Unfortunately, social competence difficulties are consistently cited as a concern for youth with neurodevelopmental conditions, such as spina bifida (Cunningham, Thomas, & Warschausky, 2007; Nassau & Drotar, 1997; Holmbeck et al., 2003). As compared to typically developing youth, children and adolescents with spina bifida are described as having fewer friends, smaller social networks, fewer social contacts outside of school, lower quality friendships, to be more socially isolated, and to be passive and withdrawn during social interactions (Blum, Resnick, Nelson, & St. Germaine, 1991; Cunningham, Thomas, & Warschausky, 2007; Holmbeck et al., 2003). Because social competence in this population has received relatively little attention in the literature to this point (La Greca, 1990; Nassau & Drotar, 1997), the long term effects of these social difficulties are not known. However, given the strong evidence describing negative consequences of social adjustment concerns among typically developing youth (Kupersmidt, Coie, & Dodge, 1990), there is a great need for further investigation into factors contributing to these observed social deficits in youth with spina bifida (La Greca, 1990; Nassau & Drotar, 1997) so that treatments may be developed that intervene in appropriate areas. This study addresses this important area of inquiry by testing a complex model involving condition parameters and child activity limitations, as well as demographic, psychological, and family variables, as they relate to the social competence difficulties in youth with spina bifida. The current study was designed with clinical applications in mind. By proposing activity limitations as the hypothesized mechanism

underlying associations between condition severity and social competence, this study model provides an appropriate design for testing statistical effects within a mechanism of change framework that highlights a process that is amenable to intervention. From this study, findings in favor of activity restrictions as a process that accounts for the relation between condition severity and social competence outcomes would suggest activity involvement as an appropriate target for intervention.

The purpose of this study is to test a mediation effects model examining associations among physical status, activity limitations, and social competence outcomes in youth with spina bifida (Figure 1). Specifically, greater pain intensity, overweight, and more limited motor function are believed to inhibit youth with spina bifida from participating in a range of age-appropriate activities. This limited activity participation is, in turn, expected to be associated with social difficulties. Thus, restrictions in activities are expected to mediate the relation between the proposed condition parameters and social competence outcomes in children and adolescents with spina bifida. Although several condition parameters included in the model have been associated with activity limitations in children with chronic illnesses (e.g., Nassau & Drotar, 1997, Palermo, 2000; Wilson, Washington, Engel Ciol, & Jensen, 2006; Rimmer, Rowland, & Yamaki, 2007; Simeonsson, McMillen, & Huntington, 2002), and likewise, restrictions in activities have generally been regarded as a source of reduced social competence in youth (La Greca, 1990; Reiter-Purtill & Noll, 2003), these factors have not been studied within the broader mediation model proposed in this study.

Figure 1. Proposed model examining associations among physical status, activity limitations, and social competence outcomes in youth with spina bifida.

Note. C = child/adolescent participant; M = mother; F = father; T = teacher; O = observer; N = neuropsychological testing



This study also includes three categories of moderator variables, which are expected to affect the degree to which the pain, motor function, and overweight condition parameters impact the activity involvement of children with spina bifida (see Figure 1). There is strong evidence that demographic, individual, and family factors play an important role in youths' participation in activities of daily living, social activities, and physical activities (Palermo, 2000; Farmer & Deidrick, 2006). This study will be the first to examine ways in which factors in each of these domains enhance, or inhibit, activity participation of youth with spina bifida. These moderating factors are important elements of the study model, as their inclusion could potentially identify subgroups of youth with spina bifida that are most at risk for disruptions in typical physical and social activities.

The following sections provide a description of spina bifida, followed by an overview of the three condition severity predictor variables as they relate to activity limitations and social competence in these youth. Next, the demographic, individual, and family variables predicted to moderate relations between the condition parameters and activity limitations are presented. Finally, a review of the social competence outcomes, and a justification for the path between activity restrictions and social competence difficulties, is provided. The section concludes with study hypotheses.

Overview of Spina Bifida

Spina bifida is one of the most common birth defects in the United States, with an incidence of approximately 18 per every 10,000 live births (CDC, 2008). The condition results from an incomplete closure of the neural tube during the first several weeks of

gestation. In myelomeningocele, the most common form of spina bifida, the spinal cord, meninges, parenchyma, and nerve roots protrude through the point of the back where the tube has failed to close (Burmeister, Hannay, Fletcher, Boudousquie, & Dennis, 2005), which is typically in the lumbrosacral area. Immediate surgical intervention is conducted to repair the lesion; however neurologic impairments cannot be restored with surgery. Although “spina bifida” is often used interchangeably with “myelomeningocele”, the term also refers to other forms of neural tube defects, such as myelocystocele and lipomeningocele, which are associated with less severe spinal lesions, and in turn, typically result in less severe physical impairments. Health complications associated with spina bifida result from both primary conditions directly related to characteristic physical impairments, as well as secondary sequelae and complications, that include, for example, surgical interventions, infection, repetitive use of muscle groups, poor posture, and insufficient energy expenditure (Simeonsson et al., 2002).

Primary impairments are motor, sensory, autonomic, and cognitive in nature. Individuals with spina bifida have a complete, or partial, loss of sensory, motor, and autonomic nerve functioning in those areas of the body controlled by nerves at or below the spinal lesion (Sandler, 1997). Sensory nerve impairments affect touch, pressure, temperature, pain, and body position sensations (Sandler, 1997), which can result in increased risk of injury and infection to the site if it goes unnoticed and is left untreated. Motor impairments often include disruption of voluntary control of lower-body muscles, including the abdominal, hip, and leg muscles, and may result in paraplegia (Sandler,

1997). Orthopedic complications, including club foot and scoliosis, as well mobility disabilities requiring leg braces or use of a wheelchair, are common conditions that result from primary motor impairments. Also, autonomic nerve impairments interfere with sensation and muscle control of the bladder and bowel, resulting in urinary and bowel incontinence (Sandler, 1997). Individuals with spina bifida typically perform intermittent catheterization, follow prescribed dietary guidelines, take medications, and sometimes undergo surgical intervention to preserve functioning and prevent secondary complications in these organs.

The characteristic cognitive impairments associated with spina bifida are related to several brain abnormalities that are common to this population. Hydrocephalus, a condition represented by enlarged ventricles in the brain due to an imbalance in the production and reabsorption of cerebrospinal fluid, is present in about 95% of all cases of myelomeningocele (Burmeister et al., 2005). Hydrocephalus causes damage to cortical and subcortical structures (Scott et al., 1998), resulting in the characteristic profile of neurocognitive deficits that include visuospatial processing, executive dysfunctions, inability to focus and sustain attention, and memory problems. Overall intelligence is typically in the low-average to average range (Charney, 1992). Precocious puberty, which often occurs in youth with spina bifida, is also indirectly related to hydrocephalus (Brauner, Fontoura, & Rappaport, 1991). Approximately 90% of all hydrocephalus cases require the implantation of a shunt into the ventricles, so that cerebrospinal fluid may be diverted from the ventricles and drained from the body (Burmeister et al., 2005).

Cognitive impairments associated with hydrocephalus are linked to both brain damage resulting directly from hydrocephalus, as well as damage sustained from repeated shunt infections and revision surgeries.

The Chiari II malformation is another brain abnormality seen in the majority of individuals with myelomeningocele. In this condition, the posterior fossa is reduced in size, restricting the growth and expansion of the cerebellum. This results in a herniation of the cerebellum, as it is forced upward and downward through the exit of the fourth ventricle, usually causing reduced overall cerebellar volume (Dennis et al., 2004). This brain abnormality has been associated with deficits in perceptual and motor timing (Dennis et al., 2004), as well as verbal memory and fluency (Vinck, Maassen, Mullaart, & Rotteveel, 2006) and attention and executive functioning (Brewer, Fletcher, Hiscock, & Davidson, 2001).

As is evident from the description above, spina bifida is a complex chronic illness with substantial motor, sensory, and cognitive impairments that result in many chronic health conditions and disorders that affect a number of body systems and compromises physical functioning in a range of domains. Although it is likely that the social competence difficulties described in this group of children and adolescents (Holmbeck et al., 2003) arise from a combination of these many conditions, disorders, and complications, the current study focuses on several condition parameters that have received relatively little consideration in previous studies on psychosocial outcomes in children and adolescents with spina bifida (Figure 1). This study is not intended to

address comprehensively each condition parameter that might impact social development in these youth. Rather, the aim of this study is to extend the literature on social competence difficulties in youth with spina bifida by including these condition parameters within a complex model of social competence development that considers the role of limited activity participation as well as the contribution of sociodemographic, individual, and family factors.

The following section discusses several methodological limitations of past research on associations between physical status and social competence deficits, with a description of efforts made in this study to improve upon previous work. This section also presents an overview of each of the condition parameters that are included as predictor variables in this study, with information about effects specific to youth with spina bifida, as well as empirical findings regarding associations with activity participation and social competence outcomes.

Independent Variables: Condition Parameters

Limitations of Previous Work

Past research examining the association between condition parameters and social competence outcomes in youth with spina bifida have yielded mixed findings (Hommeyer, Holmbeck, Wills, & Coers, 1999). Whereas several studies have found condition parameters to account for only a small proportion of the variance in social competence outcomes (e.g., Wallander, Feldman, & Varni, 1989), others have concluded

that physical status does play a role in youths' observed social adjustment (Nassau & Drotar, 1997; Hommeyer et al., 1999; Ammerman et al., 1989; Hirst, 1985). In those cases in which physical status has shown little relation to social adjustment, the lack of significant findings may have been due largely to methodological limitations of those previous studies. First, researchers have tended to include only a narrow range of condition parameters in their investigations, including only those aspects of spina bifida that have traditionally been considered to be major distinguishing features of the condition (e.g., lesion level, type of spina bifida). However, it is likely that other indicators of physical status, such as secondary conditions that are common to other chronic illnesses and not exclusive to spina bifida, may play a role in social development in youths with spina bifida. For example, severe pain may restrict children's participation in social activities, thereby limiting their opportunities to develop meaningful peer relationships (Nassau & Drotar, 1997; Spirito, DeLawyer, & Stark, 1991; La Greca, 1990). To this point, many secondary conditions found to have negative implications for social adjustment in groups of youth with other chronic illnesses (e.g., pain symptoms) have been largely ignored in studies of psychosocial adjustment in children and adolescents with spina bifida.

Another methodological issue that may have obscured associations between physical status and psychosocial outcomes in past research is the practice of forming severity composites by combining several condition parameters into a single index of condition severity. Composite severity indices confer equal weight to each condition

parameter, with the implication that such parameters as lesion level, hydrocephalus status, and ambulation method are equally salient for the development of psychosocial health for youth with spina bifida. Although composites create a convenient and useful index of overall physical status, they can be problematic when used as predictors of adjustment outcomes. These composites preclude the ability to parcel out the portion of variance in psychosocial outcomes explained by each of the distinct condition parameters that make up the composite (Hommeyer, Holmbeck, Wills, & Coers, 1999). The use of composites is particularly problematic when we consider that specific condition parameters are associated with different psychosocial outcomes (Holmbeck & Faier-Routman, 1995; Hommeyer et al., 1999).

Finally, some previous studies may have neglected to find significant associations between condition parameters and psychosocial outcomes due to their use of oversimplified models of direct effects, without consideration of the complex relations between condition parameters, proximal disability factors, and the more distal social competence outcomes of interest (Hommeyer et al., 1999). Although condition severity may not show strong direct relations with youths' social competence, the two may be related indirectly via a mediating factor. Studies employing more sophisticated statistical models have found some evidence for indirect effects of condition severity on "distal" psychosocial adjustment outcomes, via more "proximal" disability-related factors (Hommeyer et al., 1995). In the current study, it is predicted that a more severe symptom presentation, including more severe pain, worse motor impairment, and greater

overweight, will lead to social adjustment difficulties in youth with spina bifida, via the more proximal factor of activity restriction.

Pain Symptoms

Pain is a secondary health condition that, although largely overlooked in research with children and adolescents with spina bifida, has recently been described as more prevalent and more pertinent to psychosocial health in this population than had previously been believed (Clancy, McGrath, & Oddson, 2005; Oddson, Clancy, & McGrath, 2006). Individuals with spina bifida may develop chronic or acute pain as a result of a number of health conditions, surgical procedures, or health maintenance and prevention practices. For example, joint and musculoskeletal pain are often related to arthritis, strain from posture and positioning issues (e.g., due to improper fit of wheelchair or ankle-foot orthotics), or as a result of repetitive overuse of particular muscle groups, especially upper-body muscles used for ambulation with wheelchairs or crutches (Sobus, 2008). Long-term spasticity (i.e., involuntary continuous muscle contraction), as well as the physical therapy regimen of stretching and range of motion exercises required to maintain functioning and prevent contractures, is also a common source of chronic pain (Marge, 1994). Abdominal pain is frequently reported among children and adolescents who experience chronic constipation due to lack of adherence to a regular bladder and bowel program (Sobus, 2008).

Many children with spina bifida also begin to experience tethered cord symptoms around six to twelve years of age (Sandler, 1997), when the resulting stretching and damage to the spinal cord and surrounding blood vessels causes severe back and leg pain, as well as increased muscle spasticity, reduced bladder and bowel functioning, and orthopedic deformities (e.g., scoliosis; Sandler, 1997). Finally, frequent headaches are another common source of pain complaints among children and adolescents with spina bifida and shunted hydrocephalus. Shunt malfunction and intracranial pressure imbalances, which are fairly common occurrences, cause intense headache pain. Also, migraine and tension-type headaches are more prevalent among children with spina bifida and shunted hydrocephalus, as compared to children in the general population (Stellman-Ward, 1997; Rimmer et al., 2007). Although surgical procedures and adherence to prescribed treatment regimens may alleviate the pain associated with some of these conditions (e.g., tethered cord, shunt malfunction), complications are frequent and symptoms often return (SBA, 2007).

In the only known study of the nature and prevalence of pain in children and adolescents with spina bifida, Clancy, McGrath, and Oddson (2005) reported that the majority (56%) of the 68 participants experienced pain in the following areas at least once per week: Head, back, abdomen, neck, shoulders, legs, and hands. Eighty-eight percent of children in the study with shunted hydrocephalus, and 79% of children without hydrocephalus, reported recurrent headaches (Clancy, McGrath, & Oddson, 2005). Pain intensity, duration, and frequency were all unrelated to lesion level and method of

ambulation (Clancy, McGrath, & Oddson, 2005). Among the younger (8-12 year old) children in the study, males described pain as significantly more intense than did females; however, there was no difference between male and female reports of pain intensity among older (13-19 year old) adolescents (Clancy, McGrath, & Oddson, 2005). Notably, parents of participants significantly under-estimated the intensity of their children's pain, prompting authors to conclude that although children and adolescents with spina bifida experience clinically significant pain, their symptoms are often under-recognized, and thus, insufficiently treated (Clancy, McGrath, & Oddson, 2005).

Although the impact of pain symptoms on activity involvement has not been examined in youth with spina bifida, this relation has been described in youth with other chronic health conditions. For example, children with illnesses that involve significant pain (e.g., sickle cell disease) report a moderate restriction in social, leisure, and physically-demanding activities (Walters & Williamson, 1999; Lemanek et al., 1994; Larsson & Sund, 2007; Meijer, Sinnema, Bijstra, Mellenbergh, & Wolters, 2000) and less frequent contact with peers across a range of settings (Fuggle, Shand, Gill, & Davies, 1996). Many youth also attempt to cope with their considerable pain by isolating themselves (Gil, Williams, Thompson, & Kinney, 1991) and by limiting their involvement in social, athletic, and daily activities (Palermo, 2000). Thus, activity restriction and reduced social contact with peers is a well-documented consequence of pain in youth with various chronic health conditions.

Relations between pain experience and social competence outcomes have been a neglected area of study, both within the broader literature on child and adolescent pain (Palermo, 2000), and concerning youth with spina bifida, specifically. However, in a single study on this topic, Larsson & Sund (2006) reported that within a community sample of adolescents, participants who frequently experienced pain in multiple sites also had fewer friends as compared to adolescents who reported single pain locations. This finding provides some preliminary support for a relation between pain and social competence, although this area of study deserves greater consideration (Palermo, 2000).

Motor Function

The majority of individuals with spina bifida have motor impairments that significantly reduce their voluntary movement capacity, thus limiting their ability to ambulate and to perform other motor skills without assistive mobility devices. In children and adolescents with spina bifida, degree of motor function is closely associated with lesion level, with higher spinal lesions typically resulting in greater degree of muscle paralysis. Other factors, including difficulties with balance, motor planning and coordination, as well as visuospatial deficits (which are each related to cognitive impairments associated with hydrocephalus and the Chiari II malformation), also present challenges for attaining a high level of motor function for these youth (Sandler, 1997; Rowe & Jadhav, 2008; Norrlin, Strinnholm, Carlsson, & Dahl, 2003). Children with spina bifida are encouraged to walk with the use of crutches, orthoses, and other assistive

devices as long as they are capable (Sandler, 1997). However, due to progressive orthopedic concerns, including hip dislocation, knee contractures, and foot and spinal deformities, as well as increased energy required to ambulate, many youth with lesions at the mid-lumbar area and higher gradually rely more on assistive mobility devices during adolescence, and full-time wheelchair use becomes more common around this time (Rowe & Jadhav, 2008).

Many studies have described the relation between mobility limitations and difficulty with performance of developmentally-appropriate daily activities in children and adolescents with chronic health conditions (e.g., Wilson et al., 2006; Varni, Setoguchi, Rappaport, & Talbot, 1992). For youth with spina bifida, motor impairments interfere with their capacity to perform self-care tasks, such as transfers (i.e., relocation from the wheelchair to other positions and locations), toileting, and other activities of daily living (Buran et al., 2004; Bier et al., 2005; Schoenmakers et al., 2005). Moreover, participation in activities outside the home is dependent on youths' ability to care for some of these basic needs themselves, as adult supervisors are often not capable of, or comfortable with, assisting with these tasks. Thus, youth with spina bifida who have more severe motor impairments that restrict self-care tasks, may have limited opportunity to participate in social and extracurricular activities in the community because they are unable to be away from caregivers for extended periods of time. It has also been suggested that children and adolescents with more severe motor dysfunction may find participation in social activities to be difficult because of accessibility issues (Rimmer et

al., 2007). Additionally, involvement in physical activities, such as sports, may be especially challenging for youth with severe motor dysfunction, due to the insufficient availability of school- and community-based recreation programs for youth with physical disabilities and a lack of facilities offering adequate adaptive exercise equipment (Kasser & Lytle, 2005; Rimmer et al., 2007).

Although there is strong empirical evidence that the activity involvement of youth with chronic health conditions is inversely related to their degree of motor control (Meijer, Sinnema, Bijstra, Mellenbergh, Wolters, 2000; Padua et al., 2002), the impact of motor function on social competence outcomes is less clear. Whereas some investigators have reported that severity of mobility limitations has no effect on the perceived social acceptance of youth with a variety of chronic health conditions (Meijer et al., 2000), others have concluded that, for youth with spina bifida, greater mobility limitations result in worse social competence outcomes (Ammerman et al., 1989). Although the divergence in findings may be explained, at least in part, by methodological inconsistencies between the studies (e.g., use of different measures of social competence and motor function), it is possible that the connection between mobility limitations and social competence deficits is better explained via their shared relation with activity limitations. The current study will be the first to test a model of social competence outcomes in youth with physical disabilities wherein activity limitations is hypothesized to mediate the association between restricted motor function and reduced social competence.

Weight Status

Children and adolescents with spina bifida are at high risk for becoming overweight. At least 50% of these youth over the age of six years meet criteria for obesity [body mass index-for-age (BMI-percentile) greater than or equal to the 95th percentile], and many more are overweight (BMI-percentile between the 85th and 95th percentile; SBA n.d.). The prevalence of overweight and obesity in adults with spina bifida is also very high (i.e., 50% obesity rate; SBA n.d.), suggesting that many youth continue to have weight management difficulties throughout their lives. For individuals with spina bifida, overweight is associated with the same health complications as occur in able-bodied individuals (e.g., hyperlipidemia, hypertension, insulin resistance), but also increases the risk for issues specific to people with physical disabilities (e.g., pressure sores), and creates further challenges for self-care (e.g., difficulty with transfers and toileting tasks; Sandler, 1997; SBA, n.d.).

Many factors contribute to the development of obesity in youth with spina bifida. These children and adolescents generally have a very low energy expenditure, due to their low levels of physical activity (Liusuwan, Widman, Abresch, & McDonald, 2004; Rimmer et al., 2007) and an altered body composition (i.e., relatively higher body fat percentage and low lean muscle tissue) that results in a lower resting metabolic rate (Liusuwan et al., 2004). Youth with spina bifida also have reduced caloric needs as compared to able-bodied peers and often consume far more calories than they expend. Overeating of unhealthy calorie-dense foods has been described as common in youth with

spina bifida (American Dietetic Association, 2004). Parents often inadvertently contribute to overweight by using food as a reinforcer for good behavior (SBA, n.d.; Simpson, Swicegood, & Mark, 2006) and encouraging the use of food as a coping mechanism when children are emotionally distressed (Leibold, 1994). Finally, healthcare providers may not adequately address the importance of proper nutrition and physical activity, or describe the additional health risks associated with overweight for these children (Rimmer et al., 2007), leaving families uninformed about the severity of their child's condition.

In children and adolescents with spina bifida, obesity has been associated with activity restriction through its exacerbation of mobility limitations (SBA, n.d.). For example, overweight may contribute to motor dysfunction in these youth by further inhibiting range-of-motion, increasing burden of ambulation and fatigue, and decreasing physical fitness (SBA, n.d), thus presenting challenges for participation in physical activities. Youth with spina bifida who are overweight also have more difficulty carrying out self-care tasks (SBA, n.d.; Simeonsson, et al., 2002; Liou, Pi-Sunyer, & Laferrere, 2005), which, as described above, often prohibits them from participating in social activities away from home. Although obesity is generally cited as a major contributing factor to activity limitations in youth with physical disabilities (Simeonsson et al., 2002), findings from one study have disputed the relation between overweight and activity restrictions by reporting that increases in body weight do not incrementally reduce the activities of young adults with spina bifida (Buffart, Roebroek, Rol, Stam, & van den

Berg-Emons., 2008). The current study will provide important information about the relative salience of overweight, as compared to mobility limitations and pain, in youths' participation in activities to more explicitly describe the impact of different condition parameters on activity participation in these youth.

Typically developing youth who are overweight experience significant problems with peer relations (Reiter-Purtill & Noll, 2003), which likely compromises their social functioning. They are often teased because of their weight (Neumark-Sztainer, Falkner, Story, Perry, Hannon, & Mulert, 2002; Griffiths, Wolke, Page, & Horwood, 2006) and are ascribed negative attributions (e.g., "lazy", "unattractive") by their peers (Neumark-Sztainer, Story, & Faibisch, 1998). Perhaps because of extensive peer rejection and social marginalization, overweight children and adolescents are described as having social competence difficulties (Braet, Mervielde, & Vandereycken, 1997) and report substantial body image concerns and low self-perceived physical appearance competence (French, Story, & Perry, 1995).

Because social competence difficulties are also a major concern for youth with spina bifida, it might be assumed that overweight would further impair the social functioning of these youth who have the additional concern of excess weight. In fact, overweight has been suggested as a factor that might further contribute to the social competence difficulties in children and adolescents with spina bifida (Rimmer et al., 2007; Simeonsson et al., 2002). However, this relation has not been validated empirically in a study comparing the relative salience of overweight to other condition parameters.

Also absent from the literature on the social consequences of overweight in youth with spina bifida, is an elucidation of the pathway between these two factors. This study will expand the literature on the impact of overweight in children and adolescents with spina bifida by examining activity restrictions as a potential mediator of the relation between overweight and the social competence difficulties observed in these youth.

Mediator Variables: Activity Participation

Participation in a range of age-appropriate daily activities—such as school attendance, self-care tasks, chores, and physical and social activities—is important for the psychosocial development of children and adolescents (Barber, Stone, & Eccles, 2005). Collectively, normative, daily activities provide opportunities to develop essential life skills, as well as practice with planning and problem-solving abilities, that are necessary for autonomy and serve as the basis for later employment skills. Involvement in sports and athletic programs, volunteer groups, organized social activities, and other extracurricular activities are also imperative for identifying and fostering talents, which provide a sense of mastery, creativity, and bolsters self-esteem and psychological health (Eccles, 2004).

Just as importantly, and of greatest relevance to the current study, is the role of activity involvement in youth social development. Activities provide an important context for peer contact through which children learn social norms (Hansen, Larson, & Dworkin, 2003), develop social skills through interpersonal interactions (La Greca,

1990), and form peer relations that evolve into friendships. Unfortunately, children and adolescents with spina bifida have limited activity involvement, which severely restricts their opportunities for peer interaction. These youth require a great deal of assistance to carry out daily activities, including chores and self-care tasks (Dahl et al., 2000), which, as described previously, limits their ability to engage in activities independently outside the home. Even those youth who are skilled at self-care are severely limited in their participation in social activities (Blum, Resnick, Nelson, & St. Germaine, 1991; Stevens, Steele, Jutai, Kalnins, Bortolussi, & Biggar, 1996) such as school extracurricular activities and both organized social activities and activities with peers that are not arranged through programs or groups (Buran, Sawin, Brei, & Fastenau, 2004).

Although it is often been speculated that restrictions to normative daily, social, and physical activities are responsible, to some extent, for the social competence difficulties seen in youth with physical disabilities (La Greca, 1990; Schuman & La Greca, 1999), this connection has not yet been verified by empirical study. The current study will examine this hypothesized relation as an element of a more comprehensive model of social competence difficulties in youth with spina bifida (Figure 1). Because it is believed that participation in a range of age-appropriate normative activities is essential for the development of social competence, this study will assess participants' functioning in the following: self-care tasks; daily leisure-, school-, and chore-related activities; social activities; and physical or athletic activities. Additionally, to further clarify the degree to which physical status plays a role in activity involvement, a measure of activity

limitations will also be included. This instrument will allow for an examination of whether or not reported activity restrictions are attributed to participants' pain or other physical discomfort.

Moderator Variables: Demographic, Individual, and Family Factors

Although pain, motor dysfunction, and overweight physical status variables are each expected to have a strong impact on the activity participation of youth with spina bifida, many other factors inherent to youth and their family contexts are believed to influence the extent of this relation. The next sections provide an overview of demographic, individual, and family characteristics that are hypothesized to moderate associations between condition severity and activity involvement. The factors included in this model were selected based on previous research demonstrating their impact on activity participation in youth with chronic health conditions.

Demographic Characteristics: Age

Condition severity is expected to more greatly restrict the activity involvement of youth with spina bifida as they grow older (see Figure 1). As children enter adolescence, they become more aware of their strengths and weaknesses and begin to judge their abilities based on perceptions of themselves in comparison to others. During this time, adolescents with physical disabilities are likely to become more aware of, and begin to focus more on, the physical differences between themselves and peers (Spirito,

DeLawyer, & Stark, 1991). Thus, as they grow older, children and adolescents with spina bifida who suffer from greater pain intensity, are more overweight, and have greater motor limitations may become more hesitant to participate in all forms of activities for several reasons. Older youth are more likely to be concerned that their condition will impede their performance and to expect that aspects of their condition will more negatively affect others' perceptions of them and others' willingness to interact with them.

Additionally, the changing demands of some activities may restrict participation for youth with spina bifida as they grow older. Whereas, organized activities for younger children are often inclusive and available to youth with a range of abilities, some activities, such as sports and other physical activities, may become more competitive as children enter more advanced age groups. Expectations for organized social activities, as well as for school and household tasks also often increase with age (Holler, Fennell, Crosson, Boggs, & Mickle, 1995), and adolescents with greater physical impairment may have increasingly greater difficulty keeping up with their peers in these tasks, as well.

Several studies have described greater pain-related activity limitations as a function of youth's age (Perquin et al., 2000; Roth-Isigkeit, Thyen, Stoven, Schwarzenberger, & Schmucker, 2005). However, no study to date has examined the potential interactive effect of age and pain, overweight, or motor dysfunction in relation to youth's activity involvement. In the current study, age is expected to moderate the relation between physical status and activity participation, such that as children and

adolescents grow older, condition severity is expected to more greatly restrict their participation in daily, social, and physical activities.

Individual Characteristics: Internalizing Symptoms

Condition severity is expected to more strongly inhibit participation of activities in youth with spina bifida who exhibit internalizing symptoms. Many symptoms described in the criteria for depressive and anxiety disorders, such as fatigue, diminished interest in activities, reduced capacity for concentration, and prolonged or extensive worry (APA, 1994), are likely to decrease ability and motivation for functioning in daily and leisure activities. Furthermore, negative cognitions, which are considered to be a major component of depression according to cognitive theory (Beck & Greenberg, 1974), may magnify pre-existing beliefs of inadequacy and discontent about oneself and one's condition. Thus, condition severity may also become more restrictive of activity involvement for individuals with spina bifida when internalizing symptoms activate beliefs of doubt and insufficiency.

Given that youth with spina bifida are at increased risk for developing internalizing symptoms, as compared to typically developing youth (Appleton et al., 1997; Holmbeck et al., 2003; Lavigne & Faier-Routman, 1992), focused attention on the potential outcomes associated with these psychological symptoms is necessary. Thus, an examination of the potential role of internalizing symptoms in activity restrictions for youth with physical disabilities is an important next step.

In research with children and adolescents with pain disorders, both depressive symptoms and anxiety have been linked to functional disability (Flato, Aasland, Vinje, & Forre, 1998; Walters & Williamson, 1999; Peterson & Palermo, 2004; Kashikar-Zuck, Goldschneider, Powers, Vaught, & Hershey, 2001). Although this relation has not been addressed in youth with spina bifida, it is believed that the presence of internalizing symptoms will further diminish the ability and motivation of these youth to participate in activities. Thus, in the current study, internalizing symptoms are expected to moderate the relation between physical status and activity participation, such that for children with more internalizing symptoms, condition severity is expected to more greatly restrict their participation in daily, social, and physical activities. Due to the overlap among criteria for depressive and anxiety symptoms, the broader construct of internalizing symptoms will be used rather than assessments of depressive and anxiety symptoms separately.

Family Characteristics: Parental Intrusiveness

Condition severity is expected to more greatly restrict the activity involvement of youth in families in which parents use a more intrusive parenting style. Parents of youth with chronic illnesses that require intensive medical care regimens often adapt more controlling parenting behaviors in an effort to maintain and ensure the long-term health of the child. Although close monitoring of medical care is often adaptive and has positive health outcomes for these youth (Ellis, Templin, Naar-King, & Frey, 2008), controlling behavior may become intrusive when efforts to care for the child's health are in excess of

that which is appropriate for the individual child's needs at their developmental level (Holmbeck et al., 2002). In a previous study of youth with spina bifida, parenting style characterized by high levels of intrusiveness was associated with lower levels of youth behavioral autonomy (Holmbeck et al., 2002).

Based on this finding of the relation between intrusive parenting behavior and restricted autonomy for decision-making, it is also likely that families who use a more intrusive parenting style are also more likely to discourage children from participating in normal activities in response to greater condition severity factors. In a well-intentioned, but overly protective, attempt to avoid further discomfort or injury to the child, parents of youth with spina bifida may tightly limit the child's activities. Although intrusiveness, per se, has not been examined for its' role in activity limitations of these youth, there is growing evidence that parenting behaviors in response to child illness play a strong role in maintaining or reducing functional disability in youth with chronic health conditions (Palermo & Chambers, 2005; Walker, Levy, & Whitehead, 2006). In the current study, parental intrusiveness is expected to moderate the relation between physical status and activity limitation, such that for children of parents who use more intrusive parenting behaviors, condition severity is expected to be more highly associated with their participation in daily, social, and physical activities.

Dependent Variables: Indicators of Social Competence

Cavell's (1990) hierarchical, tri-partite model of social competence provides a useful conceptualization of the numerous social behaviors, skills, practices, and relationships between youth and their peers. The subcomponents of social skills, social performance, and social adjustment are described as distinct constructs within the broader social competence domain. Social skills, the specific abilities that allow for competent performance during a range of social tasks, and social performance, the degree to which the child's actual responses within specific, relevant social situations effectively meet socially accepted criteria, are under the control of the individual child (Cavell, 1990). In his model, affect recognition and emotion regulation abilities would be considered social skills, whereas the act of approaching a peer to introduce oneself when in an unfamiliar environment would be an example of social performance. Social adjustment, defined as the degree to which children are currently achieving developmentally appropriate social goals, subsume social skills and social performance, and thus, is at the top of the social competence hierarchy. Although youths' social skills and social performance contribute greatly to their social adjustment, this element of social competence is also strongly influenced by other factors outside the child's control, such as her sex, race, physical appearance, academic abilities, etc (Cavell, 1990). Examples of social adjustment include degree of peer acceptance and number of friends. In an attempt to expand previous work on social competence in children and adolescents with spina bifida, the current study includes measures of both social adjustment and social performance.

As described previously, research findings consistently indicate that youth with spina bifida demonstrate difficulties with most areas of social competence (e.g., Holmbeck, et al., 2002; Holmbeck et al., 2003; Nassau & Drotar, 1997; Buran, Sawin, Brei, & Fastenau, 2004). Studies of social competence in youth with chronic health conditions, including spina bifida, have been restricted largely to the examination of constructs that fit within the social adjustment domain (Nassau & Drotar, 1997). The findings that children and adolescents with spina bifida have smaller social networks (Ellerton, Stewart, Ritchie, & Hirth, 1996) and fewer friends (Holmbeck et al., under review), experience less social acceptance from peers (Holmbeck et al., under review), and are more socially isolated (Borjeson & Lagergren, 1990) are examples of specific social adjustment difficulties documented in these youth. In order to expand understanding of factors that contribute to social adjustment difficulties documented previously, this study will include social acceptance and number of friends as measures of the social adjustment within the broader social competence outcomes.

The interest in social adjustment is understandable, given that several of these factors are associated with negative consequences across other domains of psychosocial adjustment (Kupersmidt et al., 1990) and are frequently cited as concerning for parents. However, it is important to also include investigations of other areas of social competence, as these components influence social adjustment attainment and may also represent more modifiable areas for intervention. That is, because social performance is more directly under the control of the individual child (as opposed to social adjustment

factors, which are much more contingent on issues extraneous to just the individual of interest), treatments aimed at improving youth's interactions with peers are likely more effective than efforts aimed at directly ameliorating social adjustment problems by, for example, attempting to increase a child's number of friends. Thus, social performance is an important area of study because of its potential for change.

One initial finding on social performance of children and adolescents with spina bifida is the report that these youth tend to withdraw during social interactions (Holmbeck et al., 2003). The current study will further assess quality of social interactions between youth with spina bifida and their peers. Standardized measures of social performance, such as the one that will be used in this study, are ideal for observing and comparing youth's actual social behaviors in situations with peers. Because observational assessments of interpersonal interactions are rare in the pediatric psychology literature, a major strength of the current study is the strong methodology used to assess social competence outcome variables.

Study Hypotheses

Study hypotheses follow directly from the previous literature review and the mediation model presented in Figure 1, with each hypothesis representing a required step for statistical testing of mediation effects (Baron & Kenny, 1986).

Hypothesis Ia

Condition severity is expected to be associated with activity involvement, such that more intense pain, worse motor function, and more overweight will be associated with less activity involvement (i.e., more activity limitations, lower activity scores, and less involvement in social groups).

Hypothesis Ib

This association is expected to be moderated by psychosocial characteristics, such that the relations between condition parameters and youth's activity involvement is expected to be stronger for participants who are older, those who report greater internalizing symptoms, and for participants whose parents report a more intrusive parenting style.

Hypothesis II

Condition severity is expected to be associated with social competence outcomes, such that more intense pain, worse motor function, and more overweight will be associated with less social acceptance, fewer friends, and lower quality social interactions.

Hypothesis III

Activity involvement is expected to be associated with social competence outcomes, such that less activity involvement (i.e., more activity limitations, lower activity scores, and less involvement in social groups) is expected to be associated with less social acceptance, fewer friends, and lower quality social interactions.

Hypothesis IV

The impact of condition severity on social competence outcomes is expected to be significantly reduced after controlling for the activity involvement mediator variables (i.e., activity involvement is expected to mediate associations between condition severity and the social competence outcomes).

CHAPTER TWO

METHOD

Participants

Sample Recruitment

Participants in the current study were part a larger, longitudinal study examining positive trajectories of psychosocial adjustment in youth with spina bifida during the transition to adolescence, conducted at Loyola University Chicago under the direction of Grayson Holmbeck, Ph.D. For the larger study, families of children with spina bifida were recruited from four sources: the Spina Bifida Association of Illinois, two metropolitan children's hospitals, and a specialty children's hospital serving children with neurodevelopmental and orthopedic conditions. Participants were screened for eligibility based on demographic information that matched inclusion criteria according to age (eight to 15 years of age), diagnosis (spina bifida myelomeningocele, lipomeningocele, or myelocystocele), place of residence (within 300 miles of Loyola University Chicago), language proficiency (fluent in English or Spanish), and absence of co-occurring psychiatric or chronic medical conditions (e.g., mental retardation, visual or auditory impairments, severe mental illness, substance dependence disorders). Following initial identification by nurse coordinators and medical staff, eligible families were notified about the study via mailed recruitment letters, telephone contact, or in-person recruitment procedures during regularly scheduled clinic appointments at the children's

hospitals. Families who expressed interest in participation after initial notification of the study were contacted by telephone to schedule the first of two home-based data collection visits.

Two hundred forty-six families were contacted about study participation. Of these families, 163 agreed to participate; however, 21 families who originally agreed to participate were unable to be contacted or declined at a later time and two families were later found to not meet eligibility criteria. The final sample for the larger study consists of 140 families (57% participation rate). Analyses conducted to compare spina bifida-related medical variables for enrolled families versus those who declined to participate revealed no significant differences with respect to spina bifida type (i.e., myelomeningocele vs. other) $\chi^2(1) = 0.0002$, *ns*, shunt status, $\chi^2(1) = 0.003$, *ns*, or occurrence of shunt infection, $\chi^2(1) = 1.08$, *ns*.

Enrolled families were asked to identify a friend of the child with spina bifida to participate in several study activities. Peer eligibility was dependent on age (six to 17 years of age, or within two years +/- the age of the child with spina bifida) and language proficiency (English or Spanish fluency). Children with spina bifida were encouraged to choose non-relative friends; however, family relatives (e.g., cousins) were permitted to participate if families were unable to identify a friend outside the family. Families of children with spina bifida were provided guidelines to use when contacting potential friend participants, which included information about the researchers, instructions for describing the study purpose and procedures, and a request for permission for research assistants to contact them about the study. After parents of children with spina bifida had

spoken with the parents of identified friends, research assistants contacted the friends' parents by telephone to provide further details about the study. Of the 140 participants in the larger study, 121 families (86%) identified a peer within the inclusionary age range (two peers were excluded due to being older than 17 years).

Current Study: Reduced Sample

Data for the current study, participants were taken from the first wave of data collection, which was completed in July 2010. The sample for this study is comprised of the 108 children and adolescents with shunted hydrocephalus, their caregivers, and peers selected by the families. Information regarding demographic characteristics, as well as spina bifida type, lesion level, and number of shunt revisions of child and adolescent participants are presented in Table 1. Briefly, youth with spina bifida ranged from eight to 15 years of age ($M = 11.54$ years, $SD = 2.45$). The number of male and female participants was relatively equal and there was considerable variability in family socioeconomic status (SES). The sample also included a diverse representation of racial and ethnic backgrounds. Given the relatively high prevalence of spina bifida in Latino populations, an effort was made to over-sample participants from this ethnic group so that within-group analyses would be possible for the larger, longitudinal study. Thus, the reduced sample for the current study also includes a relatively large subgroup of Latino participants. The distribution of spina bifida type and lesion level, as well as mean number of shunt revisions, is consistent with what would be expected for children and adolescents with shunted hydrocephalus as compared to national population norms.

Table 1. Youth demographics and spina bifida characteristics.

<i>n</i> = 108	
	<i>n</i> (Percent) or <i>M</i> (<i>SD</i>)
Age	11.5 (2.5)
8-9	28 (25.9%)
10-11	22 (20.3%)
12-13	29 (26.9%)
14-15	29 (26.9%)
Sex	
Male	54 (50.0%)
Female	54 (50.0%)
Race/ Ethnicity	
White	57 (52.8%)
Latino	31 (28.7%)
African American	14 (13.0%)
Asian	1 (0.9%)
Biracial or Bi-ethnic	5 (4.6%)
SES ^a	39.0 (15.83)
Spina bifida type	
Myelomeningocele	106 (98.1%)
Lipomeningocele	2 (1.9%)
Lesion level	
Sacral	17 (15.7%)
Lumbar	69 (63.9%)
Thoracic	19 (17.6%)
Missing data	3 (2.8%)
Number shunt revisions ^b	3.17 (5.1)

Note. ^a*n* = 102 due to missing data; ^b*n* = 102 due to missing data;
SES measured by Hollingshead Four Factor Index

Among the 108 participants with spina bifida in the current study, 94 invited peers who met eligibility criteria to participate in the study with them. Of these 94 peers, 79 were non-relative peers and 15 were relatives of the participants with spina bifida. Although it was recognized that the social interactions between children with spina bifida and their family relatives may be qualitatively different than interactions between participants and peers who are not related to them (and thus may affect social performance ratings based on observed interactions between youth with spina bifida and designated peers), the decision was made to include all child-peer dyads, no matter the family relation status, in order to maximize the peer group sample size for statistical purposes.

Design and Procedure

All data for the current study were collected during two three-to-four hour visits to the homes of families of youth with spina bifida conducted as part of the larger, longitudinal study from which the data were taken. Trained graduate and undergraduate research assistants conducted all study procedures and Spanish-speaking research assistants attended all visits involving families who reported Spanish as their preferred language. At the beginning of each home visit, the purpose of the study and an overview of procedures were reviewed with all participants. Parental informed consent and child assent for participation were attained during the first home visit. Families were also asked to provide authorization to access medical information and permission to contact one of the child's teachers and medical professionals to request completion of a brief

questionnaire about the child's functioning. Questionnaires were mailed to teachers and medical professionals following the first home visit.

During both home visits, all participants completed a set of questionnaires in separate rooms to ensure privacy. Research assistants provided assistance as needed, which included reading the questionnaires aloud to participants, if necessary. The order of questionnaires was counter-balanced across families. Caregiver participants also completed audio-recorded self-administered interviews in which they read and responded aloud to questions about their perceptions of their child's functioning across a range of domains. These interviews were performed in private areas of the home to preserve confidentiality of responses. Youths with spina bifida also were administered a standardized battery of neuropsychological measures by trained research assistants. Neuropsychological tests assessed domains such as executive functions, language pragmatics, inference-making skills, emotion recognition, visual-motor processing, and intelligence.

During the first home visit, parents (or primary caregivers) and youth with spina bifida participated in a set of standardized interaction tasks that were audio- and video-recorded. The tasks included: (1) a board game, (2) a discussion about two developmentally-appropriate vignettes, (3) a discussion about the process of transferring medical care responsibilities from caregivers to the child, and (4) a discussion about topics rated by parents and children as frequent sources of conflict within the family (Smetana, Yau, Restrepo, & Braeges, 1991). Each of these tasks, with the exception of the conflict task, was created specifically for the longitudinal study. The board game was

used as a warm-up task for all families and other tasks were counter-balanced across families.

For each of the family interaction tasks, research assistants read task instructions aloud to participants and then left the room while family members engaged in the task for 10 uninterrupted minutes. For the board game task, participants were presented with a game that had been purchased from a local toy department and, after brief play instructions, were allowed to complete one round of the game.

The Vignette Task required family discussion about two vignettes about typical social situations that children and adolescents with spina bifida might experience. One vignette presented a situation that included a normative, developmentally-appropriate circumstance unrelated to spina bifida, and the second vignette described a social situation in which a character was presented with a challenge specific to having spina bifida. Families read the vignette and responded aloud to several questions provided (e.g., *What is a good way to handle this situation? If this situation were to happen to you, what would you do?*).

The Transfer of Responsibility Task consisted of a collaborative family discussion about medical care management of the child or adolescent with spina bifida. Participants were first asked to identify a spina bifida-related medical task that was, at the time, managed by parents, but would be transferred to the youth's care at some point in the future. After agreeing on one medical care task, parents and children discussed steps each of them might take to ensure successful transition and identified a point in the future at which they believed the child should attain full responsibility. Families were encouraged

to discuss transfer of spina bifida-specific tasks, but could talk about normative tasks related to child autonomy if they were unable to agree on a task related to spina bifida. Family members also recorded the steps of their transfer plan on paper provided by research assistants.

Finally, the Conflict Task was based on procedures established by Smetana and colleagues (Smetana, Yau, Restrepo, & Braeges, 1991). Family members first completed the Parent-Adolescent Conflict Scale (PAC), which was a brief version of the Issues Checklist (Robin & Foster, 1989), and responses to the items on this questionnaire were used to determine topics perceived by each family member as sources of conflict between parents and youth with spina bifida. Five topics rated across family members as most frequent and intense areas of conflict were transferred to laminated cards and presented to the family. Participants chose three topics and were instructed to attempt to resolve the issues through discussion during the allotted time.

The second home visit was completed within several weeks of the initial data collection. Informed consent and assent procedures were carried out with the friend of the child with spina bifida and the friends' parents. All participants completed questionnaires and children with spina bifida were administered additional neuropsychological tests assessing those domains listed previously. Peers and children with spina bifida also took part in audio-recorded interviews about their own friendships and social relationships, as well as their problem-solving strategies for hypothetical social situations. Research assistants conducted interviews with peers and children with spina bifida separately and

in private areas of the home. Questions were read by research assistants and participants responded aloud.

During this second home visit, youth with spina bifida and peers also participated in a set of standardized interaction tasks, created specifically for the study, which were audio- and video-recorded. These tasks included: (1) a toy-ranking task, (2) a discussion about an unfamiliar object, (3) an adventure-planning task, and (4) a discussion about experiences with social conflicts. Each of these tasks was created specifically for this longitudinal study. Similar to procedures used for the family interaction tasks during the first home visit, research assistants read task instructions aloud to participants and then left the room while children and peers engaged in the task for five uninterrupted minutes. Tasks were counter-balanced across child-peer dyads.

For the Toy Ranking task, children were presented with five toys that had been purchased from a local toy store, and instructed to engage in a discussion about the pros and cons of each toy. Children ranked toys according to their agreed-upon preferences and recorded rankings on a sheet of paper provided for the task.

The Unfamiliar Object task required participants to collaboratively name and create a use for a household object that was not well-known or easily identifiable. If children had prior knowledge of the true use for the object, they were instructed to imagine a new use for it. After determining a use for the object, children were encouraged to create and perform a commercial that could be used to advertise the object, and would inform potential buyers about the benefits of the object.

For the Plan an Adventure task, children were asked to describe an adventure that they agreed they would both like to go on together. After deciding where to go, children were instructed to collaboratively plan details of the trip, such as transportation and agenda, and to either draw a scene of the adventure or create a travel itinerary. Finally, the Social Conflict task involved a discussion about social problem-solving. Children with spina bifida and their peers were instructed to think about a time when they had become upset because of an interaction with a friend and to discuss, (1) how they felt during the situation, (2) how they believe they would have felt if they had experienced the situation described by the peer, and (3) alternative ways they might have reacted to the situation if it had happened to them.

All participants received monetary compensation for their time spent on study procedures. Families received \$50 at the conclusion of the first data collection visit and an additional \$100 following the completion of all study procedures. Peers participating in the study as peers received \$50 for their time. Teachers were given \$25 and medical professionals were given \$10 upon completion of a short questionnaire regarding the functioning of the target children with spina bifida.

Measures

Condition Severity Independent Variables

See Table 2 for a list of variables used to assess each construct described below.

The following section provides a description of all study measures. Scale-level descriptive data, including scale means, standard deviations, response ranges, and internal

Table 2. Measures Used in the Current Study.

Domain Assessed	Measure	Reporter
Covariate		
Intellectual functioning	WASI	C
Condition Severity Independent Variables		
Pain Intensity	VAS	C
Gross motor function	GMFCS	M
Weight status	BMI-percentile	M
Activity Mediator Variables		
Activity involvement and skill	CBCL Activities scale	M, F
Social organization involvement*	CBCL social org item	M, F
Activity limitations*	CALI	M, F
Psychosocial Moderator Variables		
Child age	Questionnaire item	M
Internalizing Symptoms	CDI	C
	CBCL Internalizing Symptoms	M, F, T
Parent Intrusiveness	Observational coding	O
	PPS	M, F
Social Competence Dependent Variables		
Social acceptance	SPPC Social acceptance scale	C, M, F, T
Number of friends	CBCL item	M, F
Quality of social interactions	Observational coding	O

Note. C = child/adolescent participant report, F = father, M = mother, T = teacher, O = observer.

* Denotes variables planned for use in analyses, but excluded due to weak psychometric properties.

reliability for the current study sample are presented in the *Results* section, under the subheading, *Scale Descriptives*, and displayed in Table 4.

Pain Intensity

Pain intensity was assessed via youth report with the Visual Analogue Scale (VAS), as part of the Spina Bifida Pain Questionnaire (SBPQ), which was adapted from other pediatric pain measures for the purposes of this study. Participants were instructed to mark the point along a 10 centimeter line that most accurately represented their usual level of pain, ranging from “no pain” at the extreme low end to “worst pain ever” at the extreme high end of the pain spectrum. Pain intensity scores were calculated by measuring the distance from the left end point of the scale to the mark made by the child. VASs are a commonly-used tool for assessment of pain intensity in pediatric populations and have been shown to correlate significantly with parent and medical providers’ ratings of child pain and with physical indicators of pain (e.g., joint swelling; Cohen et al., 2008). VASs have been designated as “well-established” measures of pain intensity, due to their demonstrated strong psychometric properties in studies conducted by multiple research teams (Cohen et al., 2008).

Motor Function

The Gross Motor Function Classification System for Spina Bifida (Wilson et al., 2006) was adapted for use with children with spina bifida and neuromuscular disease from the Gross Motor Function Classification System for Cerebral Palsy (GMFCS; Palisano et al., 1997; Palisano, Rosenbaum, Bartlett, & Livingston, 2007). The classification system is based on a child or adolescent’s degree of self-initiated

movement, with emphasis placed on ambulation modality (e.g., wheelchair, walker, orthoses). The system is also designed to capture clinically-meaningful distinctions in motor control, with Level I indicating very minimal limitations in gross motor function (i.e., child or adolescent walks independently in all settings, is able to walk up and down stairs unassisted, and can run and jump) to Level V corresponding with the most significant motor impairments (i.e., child or adolescent is transported in a wheelchair in all settings, has limited control over head and limb movement, and is propelled by others or requires extensive adaptation to power wheelchair for self-mobility). For training purposes, motor classification was independently coded by two research assistants, who obtained information about motor function and mobility from mother (or other caregiver when no mother was available) responses to several items of the Medical History and Adherence Questionnaire and from medical chart data. Following training, at which point the primary coder achieved pre-determined standards for inter-rater reliability (i.e., $Kappa \geq .70$), the motor classification was assigned by one coder. The original GMFCS scale has demonstrated fair to good inter-rater agreement ($Kappa = .75$ for children 2 years and older; Palisano et al., 1997).

Weight Status

BMI-percentile is a commonly-used approximation of body adiposity in children and adolescents two- to 19-years of age that correlates with direct measures of body fat (e.g., underwater weighing and dual energy x-ray absorptiometry; Mei et al., 2002). This measure is calculated by dividing the child's weight by height squared (i.e., kilograms/meters²) and plotting the BMI score on standardized gender-specific Centers

for Disease Control and Prevention (CDC) growth charts (Kuczmarski et al., 2002). BMI-percentile is considered a more appropriate assessment of excess weight in children and adolescents than the BMI measure that is the standard in adult body fat composition studies because, unlike BMI, it accounts for normal changes in body composition that are expected with age, as well as variations in body fat by gender (Kuczmarski et al., 2002). For the current study, height and weight were obtained from mother-report (or other caregiver report, if no mother-report was available) on items from the Health Questionnaire, an abbreviated version of the Centers for Disease Control and Prevention's 1999 Youth Risk Behavior Survey (Centers for Disease Control and Prevention, 1999). BMI-percentile scores for each participant with spina bifida were computed by entering gender, age, height, and weight into the *Children's BMI group calculator* Excel spreadsheet, publically available on the website of the Centers for Disease Control and Prevention at http://www.cdc.gov/healthyweight/assessing/bmi/childrens_bmi/tool_for_schools.html (CDC, n.d.).

This calculator references nationally-representative 2000 CDC growth charts (Kuczmarski et al., 2002) for the purpose of figuring BMI-percentile.

Activity Involvement Mediator Variables

Activities

Involvement in, and demonstrated skill for, developmentally-appropriate athletic, social, and household tasks were measured with the Activities subscale of the Child

Behavior Checklist (CBCL; Achenbach & Rescorla, 2001). Parents are instructed to list up to three sports, hobbies or non-athletic activities, and jobs or chores that their children enjoy most or are required to complete. For each sport and hobby listed, parents indicate how much time the child spends in the activity (on a three-point Likert scale ranging from “less than average” to “more than average”, with an option of “don’t know”) and their rating of the child’s skill for the activity (three-point Likert options ranging from “below average” to “above average”, and a “don’t know” option), as compared to others the same age. Jobs and chores are rated on skill only. T-scores are derived from the combination of the parent’s responses to the three activity items, as compared to normative data. T-scores below 30 are classified as within the clinical range and indicate significant deviation from the normative sample in the respective area of competence (i.e., a low level of activity involvement and skill). T-scores between 30 and 35 are considered to be within the borderline clinical range.

Social Organization Involvement

Degree of child involvement in social organizations, clubs, and groups was measured with an item from the CBCL (Achenbach & Rescorla, 2001). Format for this item is similar to Activities subscale items described above. Parents list social organizations in which the child is involved and provide a rating of the child’s level of involvement in the group, as compared to others the same age (three-point Likert options ranging from “less active” to “more active”, with a “don’t know” option).

Activity Limitations

The Child Activity Limitations Interview (CALI; Palermo, Witherspoon, Valenzuela, & Drotar, 2004) was used to assess functional impairment in school-age children and adolescents due to recurrent pain or discomfort. Parents indicate whether normative, daily life activities (e.g., bathing, schoolwork, chores) are difficult or bothersome for their children to complete because of discomfort/pain. Response options include “yes”, “no”, and “not applicable”. For items describing activities that parents believe have been restricted for their child because of pain or discomfort, respondents are asked to rank the degree of difficulty for completing the task (on a five-point Likert scale ranging from “not very” to “extremely”) and importance of the task to the child (on the same five-point Likert scale). In initial studies of measure of development, internal consistency of the CALI was excellent ($\alpha = 0.95$ parent version; Palermo, Witherspoon, Valenzuela, & Drotar, 2004).

For the current study, activity limitation was assessed by parent ratings of the degree of difficulty the child experiences for each activity due to discomfort/pain (according to the five-point Likert scale ranging from “not very” to “extremely”). For those activities for which parents reported that their child does not experience difficulty because of discomfort/pain, degree of difficulty was coded as “zero”, to indicate a lack of difficulty. For those activities described by parents as “not applicable” for their child, degree of difficulty was coded to indicate a non-response by the parent.

Demographic, Individual, and Family Moderator Variables

Age

Ages of child participants with spina bifida were derived from mother-report of the child's date of birth and the date of interview, which were included in the Parent Demographic Questionnaire for this study. Ages were reported as whole numbers (e.g., eight years of age).

Internalizing Symptoms

Due to widely-reported discrepancies between youth- and parent-report of child and adolescent internalizing symptoms (e.g., Braaten et al., 2001; De Los Reyes & Kazdin, 2005), perceptions of youth internalizing symptoms were obtained from all informants and youth-report was examined separately from caregiver- and teacher-reports in study analyses. Parent and teacher responses to items of the Anxious/Depressed and the Withdrawn/Depressed subscales of the CBCL (Achenbach & Rescorla, 2001) were used to assess parent perception of child internalizing symptoms. These two subscales, along with the Somatic Complaints subscale, comprise the Internalizing Problems composite score (Achenbach & Rescorla, 2001). However, due to overlap between items on the Somatic Complaints subscale, which are intended to represent physical symptoms of psychosocial difficulties, and somatic symptoms related to the spina bifida condition (e.g., headache, stomachache, skin problems), Somatic Complaints items were eliminated from the composite for the current study (Friedman, Bryant, & Holmbeck, 2007). Items are rated on a three-point Likert scale with the following options: "0" (not true), "1" (sometimes true), or "2" (often true).

Child depressive symptoms were assessed with youth-report on the Child Depression Inventory (CDI; Kovacs, 1992). This self-report measure quantifies 27 symptoms of depression according to five domains: depressed mood, hedonic capacity, vegetative functions, self-evaluation, and interpersonal behaviors. Respondents are instructed to choose one of three statements that most accurately describes their functioning over the past two weeks. Statements range in severity from symptom absent (scored as zero), symptom present some of the time (scored as one), and symptom present most of the time (scored as two), with higher scores indicating a greater degree of depressive symptoms. Thirteen items are reverse-coded. Previous research utilizing this measure with youth with spina bifida has demonstrated alpha coefficients ranging from .81 to .92 (Friedman, Holmbeck, Jandasek, Zukerman, & Abad, 2004; Essner & Holmbeck, 2010).

Parental Intrusiveness

This study includes observational and questionnaire assessments of parental intrusiveness. For the observational intrusiveness measure, data from the video-recorded family interaction tasks were coded according to a global coding system created for this study (Holmbeck, Shapera, & Hommeyer, 2002; Holmbeck, Zebracki, Johnson, Belvedere, & Schneider, 2007b) and based on methodology developed by Smetana et al. (1991). Coding was performed by research assistants who had each undergone approximately 10 hours of training during which they achieved at least 90% agreement with an expert coder. Each interaction task was independently coded by two research assistants. Adequate inter-rater reliability (i.e., Kappa \geq .80) was achieved during training

and was confirmed through random reliability checks for a portion of the total number of tasks.

After viewing an entire family interaction task, coders rated each parent separately on a range of behaviors. Each code was rated on a five-point scale ranging from “not at all” to “very often”, to indicate the degree to which parents performed the designated behavior described in each code. Four dimensions of intrusiveness, as described in Levy’s (1943) model of parental overprotection, were assessed with five items from the coding system: (1) parental prevention of independent behavior in the child (i.e., promotion of autonomy reverse-coded), (2) excessive physical contact with the child, (3) infantilization, (4) active catering to the child, (5) excessive parental dominance or control. All codes index parental behaviors that are excessive, rather than normative, given a child’s developmental level.

Parental intrusiveness was also measured by mother and father responses to the Parent Protection Scale (PPS; Thomasgard, Metz, Edelbrock, & Shonkoff, 1995), a 25-item self-rating scale that assesses parenting behavior across the subscales of Supervision (e.g. “I keep a close watch on my child”), Dependence (e.g. “I trust my child on his/her own”; reverse-scored), Separation Problems (e.g. “I urge my child to try new things”; reverse-scored), and Control (e.g. “I blame myself when my child gets hurt”). Each item is rated on a four-point scale: (0) never, (1) sometimes, (2) most of the time, and (3) always, with higher total scores represent greater levels of protection. Seven items are reverse-coded. The test-retest reliability of the total PPS score is good, with $r = .86, p = .001$ (Thomasgard, et al., 1995).

Social Competence Dependent Variables

Perceived Social Acceptance

The Social Acceptance subscale of the Self-Perception Profile for Children (SPPC; Harter, 1985) was completed by children with spina bifida to assess their perception of their own social acceptance by peers. For each of the six items in the subscale, the respondent first chooses which one of two statements that better describes her (e.g. “Some kids find it *hard* to make friends BUT other kids find it’s pretty *easy* to make friends”) and then decides if the statement is “really true” or “sort of true” for herself. Previous studies in youth with spina bifida have obtained alpha coefficients that range from .67 to .93 (Holmbeck, et al., 2003).

Social acceptance of the child with spina bifida was also reported from the perspective of mothers, fathers, and teachers. The parent and teacher versions of this measure contain three items with similar format to the child-report SPPC. Parent and teacher respondents are instructed to choose which of two statements best describes the social acceptance of the child with spina bifida, along with to what extent respondents believe that the chosen statement is true for the child. Parent- and teacher-versions of the SPPC have demonstrated adequate psychometric properties in previous studies (Cole, Gondoli, & Peeke, 1998).

Number of Friends

Child number of friends was measured with an item from the CBCL (Achenbach & Rescorla, 2001). Parents are asked to estimate the number of close friends their child

has. Response options are on a four-point Likert scale: “none”, “1”, “2 or 3”, or “4 or more”.

Quality of Social Interactions

Observed social performance was based on data from the video-recorded child-peer interaction tasks, which were coded according to a global coding system created for this study (Holmbeck et al., 2002; Holmbeck, Zebracki, Johnson, Belvedere, & Schneider, 2007a), and based on previous global coding systems for family interaction tasks (Holmbeck et al., 2002; Holmbeck, Zebracki, Johnson, Belvedere, & Schneider, 2007b). Coding procedures for this system were identical to those described above for the family interaction coding system in terms of coder training, reliability requirements, and number of research assistants coding each task. Also, as with the family interaction coding procedure, coders viewed an entire child interaction task and then rated each participant separately on a range of behaviors, and rated the dyad on several measures of interaction quality. A summary code assessing overall quality of the social interaction was created for this study from the following dyad codes: (1) degree of mutuality, (2) degree of impairment within the child-peer dyad (reverse-coded), (3) isolation, apathy toward one another (reverse-coded), and (4) openness, comfortableness, optimism, and warmth.

Intellectual Functioning

To hold constant the potential effects of child intelligence (IQ) on the outcome measures, a measure of general intellectual functioning was included as a covariate in each statistical analysis. For the current study, the Vocabulary and Matrix Reasoning subtests of the Wechsler Abbreviated Scale of Intelligence (WASI; Wechsler, 1999) were used as a brief measure of general IQ. This two-subtest combination is commonly used as a brief measure of general intellectual functioning. The WASI was standardized using a nationally-representative sample of 2,245 individuals ages 6-89. For the Vocabulary and Matrix Reasoning subtests, the average reliability coefficients for children 6-16 years old were found to be .89 and .92, respectively.

The Vocabulary subtest is a 42-item task assesses expressive vocabulary, verbal knowledge, and fund of information. It is also regarded as a strong measure of crystallized intelligence and general intelligence. The first four items of this subtest require the examinee to name pictures; subsequent items are presented orally and visually and the examinee defines the word. The Matrix Reasoning subtest is a measure of nonverbal fluid reasoning and general intellectual ability. For the Matrix Reasoning subtest, the examinee is presented with a series of 35 incomplete gridded patterns and asked to indicate which of five response options best completes the gridded patterns.

Demographic Information and Spina Bifida Characteristics

Caregivers of youth with spina bifida completed a demographic questionnaire that was created for this study. Factors assessed by this questionnaire included, among others,

child or adolescent age, ethnicity, school information (school name and youth's grade level), parent education levels, and parent occupations. SES based on parents' education levels and occupations were computed according to the Hollingshead Four Factor Index of Social Status (Hollingshead, 1975). Data on spina bifida type, lesion level, and number of shunt revisions was obtained from medical records after receiving parent authorization to review medical charts. See Table 1 for sample demographic and spina bifida-related descriptive data.

Proposed Data Analyses

To test the proposed mediation model presented in Figure 1, a series of hierarchical multiple regression analyses were conducted according to established guidelines (Baron & Kenny, 1986; Holmbeck, 1997). Four conditions are required for statistical mediation: (1) the predictor must be significantly associated with the hypothesized mediator, (2) the predictor must be significantly associated with the dependent measure, (3) the mediator must be significantly associated with the dependent variable after controlling for the predictor, and (4) the impact of the predictor on the dependent measure must be reduced after controlling for the effects of the mediator (Baron & Kenny, 1986). These four conditions were tested through a series of three multiple regression analyses (Holmbeck, 1997), as described below. Moderation effects were also tested according to guidelines described by Aiken & West (1991; Holmbeck, 1997).

For each construct assessed by multiple measures or multiple informants (i.e., child internalizing symptoms, parent intrusiveness, and perceived child social acceptance), variable composites were created to reduce the number of reports for each construct. Following z-score transformations, correlations between the standardized scores of the multiple respondent measures were calculated. Composites were created when bivariate correlations met the predetermined $r \geq .40$ criterion (or when mean correspondence across all respondent pairs was $r \geq .40$ when there existed more than two measures or informants for a given construct). If the criterion was not met, each measure for the construct was used separately in the study main analyses (see Results section for further information about data reduction procedures and outcomes for this study).

Prior to running statistical analyses, all variables measured on a continuous scale were centered by subtracting the overall sample mean for the variable from each individual score (Aiken & West, 1991; Holmbeck, 2002). This procedure produces a revised sample mean of “0” for each variable (regardless of the original metric), which facilitates the interpretation of significant interaction effects. Additionally, to hold constant the effects of child intellectual functioning throughout analyses, IQ was included as a covariate in the first step of all regression analyses.

Hypotheses Ia and Ib

Condition severity was expected to be associated with activity involvement, such that more intense pain, worse motor function, and greater degree of overweight would be associated with less activity involvement (i.e., more activity limitations, lower activity

scores, and less involvement in social groups). This association was expected to be moderated by psychosocial characteristics, such that the relations between condition parameters and youth's activity involvement was expected to be stronger for participants who were older, those experiencing greater internalizing symptoms, and for participants whose parents had a more intrusive parenting style.

To test the main effects and interaction effects of this hypothesis, nine multiple regression analyses were proposed. For each regression, the three condition severity variables, one of the three proposed moderator variables, and two-way interaction terms representing the multiplicative effect of condition severity variables and the moderator variable were entered as independent variables. Separate regression analyses were planned to test associations with each of the proposed activity mediator variables (i.e., activity involvement, social activities, and activity limitations), resulting in nine cross-sectional regressions with independent variables entered in the following sequence: (1) Step 1: child IQ; (2) Step 2 (using forward entry): pain intensity, motor function, weight status, child age (or child internalizing symptoms or parental intrusiveness moderator variables in place of child age); (3) pain intensity X child age, motor function X child age, weight status X child age (or child internalizing symptoms or parental intrusiveness in place of child age).

An additional exploratory analysis examining the moderating effect of child ethnicity on the association between condition severity and activity involvement was also added to Hypothesis Ib. Because the larger study from which this sample was drawn was originally designed to compare findings for Latino families versus families of other

ethnic backgrounds, and due to the relatively small subsample of all other ethnic and racial minority groups in the current study sample, it was decided that for this exploratory analysis ethnicity would be examined as a dichotomous variable comparing effects for Latino versus White participants. Thus, only data for participants whose parents identified them as Latino or White were included in this exploratory analysis. Additionally, SES was also included as a covariate in this exploratory regression to control for the possible confounding effect of SES on findings for ethnicity. Variables were entered in the following sequence: (1) Step 1: child IQ, SES; (2) Step 2 (using forward entry): pain intensity, motor function, weight status, child ethnicity; (3) Step 3 (forward entry): pain intensity X ethnicity, motor function X ethnicity, weight status X ethnicity. Because there is little extant research on whether condition severity factors would more greatly restrict activity involvement in White versus Latino youth with spina bifida, no a priori hypothesis was made for this exploratory analysis.

Hypothesis II

Condition severity was expected to be associated with social competence outcomes, such that more intense pain, worse motor function, and greater degree of overweight would be associated with less social acceptance, fewer friends, and lower quality of social interactions.

To test the main effects of this hypothesis, three separate cross-sectional multiple regression analyses to predict each of the social competence dependent variables (i.e., perceived social acceptance, number of friends, and quality of social interactions) were

planned, with independent variables entered in the following sequence: (1) Step 1: child IQ; (2) Step 2 (using forward entry): pain intensity, motor function, and weight status.

Hypotheses III and IV

Activity involvement was expected to be associated with social competence outcomes, such that less activity involvement (i.e., greater activity limitations, less social organization participation, and lower Activities scores) was expected to be associated with less social acceptance, fewer friends, and lower quality of peer social interactions. Furthermore, the impact of condition severity on social competence outcomes was expected to be reduced after controlling for the activity involvement mediator variables (i.e., activity limitations, social organization participation, and Activity scores).

To test the main effects of this hypothesis, and to assess the degree to which the impact of the condition severity independent variables was reduced when controlling for the effects of the activity mediator variables (i.e., the fourth condition of the mediation test described above), nine multiple regression analyses were planned. For each regression, the three condition severity parameter variables (i.e., pain intensity, motor function, and weight status) and one of the three mediator variables (i.e., activity limitations, social organization participation, and Activity scores) were entered as independent variables. Separate regression analyses were planned to predict each of the social competence dependent variables (i.e., perceived social acceptance, number of friends, and quality of peer social interactions), resulting in nine cross-sectional regressions with independent variables entered in the following sequence: (1) Step 1:

child IQ; (2) Step 2 (using simultaneous variable entry): pain intensity, motor function, weight status, activity limitations (or social organization participation or Activity scores in place of activity limitations).

To establish mediation, the condition severity independent variables should be less highly associated with the social competence dependent variables in the regression analysis conducted in this step, as compared to the association between these variables in the regression used to test Hypothesis II. In that case, the Sobel equation (1982) was to be used to test the degree to which this effect was reduced via the mediator variables. A significant finding for the Sobel equation indicates that the activity mediator variable explains a significant portion of the association between the independent and dependent variables.

Power Analysis

Data for this study were collected as part of a larger, longitudinal study examining psychosocial adjustment of youth with spina bifida during the transition to adolescence. Due to the archival nature of the data, it was not possible to manipulate any study features or procedures, including sample size. For this reason, a power analysis was performed prior to running the multiple regression analyses specified for Hypothesis I (which are the analyses that include the greatest number of independent variables among all regressions described above). Guidelines set forth by Cohen (1992) were used to determine the sample size necessary to detect small, medium, and large effects at Power = .80 and $\alpha = .05$, given the number of independent variables for each of these analyses.

The regression analyses proposed to test Hypothesis I included eight independent variables (e.g., child IQ, pain intensity, motor function, weight status, child age, and pain intensity X child age, motor function X child age, and weight status X child age interaction terms). At Power = .80 and $\alpha = .05$, it was determined that a sample size of $N = 50 - 106$ would be sufficient to detect a large effect ($r = .50$), $N = 107 - 756$ would be sufficient to detect a medium effect ($r = .30$), and $N \geq 757$ would be sufficient to detect a small effect ($r = .10$). Based on the reviewed literature, it was expected that main effects and interactions would be small to medium in magnitude; however, given the $N = 108$ sample size of the current study, only medium to large effects were detectable with conventional significance parameters. Thus, the proposed analyses were generally under-powered and the ability to detect statistically significant findings in this study was greatly compromised.

CHAPTER THREE

RESULTS

Preliminary Analyses

Prior to conducting formal preliminary analyses, variable distribution and number of valid responses for each variable were examined. Two of the activity involvement mediator variables, specifically social organization involvement and activity limitations, had an insufficiently low number of valid responses (e.g., only 56 valid mother- and 39 father-reports of activity limitations were found for $N = 108$) and an extreme negative distribution skew rendered the variables unusable. Thus, these two variables were eliminated from further study analyses, leaving the Activity score (assessing degree of involvement in, and skill for, sports, hobbies or non-athletic activities, and jobs or chores) as the sole activity involvement mediator variable for main study analyses.

Outliers

Variable distributions were first examined for outliers at the scale level and corrected according to procedures recommended by Tabachnick and Fidell (2006). Specifically, scale variables greater than or equal to three standard deviations from the scale mean were recoded to a value equal to the next most extreme score. One variable from each of the following scales were corrected through this process: father report of

child internalizing symptoms, child depressive symptoms, and observed measure of parent intrusiveness.

Skewness

Variables with a significantly skewed distribution were identified and transformed according to procedures described by Tabachnick and Fidell (2006). Following outlier corrections, variables were examined for skewness by comparing the standard error for skewness of each scale against zero using the z distribution. Each skewness value was converted to a z -score and scales for which the obtained z -score exceeded ± 3.29 (which is the z -value that is equivalent to an α level of .001, conventionally considered the criterion for significantly different from zero) were transformed to change the shape of the distribution to more closely resemble normal. See Table 3 for pre- and post-transformation skewness z -scores. The z -score skew values for seven variables exceeded the ± 3.29 cut-off and were transformed with a square root transformation. Log transformations were required for two variables that remained significantly skewed following square root transformation and required a more extreme correction. Although z -score skew values for these two variables remained greater than 3.29, the decision was made to use the log transformed variable in analyses rather than to attempt transformation processes that would more drastically alter the original variable values and distributions.

Table 3. *Skewness Z-score Values and Transformations Used for Variables in Regression Analyses.*

Measure	skew z-score		z-score after sq root transf		z-score after log transform
WASI	2.05				
VAS	4.21	→	2.47		
GMFCS	-2.71				
BMI-percentile*	-4.41	→	2.26		
CBCL Activities scale (M)	1.30				
CBCL Activities scale (F)	3.19				
Child age	-0.38				
CDI	3.65	→	2.93		
CBCL Internalizing Sym (M)	3.78	→	3.18		
CBCL Internalizing Sym (F)	5.50	→	5.14	→	4.79
CBCL Internalizing Sym (T)	4.48	→	3.94	→	3.44
Parent Intrusiveness (O)	3.32	→	2.33		
PPS (M)	-0.04				
PPS (F)	1.10				
SPPC Social Acceptance scale (C)	-2.14				
SPPC Social Acceptance scale (M)	-0.58				
SPPC Social Acceptance scale (F)	-0.53				
SPPC Social Acceptance scale (T)	0.16				
Number of friends CBCL item (M)	-3.09				
Number of friends CBCL item (F)	-2.55				
Quality of Soc Interact (O)	-1.93				

Note. C = child/adolescent participant report, F = father, M = mother, T = teacher, O = observer.

*Denotes variables that were reflected prior to transformations and reflected back to original direction for use in regression analyses.

Scale Descriptives

Internal consistency was also examined for each scale-level variable. Alpha coefficients indicated acceptable scale reliability for child-, parent-, and teacher-report of internalizing symptoms; father-report of parent intrusiveness; observed parental intrusiveness; mother-, father-, and teacher-report of social acceptance, and observed social performance (α 's ranged from .71 – .92). Reliability statistics for mother-report of parent intrusiveness and youth-report of social acceptance were lower than what is conventionally accepted for scale internal consistency ($\alpha = .64$ and $\alpha = .58$, respectively) and scale reliabilities could not be increased through item elimination. However, the decision was made to include both scales in the main study analyses despite less than ideal internal reliability due to the importance of each measure in study hypotheses. Additionally, high inter-rater reliability was also found for observed parental intrusiveness (ICC = .76) and observed social performance (ICC = .85), providing another degree of psychometric assurance for the digitally recorded interaction task measures.

Descriptive statistics for all variables included in the main study analyses are presented in Table 4. Transformed variables were used in analyses, but data presented in the table and within text refers to the original, non-transformed metric. Intellectual functioning for this sample was in the low average range, with scores ranging from the mildly deficient to very superior ability ranges. Pain intensity, as measured by a visual analogue scale, was reported by youth participants to be low-to-moderately intense with a

Table 4. Scale Means, Standard Deviations, Alphas, and Ranges

Domain Assessed	Variable	Mean *	SD **	Alpha	Range
Covariate					
Intellectual functioning	WASI ^a	82.09	19.55	--	55 – 137 ^{***}
Condition Severity Ind. Var.					
Pain Intensity	VAS	3.48	3.22	--	0 – 10
Gross motor function	GMFCS ^b			--	I – V
	I	9	8.3		
	II	23	21.3		
	III	23	21.3		
	IV	48	44.4		
	V	0	0		
Weight status	BMI-percentile ^c	75.77	28.47	--	.30 – 99.80 ^{***}
Activity Mediator Variable					
Activity involvement/skill	CBCL Activities scale (M) ^d	37.97	9.27	--	20 – 60 ^{***}
	CBCL Activities scale (F) ^d	37.26	10.56	--	20 – 65 ^{***}
Psychosocial Mod. Var.					
Child age	Child age	11.54	2.45	--	8 – 15
Internalizing Symptoms	CDI ^e	1.31	.23	.81	1 – 4
	CBCL Internalizing Sym (M) ^d	56.33	6.69	--	50 – 74.50 ^{***}
	CBCL Internalizing Sym (F) ^d	54.37	5.34	--	50 – 71.50 ^{***}
	CBCL Internalizing Sym (T) ^d	56.86	6.33	--	50 – 78.50 ^{***}
Parent Intrusiveness	Parent Intrusiveness (O) ^e	2.20	.29	.71	1 – 5
	PPS (M) ^e	1.22	.27	.64	1 – 4
	PPS (F) ^e	1.16	.31	.76	1 – 4

Table 4 (continued)

Domain Assessed	Variable	Mean [*]	SD ^{**}	Alpha	Range
Social Competence Dep. Var.					
Social acceptance	SPPC Social Accept scale (C) ^e	2.90	.62	.58	1 – 4
	SPPC Social Accept scale (M) ^e	2.71	.76	.75	1 – 4
	SPPC Social Accept scale (F) ^e	2.84	.80	.85	1 – 4
	SPPC Social Accept scale (T) ^e	2.57	.89	.90	1 – 4
Number of friends	Number friends CBCL item (M) ^f				
	None	<i>11</i>	<i>10.2</i>	--	1 – 4
	1	<i>10</i>	<i>9.3</i>		
	2 or 3	<i>41</i>	<i>38.0</i>		
	4 or more	<i>29</i>	<i>26.9</i>		
	Number friends CBCL item (F) ^f				
	None	<i>7</i>	<i>6.5</i>	--	1 – 4
	1	<i>11</i>	<i>10.2</i>		
	2 or 3	<i>32</i>	<i>29.6</i>		
	4 or more	<i>24</i>	<i>22.2</i>		
Quality social interact	Quality Soc. Interact. (O)	3.39	.58	.92	1 – 4

Note. For all variables transformed due to skewness, Means, SDs, and Ranges listed in this table refer to pre-transformed data.

C = child/adolescent participant report, F = father, M = mother, T = teacher, O = observer.

*Values listed in *Mean* column printed in italic font are *n* corresponding to values listed

**Values listed in *SD* column printed in italic font are percentage corresponding to categories listed

***Values listed for *Range* indicate possible item range with exception of variables marked **, for which *Range* indicates lowest to highest values for participants in the current study sample.

^a Standard score scaling

^b GMFCS is an ordinal variable and thus scale descriptives are inappropriate.

^c Percentile score scaling

^d T-score scaling

^e Item mean scaling

^f Number of friends is an ordinal variable and thus scale descriptives are inappropriate.

relatively broad range of pain scores among participants in the sample. Of note, pain intensity scores reported by this study sample are similar to those described in previous studies of youth with spina bifida (Clancy, McGrath, & Oddson, 2005), and are also commensurate with cross-sectional pain intensity indices of other pediatric chronic illness groups in which pain is considered to be a primary clinical feature (e.g., Ilowite, Walco, & Pochaczewsky, 1992). As expected, there was a high rate of overweight and obesity within this study sample. Among the participants for whom height and weight data were available, mean BMI-percentile was 75.77 with the following weight status distribution: Two participants (2.67% of the sample) were underweight, 29 (38.67%) were within the average range (BMI-percentile 6th – 85th percentile), 19 (25.33%) were overweight (BMI-percentile 85th – 94th percentiles), 26 (34.67%) were obese (BMI-percentile \geq 95th percentile). This distribution is generally consistent with the estimated prevalence of overweight and obesity within the national population of children and adolescents with spina bifida within in the United States. In terms of motor function, children and adolescents in this sample ranged from GMFCS ratings of I – IV. Nine participants (8.3%) were classified in Level I (i.e., walks in all settings), 23 (21.3%) in Level II (i.e., walks in most settings and sometimes uses hand-held mobility devices for safety or wheeled mobility for long distances), 23 (21.3%) in Level III (i.e., may use hand-held mobility device for walking and often use self-propelled manual or powered wheelchair), and 48 (44.4%) in Level IV (i.e., uses a self-operated power wheelchair or is transported by others in a manual wheelchair in most settings). Data required to classify child and

adolescent gross motor function was unavailable for five (4.6%) participants. These participants were dropped from analyses involving motor function.

Other measures of youth psychological functioning, parent intrusiveness, youth activity involvement, and social competence revealed generally adaptive functioning across domains. Youth, parents, and teachers reported low levels of internalizing symptom in participants (CDI item $M = 1.31$, $SD = .81$; CBCL Internalizing Symptoms t -scores across reporters $M = 55.85$, $SD = 6.12$). Parent intrusiveness was low, according to parent-report ($M = 1.19$, $SD = .29$ across mother- and father-report) and observational coding ($M = 2.20$, $SD = .29$). Social acceptance by peers was also rated among all reporters as fairly high ($M = 2.76$, $SD = .77$) and social performance was observed to be adaptive, as well ($M = 3.39$, $SD = .58$). Median number of friends reported by mothers and fathers was “2 or 3” friends (with response options ranging from “none”, “1”, “2 or 3”, or “4 or more”).

Bivariate correlations between reporters (and mean correlations among all possible respondent pairs when more than two reporters were available for a given measure) were used to examine inter-informant agreement in an effort to reduce data by creating composites for the same measure, as appropriate. A correlation of $r \geq .40$ was used as the criterion for collapsing measures across multiple informants. Based on this criterion, the following composites were created for use in main study analyses: Mother/father-report of youth internalizing symptoms ($r = .44$; teacher-report remained separate due to low correlation with mother- and father-report, $r = .22$), mother/father-report of parental intrusiveness ($r = .76$), mother/father-report of youth activity

involvement ($r = .59$), and mother/father/teacher-report of youth social acceptance ($r = .41$; child-report remained separate due to low correlation with other reports, $r = .31$). Mother- and father-report of the youths' number of friends were also included as separate variables in study analyses due to a low between-reporter correlation ($r = .29$). The bivariate correlation between observed parental intrusiveness and mother/father-report of their intrusive parenting behaviors on the PPS were found to have a weak correlation ($r = .32$) and thus, were included as separate variables in regression analyses, rather than combining them into a single composite of multi-method parental intrusiveness.

Results for Study Main Hypotheses

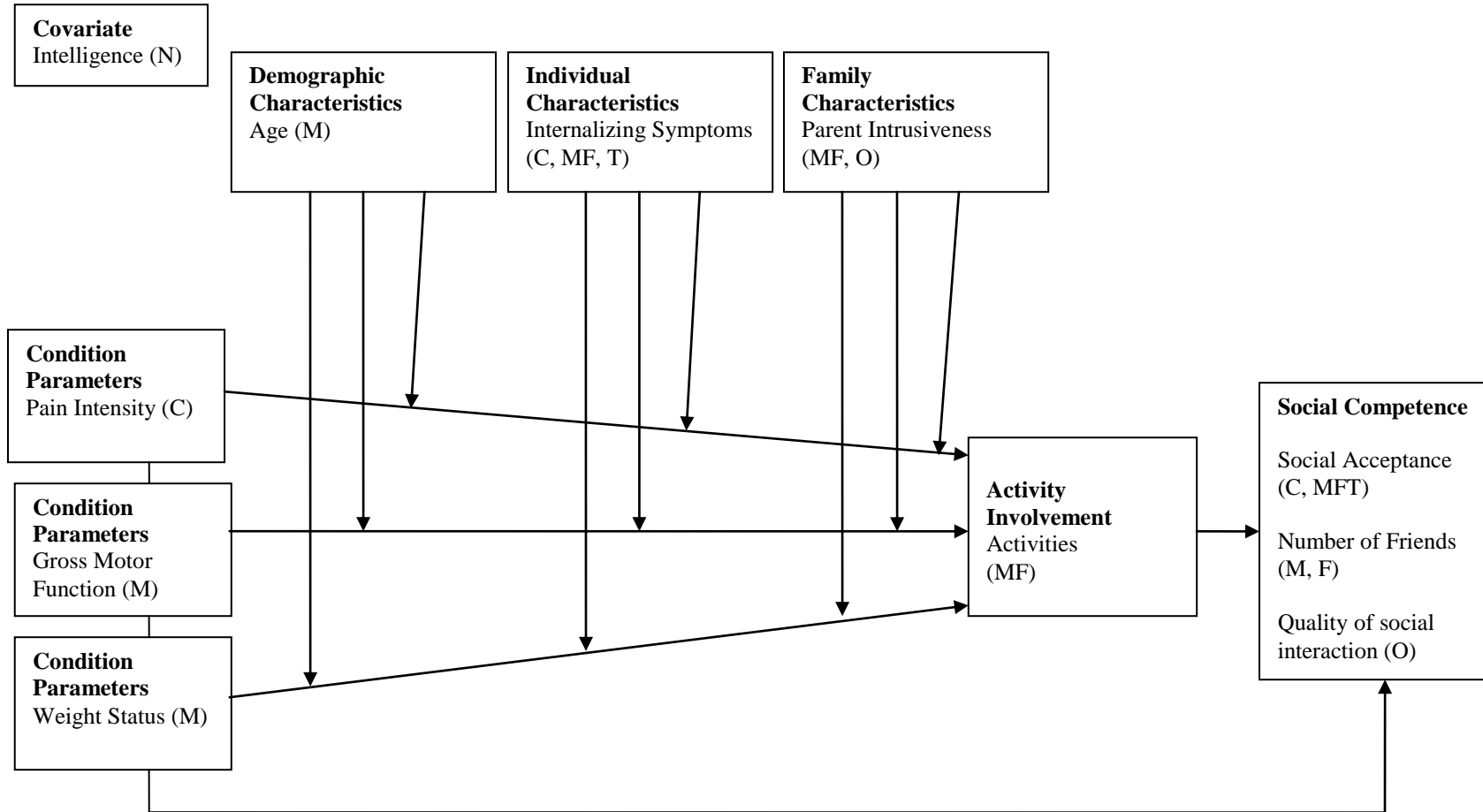
Prior to conducting analyses to test the study's main hypotheses, all independent variables were centered (as described in the Methods section above) and all two-way interaction variables to represent the multiplicative effect of the independent and moderator variables were created.

Hypotheses Ia and Ib

Hypothesis I represented the first condition of the test for mediation in the model examining associations among physical status, activity limitations, and social competence outcomes in youth with spina bifida proposed in this study (see Figure 2 for the revised mediation model displaying data informants and sources, as well as the single Activities mediator variable, following preliminary data screening and treatment procedures). Predictor variables in the overall model were tested for their associations with the

Figure 2. Revised model examining associations among physical status, activity limitations, and social competence outcomes in youth with spina bifida.

Note. C = child/adolescent participant; M = mother; F = father; T = teacher; O = observer; N = neuropsychological testing



hypothesized mediator variable in this first step. For Hypothesis Ia, more intense pain, worse motor function, and a higher degree of overweight were expected to be associated with lower activity involvement. Hypothesis Ib specified that each of these associations between condition severity and activity involvement variables would be moderated by psychosocial factors. Specifically, it was predicted that pain intensity, motor function, and overweight would limit activity involvement more strongly in youth who were older, those who experienced more depressive and anxiety symptoms, and those whose parents had a more intrusive parenting style.

Because the activity limitations and social group involvement measures described in the Methods section above were eliminated from analyses due to low response rates (and thus insufficient psychometrics), regression analyses conducted to test Hypothesis Ia and Ib used the lone remaining involvement variable (i.e., the Activities subscale of the Child Behavior Checklist assessing involvement in, and demonstrated skill for, developmentally-appropriate athletic, social, and household tasks) as the dependent variable. Seven regression analyses were conducted, each including the three condition severity factors (pain, gross motor function, and weight status), one of the moderator variables (youth age, mother/father report of internalizing symptoms, teacher-report of internalizing symptoms, youth-report of depressive symptoms, mother/father-report of parental intrusiveness, observed parental intrusiveness, or the ethnicity variable added for the exploratory analysis), and two-way interactions representing the multiplicative effects of each of the three condition severity variables and the moderator variable specific to

that analysis. For the exploratory regression, SES was also included as a covariate to control for any confounding effect of SES on ethnicity and activity involvement.

Results of regression analyses testing Hypothesis Ia and Ib are provided in Table 5. IQ and pain intensity were significantly associated with activity involvement in all seven of the regression analyses (see Table 5 for summary statistics). Higher IQ and lower pain intensity predicted greater activity involvement for children and adolescents with spina bifida. Teacher-report of youth internalizing symptoms also emerged as a significant predictor of activity involvement in the regression that included that variable. Lower levels of internalizing symptoms were associated with increased activity involvement. Thus, pain intensity and teacher-reported internalizing symptoms fulfilled condition one of the overall mediation test proposed in Hypothesis Ia.

Contrary to predictions described in Hypothesis Ib, there were no significant interaction effects. Youth age, youth internalizing symptoms, and parental intrusiveness did not moderate the relation between condition severity and youth activity involvement (see Table 5).

Hypothesis II

Hypothesis II regression analyses tested the second condition for mediation in the overall model. The condition severity variables were included as independent variables in analyses predicting the social competence outcome variables. More intense pain, worse motor function, and a higher degree of overweight were expected to be associated with lower perceived social acceptance, fewer friends, and worse social performance.

Table 5. Results of Hierarchical Multiple Regressions Testing Hypothesis Ia and Ib: Psychosocial Variables Moderating the Association Between Condition Severity Variables and Activity Involvement

Step and Variable	β	R	R ² Δ	F Δ
1 Intellectual Functioning	.43	.43	.18	14.40**
2 Pain intensity	-.28	.51	.07	6.28*
Motor function	.10	.51	.01	.70
Weight status	.08	.52	.01	.45
Child age	-.00	.52	.00	.00
3 Pain intensity X Child age	-.18	.55	.03	2.57
Weight status X Child age	.04	.55	.00	.14
Motor function X Child age	.00	.55	.00	.00
1 Intellectual Functioning	.43	.43	.18	13.93**
2 Pain intensity	-.29	.51	.08	6.58*
MF Internalizing Symptoms	-.10	.52	.01	.82
Gross motor function	.11	.53	.01	.77
Weight status	.06	.53	.00	.29
3 Motor function X MF Intern Sym	-.21	.57	.04	3.63
Weight status X MF Intern Sym	.08	.57	.01	.47
Pain intensity X MF Intern Sym	-.07	.58	.00	.32
1 Intellectual Functioning	.44	.44	.19	14.17**
2 T Internalizing Symptoms	-.28	.52	.08	6.05*
Pain intensity	-.26	.58	.65	5.60*
Weight status	.06	.58	.00	.32
Gross motor function	.03	.58	.00	.08
3 Pain Intensity X T Intern Sym	-.16	.60	.02	2.08
Weight status X T Intern Sym	-.08	.61	.01	.47
Motor Function X T Intern Sym	.10	.61	.01	.53
1 Intellectual Functioning	.43	.43	.18	13.97**
2 Pain intensity	-.29	.51	.08	6.73*
Weight status	.09	.52	.01	.66
Gross motor function	.08	.52	.01	.42
Youth Depressive Symptoms	.06	.53	.00	.26
3 Pain Intensity X Y Dep Sym	-.13	.54	.02	1.21
Motor Function X Y Dep Sym	-.09	.55	.01	.49
Weight status X Y Dep Sym	-.08	.55	.01	.49

Table 5 (continued)

Step and Variable	β	R	R ² Δ	F Δ
1 Intellectual Functioning	.43	.43	.18	14.40**
2 Pain intensity	-.28	.51	.07	6.28*
Gross motor function	.10	.52	.01	.70
Weight status	.08	.52	.01	.45
MF Parent Intrusiveness	-.02	.52	.00	.04
3 Weight status X MF Parent Intrusive	-.10	.53	.01	.66
Pain intensity X MF Parent Intrusive	.12	.54	.01	.86
Motor function X MF Parent Intrusive	-.12	.55	.01	.75
1 Intellectual functioning	.43	.43	.18	14.40**
2 Pain intensity	-.28	.51	.07	6.28*
Gross motor function	.10	.52	.01	.70
Weight status	.08	.52	.01	.45
Obs Parent Intrusiveness	-.02	.52	.00	.04
3 Pain Intensity X Obs Parent Intrusive	.08	.53	.01	.40
Motor Function X Obs Parent Intrusive	-.03	.53	.00	.06
Weight status X Obs Parent Intrusive	-.02	.53	.00	.03
1 Intellectual functioning	.37	.51	.26	9.29**
Socioeconomic status	.18			
2 Pain intensity	-.28	.57	.07	6.28*
Weight status	.16	.60	.02	.70
Ethnicity	-.19	.61	.02	.45
Gross motor function	.10	.62	.01	.04
3 Weight status X Ethnicity	-.17	.63	.01	.40
Pain intensity X Ethnicity	.12	.64	.01	.06
Motor function X Ethnicity	.06	.64	.00	.03

* $p \leq .05$; ** $p \leq .01$

Although not originally conceptualized as a predictor of youth social competence in the proposed overall model, and thus not intended to be included as an independent variable in this set of analyses testing Hypothesis II, teacher-reported youth internalizing symptoms was also added to the set of independent variables in these analyses because it had had a significant main effect on social activity involvement in Hypothesis I and, as a result, had to be tested in further steps of the mediation model.

Five regression analyses were conducted to examine the impact of pain, motor function, and weight status on each of the five social competence outcome variables (i.e., mother/father/teacher-report of perceived social acceptance, youth-report of perceived social acceptance, mother-report of number of youth friendships, father-report of number of child friendships, and observed youth social performance). Results of these regression analyses testing Hypothesis II are listed in Table 6. Higher IQ was significantly associated with greater social competence across all dependent variables, with the exception of youth-reported social acceptance. Additionally, teacher-report of youth internalizing symptoms and youth weight status also emerged as significant predictors of MFT-reported social acceptance, with lower rate of internalizing symptoms and lower BMI-percentile associated with greater social acceptance by peers. Participants with a lower degree of overweight status also had more friends, according to mother report of youth friendships. Notably, youth-reported social acceptance was the only social competence outcome variable for which there were no significant predictors, including no association between intellectual functioning and social outcomes.

Table 6. Results of Hierarchical Multiple Regressions Testing Hypothesis II: Condition Severity Variables Predicting Five Social Competence Outcomes

Step and Variable	β	R	R ² Δ	F Δ
DV: MFT Social Acceptance				
1 Intellectual functioning	.30	.30	.90	5.91*
2 T Internalizing symptoms	-.31	.43	.09	6.58*
Weight status	-.26	.50	.06	4.90*
Pain intensity	-.07	.50	.00	.32
Motor function	.09	.51	.01	.47
DV: Youth Social Acceptance				
1 Intellectual functioning	.15	.15	.02	1.29
2 T Internalizing symptoms	-.23	.26	.05	2.76
Weight status	-.15	.30	.02	1.25
Pain intensity	-.10	.32	.01	.55
Motor function	-.04	.32	.00	.87
DV: M Number of Friends				
1 Intellectual functioning	.40	.40	.16	11.00**
2 Weight status	-.35	.53	.12	9.12**
T Internalizing symptoms	-.20	.56	.04	2.96
Motor function	.03	.56	.00	.08
Pain intensity	-.02	.56	.00	.02
DV: F Number of Friends				
1 Intellectual functioning	.36	.36	.13	7.33**
2 Weight status	-.26	.44	.06	3.70
Pain intensity	.06	.45	.00	.21
Motor function	-.04	.45	.00	.05
T Internalizing symptoms	-.02	.45	.00	.02
DV: Obs Social Performance				
1 Intellectual functioning	.29	.29	.09	5.46*
2 T Internalizing symptoms	-.21	.36	.04	2.63
Motor function	.13	.38	.02	.97
Pain intensity	-.01	.38	.00	.01
Weight status	.01	.38	.00	.01

* $p \leq .05$; ** $p \leq .01$

To fulfill Hypothesis II, and qualify for the first two conditions of mediation, the condition severity independent variables would have to have been significant predictors of the mediator variable (i.e., activity involvement) in Hypothesis I analyses, as well as significant predictors of the social competence outcome variables in Hypothesis II analyses. Although pain intensity fulfilled condition one of the mediation test via its significant association with the activity involvement mediator variable (Hypothesis I) and BMI-percentile was a significant predictor of MFT-reported social acceptance and mother-reported number of friends (Hypothesis II), neither of these condition severity variables satisfied both conditions one and two. Thus, based on findings from steps one and two, mediation could not be achieved by the indirect path described in hypotheses: greater condition severity leading to reduced social competence, via the mediating impact of limited activity involvement. However, teacher-report of youth internalizing symptoms was a significant predictor of both the activity involvement mediator variable in step one, as well as of MFT-reported social acceptance in step two. This path fulfilled the first two conditions of mediation, requiring that it be tested in subsequent mediation steps through analyses conducted to test Hypotheses III and IV.

Hypotheses III and IV

Hypotheses III and IV corresponded with the third and fourth steps of the test for mediation in the overall model. According to Hypothesis III, it was proposed that the activity involvement mediator variable would be significantly associated with each of the social competence outcome variables after controlling for the effects of the pain, motor

function, and weight status condition severity predictor variables. Additionally, Hypothesis IV specified that the associations between condition severity predictor variables and the social competence outcome variables would be reduced (as compared to findings in analyses testing step two of the mediation test, Hypothesis II), after controlling for the effects of the activity involvement mediator variable.

Regression analyses were constructed so that condition severity predictor variables, the additional teacher-report of youth internalizing symptoms variable, and the activity involvement mediator variable from the overall model were tested for their associations with each of the social competence dependent variables (controlling for child IQ). Five separate regressions were conducted to predict MFT-report of social acceptance, youth-report of social acceptance, mother-report of youth number of friends, father-report of youth number of friends, and observed social performance. The same set of five regression analyses were used to test both Hypotheses III and IV.

Teacher-report of youth internalizing symptoms, in predicting MFT-report of social acceptance, was the only variable that met the first two criteria for mediation in analyses testing Hypotheses I and II. Thus, the first regression analysis in this set to test Hypotheses III and IV, with MFT-report of social acceptance as the dependent variable, was the only one for which mediation was truly being tested. The sole purpose of conducting regression all other regression analyses in this set, which included other social competence factors as dependent variables, was to examine the impact of activity involvement (the mediator) on social outcomes.

Table 7: Results of Hierarchical Multiple Regressions Testing Hypothesis III & IV: Condition Severity Variables and the Activity Involvement Mediator Variable Predicting the Five Social Competence Outcomes

Step and Variable	β	R	$R^2 \Delta$	t
DV: MFT Social Acceptance				
1 Intellectual functioning	.29	.29	.09	2.37*
2 Pain intensity	-.04			-.28
Motor function	.10			.79
Weight status	-.28			-2.39*
T Internalizing symptoms	-.23			-1.86
Activity involvement	.25	.55	.22	1.79
DV: Youth Social Acceptance				
1 Intellectual Functioning	.13	.13	.02	1.02
2 Pain intensity	-.11			-.71
Motor function	-.10			.06
Weight status	-.18			-1.32
T Internalizing symptoms	-.16			-1.08
Activity involvement	.14	.36	.11	.83
DV: M Number of Friends				
1 Intellectual Functioning	.41	.41	.17	3.43**
2 Pain intensity	.05			.38
Motor function	.00			.03
Weight status	-.34			-2.93*
T Internalizing symptoms	-.16			-1.33
Activity involvement	.21	.58	.17	1.19
DV: F Number of Friends				
1 Intellectual Functioning	.36	.36	.13	2.71**
2 Pain intensity	.15			.98
Motor function	-.06			-.42
Weight status	-.29			-2.08*
T Internalizing symptoms	.03			.18
Activity involvement	.24	.49	.11	1.51
DV: Obs Social Performance				
1 Intellectual Functioning	.30	.30	.09	2.40*
2 Pain intensity	.09			.64
Motor function	.10			.75
Weight status	.00			.30
T Internalizing symptoms	-.14			-1.04
Activity involvement	.32	.46	.12	2.12*

* $p \leq .05$; ** $p \leq .01$

Results of regression analyses testing Hypotheses III and IV are presented in Table 7. First, child IQ was significantly associated with all social competence outcome dependent variables, except for youth-reported social acceptance. This finding, along with the absence of any significant predictors of youth-reported social acceptance, mirrors results of analyses performed to test Hypothesis II. Additionally, a higher degree of overweight was associated with decreased social acceptance (by MFT-report) and with having fewer friends (according to both mother- and father-report). These results for weight status are also comparable to findings from the Hypothesis II set of analyses, except for the slightly stronger relation with father-reported number of friends in this analysis set, which lowered the probability into the statistically significant range. This finding is due to a slight suppression effect and does not represent a major change from results of the Hypothesis II analysis. Also, in contrast to hypotheses, in which activity involvement was expected to have a significant association with all social competence outcome variables, the Activities mediator had a significant impact on only one of the social outcome dependent variables. In that case, greater activity involvement predicted higher quality social performance, as observed in the structured interaction task involving participants with spina bifida and selected peers.

As stated above, teacher-report of youth internalizing symptoms fulfilled the first two conditions of mediation in Hypotheses I and II analyses predicting MFT-reported social acceptance, and findings from the Hypotheses III and IV analysis predicting this same dependent variable were used to test the final steps of mediation. Activity involvement was not a significant predictor of the social acceptance outcome variable in

that regression analysis, and thus, condition three of the mediation sequence was not fulfilled. However, because the impact of teacher-reported youth internalizing symptoms on MFT-reported social acceptance was less after controlling for activity involvement (as compared to its impact in the Hypothesis II analysis in which the activity mediator was not included), thereby satisfying the fourth condition of mediation, the Sobel significance test (Baron & Kenny, 1986; Holmbeck, 2002) was conducted to determine whether this indirect effect was statistically significant. Although the Sobel method is typically carried out only when all four conditions of mediation are satisfied, and it was not possible for true mediation to be established in this case, it was decided that determining the significance of the indirect relation between teacher-reported internalizing symptoms and MFT-reported social acceptance, via the activity involvement mediator, would be beneficial, given that all but one condition for mediation had been met by this path. The z-score obtained by multiplying the two unstandardized coefficients and dividing by the standard error of the indirect effect was not significant, $z = -1.50$, *ns*. Thus, in summary, teacher-reported youth internalizing symptoms were significantly associated with youth activity involvement and also with MFT-reported social acceptance, but findings from this study did not provide evidence for the proposed indirect path by which greater youth internalizing symptoms predict lower social acceptance via the mediating factor of limited youth activity involvement.

Illustrated Summary of Regression Analyses Findings

Cumulative findings across all analyses conducted to test Hypotheses I, II, III, and IV did not find support for the proposed overall mediation model presented in Figure 2, which had predicted that activity involvement mediated the associations between condition severity parameters and social competence outcomes in children and adolescents with spina bifida. However, findings from each step of the model revealed important relations among youth condition severity, internalizing symptoms, activity participation, and social competence outcomes. Figures 3a, 3b, and 3c depict an illustrated summary of these findings. As seen in Figure 3a, having greater pain and a higher level of internalizing symptoms was associated with lower activity involvement. Figure 3b shows that internalizing symptoms predicted lower social acceptance by peers and that having a higher degree of overweight negatively impacted perceived social acceptance and number of friendships. Finally, as illustrated in Figure 3c, greater activity participation was associated with a higher quality social performance.

Exploratory Analyses

The associations between the activity involvement mediator variable and the social competence outcome variables were examined in analyses conducted to test testing the mediation model, they included four other independent variables (i.e., the Hypotheses III and IV. Because those analyses were constructed as the final steps in testing the mediation model, they included four other independent variables (i.e., the three condition severity variables and the teacher-reported youth internalizing symptoms variable) in

Figure 3a. Findings from test of Hypothesis Ia and Ib.

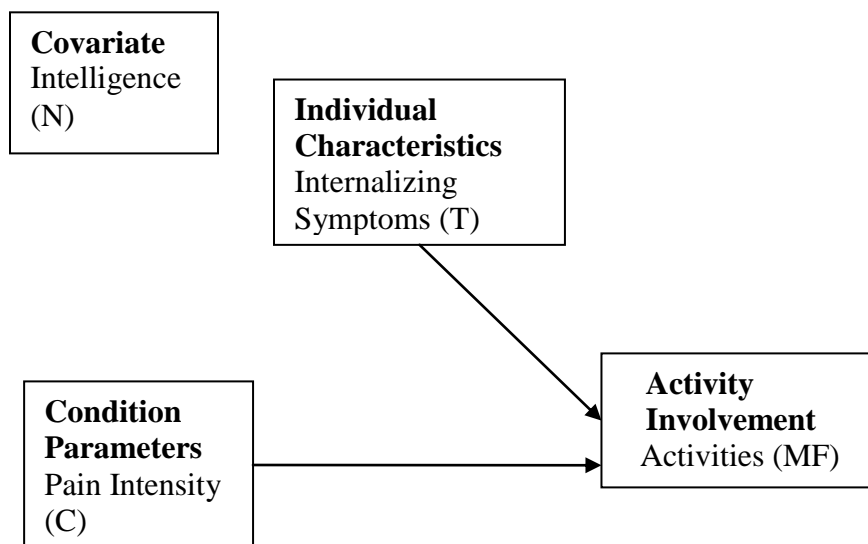


Figure 3b. Findings from test of Hypothesis II.

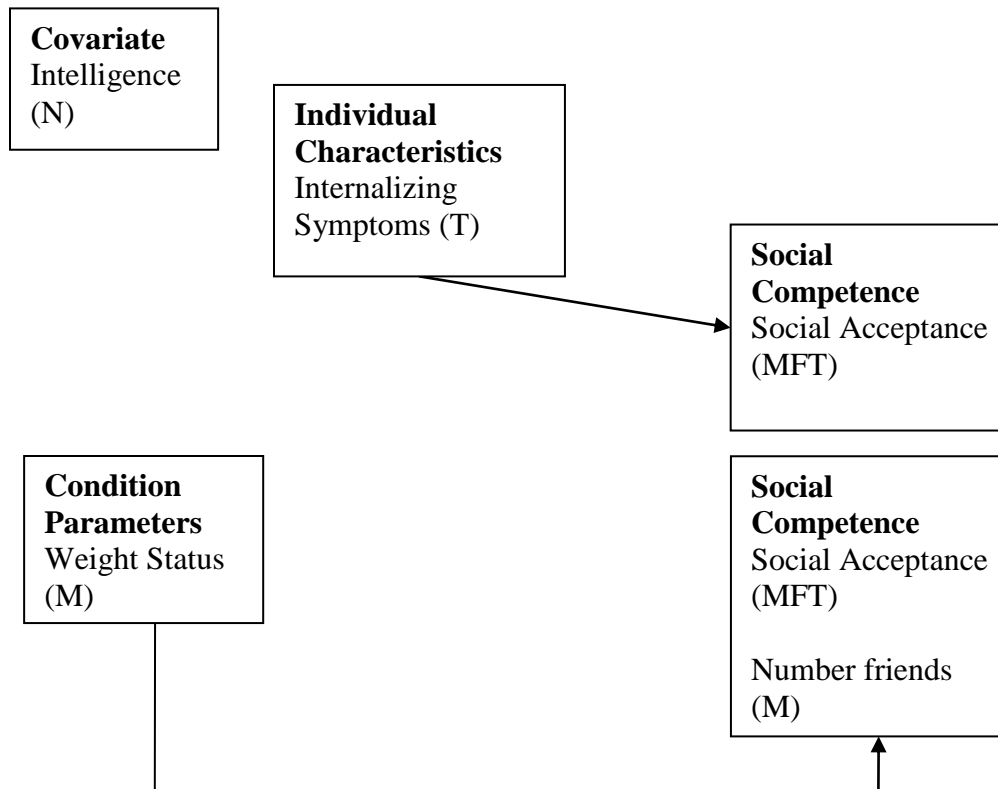
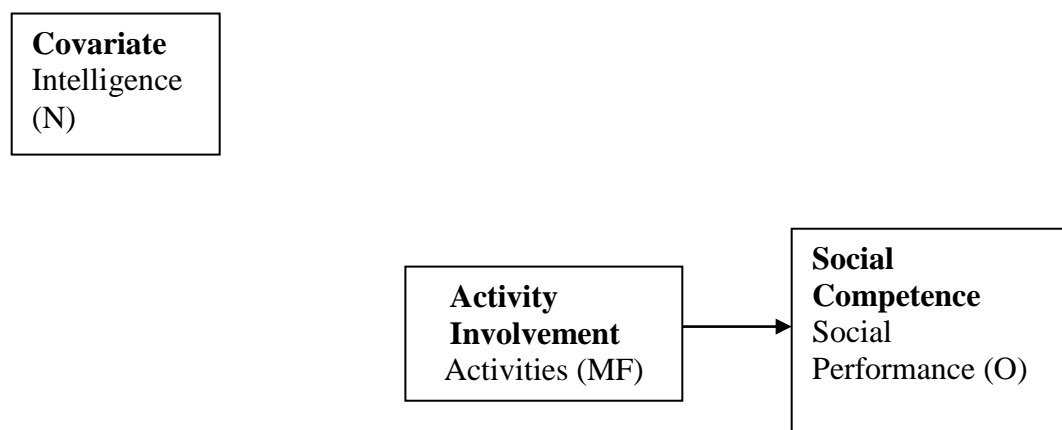


Figure 3c. Findings from test of Hypotheses III and IV.



addition to the Activities factor. In order to obtain a cleaner examination of the impact of activity involvement on social competence in children and adolescents with spina bifida, without the effects of other independent factors complicating the analyses and likely reducing the chance of finding a significant effect, an additional set of exploratory regression analyses were conducted. Five separate regression analyses were used, with IQ as a covariate and activity involvement as the only other independent variable, predicting each of the five social competence dependent variables (i.e., MFT-report of social acceptance, youth-report of social acceptance, mother-report of youth number of friends, father-report of youth number of friends, and observed social performance).

Results of these exploratory analyses are presented in Table 8. Figure 4 also provides an illustrated summary of findings from this set of supplementary regression analyses examining the impact of activity involvement on social competence outcomes, omitting all other independent variables. Greater activity involvement was associated with more adaptive social outcomes in three areas: MFT-report of social acceptance, mother-report of youth number of friends, and observed social performance. Additionally, IQ was a significant predictor of mother- and father-report of youth number of friends, as well as observed social performance. These results, in which greater activity involvement was associated with three of the five social competence outcomes is in contrast to results obtained from analyses conducted to test Hypotheses III and IV, which found activity involvement to significantly impact only one of the social competence outcome variables, social performance. Although not considered to be primary study findings, these exploratory analyses results provide evidence that involvement in sports,

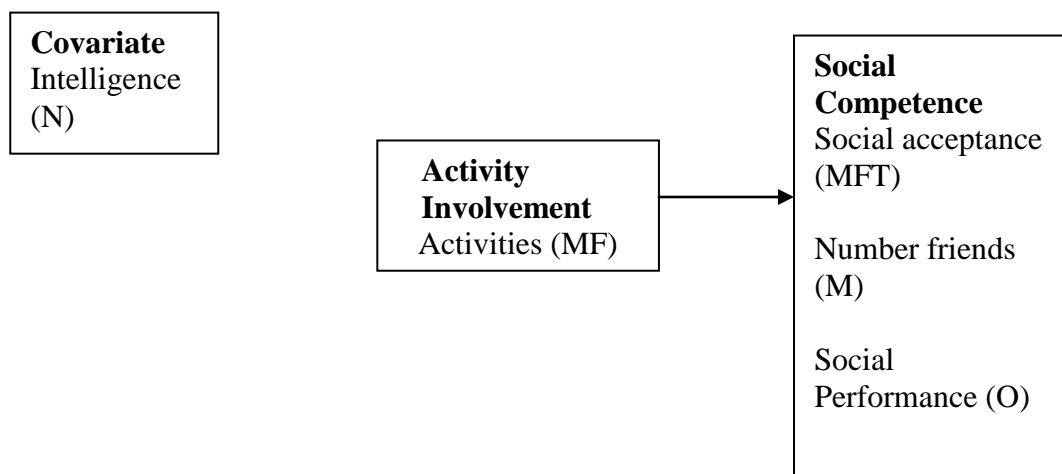
hobbies, and chores has a significant impact on the social competence of children and adolescents with spina bifida.

Table 8. Results of Exploratory Hierarchical Multiple Regressions: Activity Involvement Mediator Variable Predicting the Five Social Competence Outcomes

Step and Variable	β	R	$R^2 \Delta$	F Δ
DV: MFT Social Acceptance				
1 Intellectual functioning	.19	.19	.04	3.33
2 Activity involvement	.32	.36	.09	9.14**
DV: Youth Social Acceptance				
1 Intellectual Functioning	.12	.12	.02	1.18
2 Activity involvement	.10	.15	.01	.67
DV: M Number of Friends				
1 Intellectual Functioning	.27	.27	.07	6.16*
2 Activity involvement	.23	.34	.05	4.33*
DV: F Number of Friends				
1 Intellectual Functioning	.29	.29	.08	6.11*
2 Activity involvement	.08	.30	.01	.48
DV: Obs Social Performance				
1 Intellectual Functioning	.23	.23	.06	4.86*
2 Activity involvement	.27	.35	.07	6.20*

* $p \leq .05$; ** $p \leq .01$

Figure 4. Findings from Exploratory Analyses.



CHAPTER FOUR

DISCUSSION

Conclusions

The purpose of this study was to test a mediation effects model in which involvement in enjoyable activities and developmentally-appropriate daily chores was proposed as an intermediate mechanism underlying the association between physical status and social competence outcomes in children and adolescents with spina bifida. The study aim of delineating the complex processes that impact social competence among youth with spina bifida is highly relevant, given that children, adolescents, and young adults with this chronic health condition are at relatively high risk of demonstrating social difficulties, as compared to typically-developing peers and others with non-central nervous system related chronic illnesses and physical disabilities (Meijer, Sinnema, Bijstra, Mellenbergh, & Wolters, 2000; Reiter-Purtill, Waller, & Noll, 2009). The design of this study addressed several limitations of prior research, which had found limited support for associations between physical status and social functioning in youth with spina bifida. Advances over prior research methodology included examining condition factors previously overlooked in this group, comparing the relative impact of each condition factor rather than creating a composite severity index, and testing both direct and indirect effects via a theoretically-generated mediation design.

Findings from analyses testing the main study hypotheses did not fully support the proposed overall mediation model. However, collectively, results of this study provided valuable preliminary information about the nature and severity of pain and overweight in youth with spina bifida, as well as the interrelations among condition factors, activity, and social functioning in this population. The discussion of results below provides an overview of study findings, with consideration of ways in which results correspond with, or contradict, the hypotheses posed in this study and extant research in the field, as well as analysis of methodological issues that likely contributed to these findings. Given that support was not found for the proposed mediation model, results below are organized according to condition factors and the impact of each factor on activities and social functioning. Implications for clinical practice, study strengths, and an acknowledgement of study limitations are also discussed.

The first major finding in this study concerns the severity of pain among youth with spina bifida. Participants in this study endorsed a moderate degree of pain intensity, which mirrors findings of the only other existing study on the nature of pain among children and adolescents with spina bifida (Clancy et al., 2005). Furthermore, these moderate pain intensity ratings are commensurate with typical VAS pain intensity ratings described by children and adolescents with chronic health conditions in which pain is considered a primary feature (e.g., juvenile rheumatoid arthritis; Ilowite et al., 1992) and in studies involving clinical samples of children and adolescents presenting for treatment to specialty chronic pain clinics (Kaczynski, Claar, & Logan, 2009). Given that pain has not been considered a major area of clinical or research focus, pain intensity ratings from

this study, provided valuable confirmation of the severity of pain in this population and suggests that pain has been an under-recognized secondary condition parameter of spina bifida.

Youth-reported pain intensity emerged as a salient predictor of activity involvement and was the only condition factor among those included in the study to have a significant impact on youth's participation in sports, hobbies, and chore activities. This effect was consistently found across several regression analyses, thereby providing support for it as a robust predictor of activities. This finding on the association between pain intensity and activity involvement enhances the emerging literature on pain, and its broader effects on daily functioning, among children and adolescents with spina bifida. Although limited autonomy for daily self-care tasks and relatively low rates of social activity participation have characterized findings for activity involvement among youth with spina bifida in previous studies (Dahl et al., 2000; Stevens et al., 1996), and activity restriction has been a well-documented consequence of pain among children and adolescents with a range of chronic and recurrent pain syndromes (Palermo, 2000), pain has not previously been explored for its role in activity disruption within the spina bifida population.

Given the strong result in this study, links between pain and activity within this population appear to be a rich domain for further exploration. Future research should not only seek to replicate this finding, but also further delineate under what conditions, and for what subgroups of youth, this connection is most salient. Subtypes and locations of pain (e.g., lower back pain secondary to tethered cord versus headache) should also be

further explored to examine their differential impact on activity limitations. Additionally, given the strong association between pain and activity involvement, with no significant findings regarding the direct impact of other condition severity factors on activities in this study, future work should explore other ways in which condition severity factors might interact with pain to alter the activities of youth with spina bifida. For example, rather than the direct effect tested in this model, motor function and overweight might have a moderating effect such that youth with spina bifida who are overweight might find that pain interferes with their activity involvement more severely than it does in youth with a lower weight status. Similarly, youth with greater mobility restrictions might be more likely to eliminate activities from their routine when they are in pain than are youth who have greater motor function. Findings from this current study provide a solid initial step from which to launch further inquiry into the impact of pain on activity among children and adolescents with spina bifida.

In contrast to the strong connection noted between pain and activity interference, pain intensity did not have a significant, direct impact on social competence outcomes. There was no evidence from findings in this study that having more intense pain interferes with these youth making friends or interacting with peers appropriately, and does not negatively impact peers' perceptions of them. Thus, although children and adolescents with spina bifida may have difficulty performing typical enjoyable activities and chores when experiencing greater pain, their degree of pain intensity does not appear to affect social functioning more broadly, according to these study results. However, pain intensity, the only pain feature included in this study's analyses, may not be the most

salient pain factor affecting youth's social competence development. Future studies should study the impact of other pain factors, such as pain duration, chronicity versus recurrence, number of pain sites, pain locations (e.g., abdominal pain versus musculoskeletal pain), as well as pain-related distress and coping behaviors, on youth's social functioning. The link between chronic pain and social competence in pediatric populations has been identified as a topic in need of further investigation (Palermo, 2000). This study was the first to examine the impact of pain on social competence difficulties in youth with spina bifida, and the absence of findings in this preliminary study does not rule out the possibility of a link between pain and social functioning. Further investigation is needed to more fully explore the role of pain in social development of children and adolescents with spina bifida.

Second, unlike the findings for pain, this study found connections between overweight and social functioning, but no direct impact of weight status on activity involvement. Specifically, children and adolescents with spina bifida who were more overweight were reported to have limited social acceptance from peers (as reported by mothers, fathers, and teachers) and fewer friends (according to mother-report). The negative impact of weight status on social functioning in this study is also an especially noteworthy finding, as it mirrors the well-documented connection between overweight and poor social acceptance consistently described among typically-developing children and adolescents (e.g., Braet, Mervielde, & Vandereycken, 1997). It had previously been speculated in the literature that overweight might also play a role in the social competence difficulties so commonly observed among youth with spina bifida (Rimmer

et al., 2007; Simeonsson et al., 2002), as well, but the association had not been formally tested. The finding from the current study provides preliminary empirical evidence for this hypothesized relation. Notably, it indicates that the same factors widely believed to negatively impact social functioning among typically-developing youth also compromise social competence among youth with spina bifida. Although spina bifida entails a multitude of other cognitive, motor, and sensory impairments that have received much more attention in the scientific literature for their potential in influencing social competence outcomes, it appears plausible from this initial finding that being overweight provides the same risk for problematic social functioning independent of those other, more widely investigated condition factors. It provides an impetus for further research, such as the work carried out in this study, examining the role of non-spina bifida specific condition factors on social functioning in this population.

In contrast to pain, which had previously received little attention among professionals working with youth with spina bifida, the extremely high prevalence of overweight and obesity among children, adolescents, and adults with spina bifida has been well-documented and frequently discussed as a major health concern for individuals with this condition (SBA, n.d.). Results of this study not only replicated findings on the prevalence of overweight and obesity that were already reported in the literature, but also found overweight to negatively impact social functioning, which had not previously been described. Thus, this study found that it is not just the inherent health complications of overweight that should be a concern for youth with spina bifida, but also its negative effects on psychosocial functioning, as well.

Despite the above findings on the impact of overweight and reduced social competence found in this study, there was no association between weight status and activity involvement. This lack of significant finding was unexpected, given that overweight has been cited as a major contributing factor to activity limitations in children and adolescents with physical disabilities (e.g., Simeonsson et al., 2002). The current absence of findings might provide a hopeful indication that the link between greater excess body weight and activity interference in youth with spina bifida is not as pervasive as previously described. However, the lack of findings could also be explained by measurement issues, and specifically the way in which activity participation was operationalized.

The CBCL Activities subscale, the activity involvement scale used in this study, requires that caregivers nominate activities that youth are already performing, or with which they are already established participants, and compares their involvement and skill for these sports, hobbies, and chores to those of age-based norms. The scale pulls for a report of activities in which children and adolescents are already engaged and does not allow for an assessment of functional disability, activity disruption, or inclusion of activities that youth and their caregivers would like for them to perform, but for which they are limited in their capacity to carry out because of their chronic health condition. Thus, activity involvement of youth with spina bifida in this study might have been overestimated as compared to what would have been found if activity limitation (e.g., CALI; Palermo et al., 2004) or functional disability scales (e.g., Functional Disability Inventory; Walker & Greene, 1991) would have been used, and this activity inflation

likely compromised any ability to find a link between condition factors and activity involvement that might otherwise exist.

The CALI was included as an activity limitation measure in the original study model, but was eliminated from analyses due to poor psychometric properties. Although the reason for the low number of valid responses and negative skewness obtained with this study population is unclear, it is likely that these response patterns reflect a floor effect in the data such that these youth with spina bifida typically have such a low degree of activity that the CALI, and likely other measures of activity limitations and functional disability also, are not appropriate for assessing this construct in youth with physical disabilities. Because of their much lower base rates of activity as compared to that of typically developing youth, individuals with physical disabilities might require a specialized assessment tool, with different items and separate norms than those for non-physically disabled peers. Thus, it appears that psychometrically-sound tools for measurement of activity limitations and functional disability in youth with physical disabilities represents a major gap in the literature and is an area in need of further development in future research.

Third, gross motor function problems, which was the only condition severity factor included in the current study that had been traditionally considered to be a primary, characteristic feature of spina bifida, had no significant associations with activity participation or with social competence outcomes. Although it requires further investigation in future research, this lack of significant findings was encouraging, as there was no evidence that children and adolescents with spina bifida in this age group were

restricted in their activities specifically because of the challenges associated with their mobility limitations. Again, this cautious optimism must be tempered by the possibility that, as described above, the lack of association with activity involvement could be due to this study's use of an activity measure in which caregivers select a limited number of activities that youth already perform, rather than a functional disability measure that would likely have found greater activity disruption and, likewise, a stronger link between motor function problems and reduced activity involvement. However, the absence of a strong finding for motor dysfunction as a hindrance to activity involvement is encouraging.

There was also no evidence to indicate that their peers' acceptance of youth with spina bifida, the ability of children and adolescents with spina bifida to form friendships, or their social interactions with peers were impaired by their degree of motor function. Evidence for a link between mobility limitations and social functioning in youth with spina bifida in the extant literature had been equivocal, but the lack of a significant finding in the current study challenges prior assertions that motor impairments directly jeopardize youth's social competence. The absence of a significant relation between motor function problems and social competence is especially compelling given this study's use of the GMFCS (Palisano et al., 1997; Palisano, Rosenbaum, Bartlett, & Livingston, 2007), a pure measure of motor function not frequently applied to this population, but which likely provides a more accurate evaluation of motor function as compared to spinal lesion level or other proxy measures of mobility limitations typically used in prior studies. Future research using the GMFCS in studies of individuals with

spina bifida will further clarify the specific role of motor function in these youth's psychosocial functioning.

Fourth, in contrast to the predictions stated in study hypotheses, no support was found for youth age, internalizing symptoms, or parental intrusiveness as moderators of associations between condition severity and activity involvement. The exploratory analysis also found no evidence that ethnicity moderated this relation. One of the most likely reasons for this lack of significant findings was the limited statistical power in the analyses testing moderation effects, which greatly compromised the ability to detect small or medium effects (Cohen, 1992). There were likely other issues that specifically affected each of the proposed moderators, which also contributed to this absence of significant interaction effects in the current study. For example, participant age may have failed to display a significant moderating effect because of the truncated age range of the study sample. With a wider age range (perhaps including younger children through emerging adults), and greater variability in ages of participants, findings might have provided more evidence that older youth with spina bifida were more likely to restrict activity due to condition severity, as hypothesized. However, given that the age range spanned eight years (i.e., ages 8 – 15 years, inclusive, at this data collection), coupled with the fact that there was variability in ages of participants, this explanation may be untenable and the null hypothesis, that their age does not affect how much these youth limit activity in response to pain, should be given strong consideration.

Additionally, in regards to the assessment of parenting behaviors, lack of significant findings may also have been due, at least in part, to constructs selected and the

manner in which they were operationalized. Whereas prior studies have found evidence that in families of youth with spina bifida, parental intrusiveness (measured with the same scales and coding system used in the current study) negatively impacts youth psychosocial adjustment in a number of domains (e.g., reducing child behavioral autonomy, child decision-making autonomy, and leading to increased youth externalizing behaviors; Holmbeck et al., 2002), it appears plausible that parents' attempts to control, or intervene in, youths' pain experiences may represent an entirely different and separate construct that is more accurately assessed with measures designed to evaluate protective parenting behaviors performed specifically in response their children's pain.

Psychometrically reliable and valid measures, such as the *Adult Responses to Children's Symptoms* (ARCS; Van Slyke & Walker, 2006; Walker et al., 2006) have been developed precisely for the purpose of assessing pain-specific parenting behaviors (including overprotectiveness) and studies utilizing this measure have found evidence that parental protectiveness inadvertently amplifies functional disability in youth experiencing pain (Simons, Claar, & Logan, 2008). Due to the archival nature of this study's data, it was not possible to include a measure of pain-specific parental protectiveness, such as the ARCS. Future studies should examine whether the findings for this moderation analysis would be altered if a pain-specific parental protectiveness scale were substituted in place of the more general parental intrusiveness measures included in the current study.

Results of the exploratory analysis examining ethnicity as a moderator of the relation between condition severity and activity involvement also produced no evidence

that ethnic group membership affected participants' tendency to limit their activity in response to condition presentation. White and Latino youth showed no difference in the degree that overweight, pain experience, or motor function interfered with their activity involvement. Although it is widely accepted that sociocultural factors influence the way in which youth perceive and respond to pain, for example (Turk & Monarch, 2002), ethnicity may be too broadly-defined of a factor, containing too much within-group variability, to reliably predict group differences in pain behaviors. More specific sociocultural processes, which vary among ethnic groups, such as behavioral expectations or modeling of pain behaviors, may be more effective for detecting contextual influences that determine which individuals are most likely to show disruption in normal activities in response to condition severity than categorical designations of ethnicity. Cultural variation in pain expression and pain behaviors has been a relatively neglected area of research within the pediatric pain literature. Future research should examine not only the culturally-based messages about pain behaviors, but should also explore the protective influences that sociocultural factors have on children with chronic pain.

Internalizing symptoms was the final proposed to moderator of the relation between condition severity and activities. No support was found for the study hypothesis that participants with greater internalizing symptoms were at higher risk for limiting their activity involvement because of condition severity (i.e., internalizing symptoms did not moderate the relation between pain and activity involvement). However, there was a main effect for internalizing symptoms, whereby adolescents who demonstrated greater internalizing symptoms were also reported to have less activity involvement. This finding

is noteworthy for several reasons, both because this association existed only for teacher-reported, and not parent- or participant-reported internalizing symptoms, and also because of the direct effect finding, rather than the interaction effect that was predicted.

Participants with a higher degree of teacher-reported internalizing symptoms were reported to have less activity involvement. Although this main effect was not predicted prior to conducting study analyses, there exists strong evidence for a direct relation between youth internalizing symptoms and activity restrictions from empirical findings in prior studies involving youth with chronic pain (Claar & Walker, 2006; Logan, Simons, & Kaczynski, 2009; Kashikar-Zuck et al., 2001). Therefore, the finding in the current study is not altogether unique or unexpected. However, this is the first study to examine the relation between internalizing symptoms and activity involvement in youth with spina bifida and further research is needed to confirm this preliminary finding in this population. Additionally, further investigation would provide clues as to why teachers' report of youth internalizing symptoms were associated with activity involvement, but other informants' reports did not predict youth's activities. Based on this initial finding, the most likely explanation might be that because teachers observe youth solely in a group setting, they might be in a more opportune position to perceive the anhedonia, low energy, and social anxiety that are subsumed within the internalizing symptoms construct, and to take these symptoms into consideration when making behavioral ratings. Future research will provide further information to support or contradict this interpretation.

Teacher-reported internalizing symptoms also predicted social competence, as well. Specifically, greater teacher-reported internalizing symptoms were directly linked to lower social acceptance by peers (as reported by mother/father/teacher combined report). A test of this effect was not originally included in planned study analyses, and, thus, no hypotheses about the direction of effects were made prior to conducting analyses. However, within the broader literature on child psychopathology, youth reported to have greater internalizing symptoms have been shown to be at risk for a range of social difficulties. Anxiety and depressive disorders have been linked with social withdrawal, social skills deficits, peer rejection and neglect, and poor quality friendships (Elizabeth et al., 2006; Joiner, Coyne, & Blalock, 1999; Milling, 2001; Rudolph et al., 2000). Although the rate of internalizing symptoms was relatively low among participants in the current study, with very few youth reported to have a clinical level of symptoms and the sample average well within the normal range of emotional functioning, it seems reasonable that the above links between internalizing disorders and social difficulties could generalize to youth with subclinical symptom presentations, as well. Furthermore, many items included within the internalizing symptoms construct used in this study, such as preferring to be alone, fearing school, refusing to talk, being self-conscious and timid, and exhibiting social withdrawal (Achenbach, & Rescorla, 2001) describe behaviors that would naturally disrupt social interactions and likely interfere more broadly with social functioning. Thus, the connection between greater internalizing symptoms and lower social acceptance found in this study is understandable, as it reflects processes documented among typically developing youth with internalizing disorders.

As with the relation between teacher-reported internalizing symptoms and activity involvement discussed above, it is also not clear why teachers' report of youth internalizing symptoms was a significant predictor of social acceptance of children and adolescents with spina bifida, but other informants' reports did not have the same effect. Similar to the interpretation provided above, this finding is likely best explained by teachers having a unique vantage point from which to observe children and adolescents with their peers. Because they see youth with spina bifida in a group setting, they would be more likely to detect behaviors such as social withdrawal and timid presentation that would be detrimental to social functioning. Future research is necessary to confirm this interpretation.

Finally, analyses planned to test the final steps of the proposed mediation, in which activity involvement was expected to act as a mechanism underlying the association between condition severity and social functioning, included a test of the impact of activities on social competence outcomes. Within this set of analyses, activity involvement emerged as a significant predictor of the quality of youth's social performance during interactions with peers. Exploratory analyses, which tested this same effect but removed the condition severity variables from analyses so as to obtain a cleaner evaluation of this relation, were also conducted as follow-up. Although social performance was the only social competence outcome with a significant relation to activity involvement in the original set of planned analyses, exploratory analyses also produced findings to indicate that children and adolescents with greater activity involvement also had greater social acceptance, had more friends, and exhibited stronger

quality social performance. As with many of the effects described above, which were tested for the first time in this study, this significant finding provides support for a relation that was speculated in the literature (La Greca, 1990; Schuman & La Greca, 1999), but that had not previously been confirmed with empirical findings. Results indicate that, as had been suggested, efforts to encourage youth with spina bifida to become more highly involved in social activities, hobbies, and daily chores would not only provide the inherent benefits of increased activity, but might also enhance social functioning, as well.

It is notable that among all the analyses conducted to predict the five social outcome variables (i.e., mother/father/teacher-reported social acceptance, youth-reported social acceptance, mother-reported number of friends, father-reported number of friends, and observed social performance), youth-reported social acceptance was the only social competence factor that was not significantly impaired by IQ, condition severity factors, or activity involvement. This is likely due, at least in part, to the low internal reliability of the scale, which would have reduced the chances of finding significant associations with the predictor variables. Reasons for the weak reliability of youth-reported social acceptance are uncertain. However, given the evidence of emotion recognition difficulties and the relatively high rate of nonverbal learning disorder in the spina bifida population (Yeates, Loss, Colvin, & Enrile, 2003), it is plausible that youth with this disorder might have difficulty reporting on this construct because of deficits in social cognition secondary to their condition. Although their perceptions of social acceptance are

important to consider, the weak internal consistency of this measure provides support for the practice of obtaining multiple informant reports.

Implications for Clinical Practice

Given this study's findings that children and adolescents experience a moderately intense degree of pain, coupled with findings of previous research documenting pain as an under-recognized secondary condition in spina bifida, it is recommended that pediatric psychologists and other health care providers should alter their practice to better address pain and pain-related behaviors. First, clinicians should routinely perform comprehensive pain assessments to determine pain intensity, duration, locations, and quality, as well as contextual factors and lifestyle practices that affect pain in these youth. Based on findings from this study, it is likely that, if pain were more comprehensively evaluated, youth would describe pain to be more severe than caregivers and health care professionals are aware. Data gathered through careful clinical assessment would undoubtedly lead to more effective prevention and proactive treatment of pain symptoms through a variety of intervention approaches. Ameliorating children's pain has the inherent benefit of eliminating child suffering. Additionally, given this study's findings that pain interferes with youth's activity involvement, reducing youth's pain symptoms would therefore also enhance activity, as well.

Although eliminating pain is always the ideal treatment outcome, current multidisciplinary practice parameters for chronic and recurrent pain recognize that completely resolving all pain symptoms indefinitely is often not an attainable goal. The

more realistic treatment goal is to maintain a high level of functioning while directly treating pain symptoms with a variety of treatment approaches, but accepting that some aspects of pain may persist. Third-wave behavioral therapies, such as Acceptance and Commitment Therapy (ACT; Hayes et al., 1999) have been found to effectively reduce pain-related disability and fear of pain, as well as pain intensity, in children with chronic pain (Wicksell et al., 2009). Incorporating ACT, and other similar acceptance and mindfulness-based techniques, into multidisciplinary treatment of youth with spina bifida is recommended for addressing the pain symptoms, as well as the bolstering the low activity levels, that affected children and adolescents in this study.

The high rates of overweight and obesity among participants in this sample were reflective of the national prevalence among children and adolescents with spina bifida. Clinicians working with families of these youth should emphasize the importance of healthy weight management by providing anticipatory guidance about healthy diets and physical activity and directly counseling against common, maladaptive eating behaviors such as offering desserts and unhealthy foods as rewards. Incorporating basic nutrition education into work with youth with spina bifida, and using behavioral strategies to attain health goals, is important for achieving a high level of overall health.

Findings from the current study indicate that addressing weight concerns may also help to protect youth with spina bifida against social difficulties, as well. Given the linear relation between weight status and lower social competence, pediatric psychologists and other health care professionals should recognize that children and adolescents with spina bifida who are overweight are at greater risk for social difficulties, including lower social

acceptance from their peers, as well as and fewer friends. They should place special emphasis on screening overweight youth for social functioning concerns and referring those youth who endorse concerns with peer relationships and problematic social interactions with peers for further assessment and intervention. Efforts to improve social functioning should aim not only to enhance social skills of youth with spina bifida, but should also intervene at the contextual level by providing programming for peers with goals of decreasing stigma and social rejection of youth with spina bifida who are overweight. School-based group interventions offer an opportune avenue for intervening at the contextual level to change the social climate surrounding youth with physical disabilities. The implementation of school-based anti-bullying programs has accelerated in recent years and early research has produced promising findings on their effectiveness at reducing violence among students (Bauer, Lozano, & Rivera, 2007; Black & Jackson, 2007). However, these programs typically aim to reduce violent bullying, with little attention to ameliorating stigma or a establishing an environment of inclusivity. Because social neglect, rather than overt bullying, is a more common experience for youth with spina bifida (Holmbeck et al., 2003, school-based programs that target those concerns would be most beneficial for these youth.

Finally, although participants in this study reported a generally low degree of internalizing symptoms, more severe teacher-reported symptom presentation had a direct, negative impact on activity involvement and social competence in these youth. The fact that teachers' symptom reports were associated with worse psychosocial functioning in these domains highlights the value of clinicians' communication with teachers and other

school staff to obtain impressions about youth behaviors in that setting. Teachers may provide a unique perspective on youth emotional functioning that may also assist in identifying those children and adolescents with spina bifida most at risk for reduced activity involvement and social difficulties, as well.

Study Strengths

A major strength of this study was the inclusion of pain intensity and weight status, condition parameters that have generally been absent from studies examining the role of condition severity on psychosocial development of children and adolescents with spina bifida. Results of this study not only found these two condition factors to be significant predictors of activity involvement and social competence, respectively, but also provided basic descriptions of the severity of pain symptoms that exists among children and adolescents with spina bifida.

Other strengths of the current study included the ethnically and socioeconomically diverse sample, which was relatively large by pediatric psychology research standards (La Greca & Shuman, 1999). The use of multiple informants and multiple measure formats for many constructs enhanced validity by decreasing the chance that significant findings were an artifact of common method variance. In addition, the inclusion of multiple social adjustment and social performance outcomes expanded research on social functioning among children and adolescents with spina bifida, which has historically focused almost exclusively on variants of the social acceptance domain while ignoring other aspects of social competence (Nassau & Drotar, 1997).

A final strength of the current study was the direct relevance that findings have for clinical practice with families of children and adolescents with spina bifida. The proposed model delineated a path between relevant condition parameters and social functioning variables frequently cited in prior studies as areas in need of improvement among youth with spina bifida (Holmbeck et al., 2002; Holmbeck et al., 2003; Buran, Sawin, Brei, & Fastenau, 2004). Also, by constructing the study mediation model so as to satisfy basic conditions necessary for properly testing mechanisms of change (Kazdin & Nock, 2003), it was hoped that findings from this study would pinpoint the most appropriate targets for intervention to ultimately enhance these youth's social competence. The inclusion of individual, family, and demographic moderating factors also provided a means for identifying youth most at-risk for disruption in typical activities. It was hoped that findings from those analyses would, likewise, determine which participants would most strongly benefit from an intervention aimed at bolstering their engagement in typical enjoyable and task-oriented activities. In summary, by moving beyond the basic study of direct, main effects and testing mediation and moderation effects within the overall study model, this study provided findings that can be readily translated into the clinical practice of professionals who work with youth with spina bifida and their families.

Study Limitations

Although this study featured several methodological strengths that represented advances over prior studies, there were limitations that must be noted. First, this study

was conducted with cross-sectional data, and thus, the direction of the effect cannot be unequivocally determined. Cross-sectional data also precludes any assumption that the predictor could have a causal association with the dependent variables. Second, although the size of the participant sample was relatively large as compared to most studies in the pediatric psychology literature, it was not sufficient to produce enough power to detect small or medium effects in analyses testing associations between condition severity and activity limitations, with psychosocial moderator variables included (Cohen, 1992). Given that large effects are rare within any psychology literature (La Greca & Shuman, 1999), it is likely that limited power greatly restricted the possibility of discovering findings from these regression analyses.

Third, although an effort was made to reduce the number of analyses by collapsing multiple measures of the same construct across informants and across data formats when internal reliability allowed for it, the study included a large number of regression analyses to test all conditions of the mediation model, which increased the chance of Type I error. Because numerous analyses were conducted with the significance level set at .05, the possibility that some findings might have emerged as significant by chance occurrence must be considered. However, the consistency of findings regarding associations between pain intensity and activity involvement, as well as the observation that findings were always within the theoretically hypothesized direction, provided further assurance that findings were not solely due to chance. Regardless, results of this study provide valuable preliminary information and represent an initial step in examining unique influences of social competence outcomes in this population.

The inherent limitations of study measures introduced a final source of constraint to study findings. Activity limitations (measured by the CALI) and social organization involvement (as assessed by CBCL item parent-report of children's number and degree of involvement in social groups), two proposed mediator variables included in the original study model, were eliminated prior to conducting analyses because caregivers' provided such a low number of valid responses. Regarding the CALI, parents endorsed a high rate of "not applicable" responses, indicating that the typical daily tasks listed in the measure were not regularly performed by their children and adolescents with spina bifida. Youth in this study were likely unable to perform several activities because the nature of their physical disabilities would interfere with task completion (e.g., "walking", "bathing"). However, motor impairment could not account for the extreme high rate of "not applicable" responses for many other activities (e.g., "sleeping", "schoolwork") and it is unclear why response patterns were so highly skewed in this sample. Similarly, the measure of social group involvement was excluded from analyses because such a high rate of parents indicated that their children did not participate in any groups. Future studies examining predictors of activity disruption should consider including other measures of functional disability that would more reliably assess this construct within this population of youth.

Future research should build upon this study by continuing to investigate the complex relations among condition parameters, activity involvement, and social competence among children and adolescents with spina bifida. Additional work is needed to confirm these initial findings and further elucidate the paths between condition-related

factors and developmental outcomes. Information gained from this important area of research has the potential to greatly enhance clinical practice. By highlighting the severity of condition parameters and gaining further information about their role in disrupting typical daily activities and aspects of social competence, study findings will identify appropriate targets for intervention and be better able to enhance the functioning of children and adolescents with spina bifida.

REFERENCES

- Achenbach, T.M., & Rescorla, L.A. (2001). Manual for the ASEBA school-age forms & profiles. Burlington, VT: University of Vermont, Research Center for Children, Youth, & Families.
- Aiken, L. S. & West, S. G. (1991). *Multiple regression: Testing and interpreting interactions*. Newbury, Park, CA: Sage.
- American Dietetic Association. (2004). Position of the American Dietetic Association: Provideing nutrition services for infants, children, and adults with developmental disabilities and special health care needs. *Journal of the American Dietetic Association*, 104, 97-107.
- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, D. C.: Author.
- Ammerman, R. T., van Hasselt, V. B., Hersen, M, & Moore, L. E. (1989). Assessment of social skills in visually impaired adolescents and their parents. *Behavioral Assessment*, 11, 327-351.
- Appleton, P.L., Ellis, N.C., Minchom, P.E., Lawson, V., Boll, V., & Jones, P. (1997). Depressive symptoms and self-concept in young people with spina bifida. *Journal of Pediatric Psychology*, 22, 707-722.
- Barber, B. L., Stone, M. R., & Eccles, J. S. (2005). Adolescent participation in organized activities. In K. A. Moore & L. H. Lippman. (Eds.), *What Do Children Need to Flourish: Conceptualizing and Measuring Indicators of Positive Development* (pp. 133-146). New York: Springer.
- Baron, R. M., & Kenny, D. A., (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic, and stastical considerations. *Journal of Personality and Social Psychology*, 51, 1173-1182.
- Bauer, N., Lozano, P., & Rivara, F. P. (2007). The effectiveness of the Olweus Bullying Prevention Program in Public Middle School: A controlled trial. *Journal of Adolescent Health*, 40, 266-274.

- Beck, A. T. & Greenberg, R. L. (1974). *Coping with depression*. Bala Cynwyd, PA: Beck Institute for Cognitive Therapy and Research.
- Bier, J. B., Prince, A., Tremont, M., & Msalt, M. (2005). Medical, functional, and social determinants of health-related quality of life in individuals with myelomeningocele. *Developmental Medicine and Child Neurology*, 47, 609-612.
- Birch, S. H., & Ladd, G. W. (1996). Interpersonal relationships in the school environment and children's early school adjustment: The role of teachers and peers. In J. Juvonen & K. R. Wentzel (Eds.), *Social motivation: Understanding children's school adjustment* (pp. 199-225). New York: Cambridge University Press.
- Black, S. & Jackson, E. (2007). Using bullying incident density to evaluate the Olweus Bullying Prevention Program. *School Psychology International*, 28, 623-638.
- Blum, R. W., Resnick, M. D., Nelson, R. & St Germaine, A. (1991). Family and peer issues among adolescents with spina bifida and cerebral palsy. *Pediatrics*, 88, 280-285.
- Borjeson, M. C., & Lagergren, J. (1990). Life conditions of adolescents with myelomeningocele. *Developmental Medicine and Child Neurology*, 32, 698-706.
- Braaten, E. B., Biederman, J., DiMauro, A., Mick, E., Monteaux, M.C., Muehl, K., et al. (2001). Methodological complexities in the diagnosis of major depression in youth: An analysis of mother and youth self-reports. *Journal of Child and Adolescent Psychopharmacology*, 11, 395-407.
- Braet, C., Mervielde, I., & Vandereycken, W. (1997). Psychological aspects of childhood obesity: A controlled study in a clinical and nonclinical sample. *Journal of Pediatric Psychology*, 22, 59-71.
- Brauner, R., Fontoura, M., & Rappaport, R. (1991). Growth and puberty in children with congenital hydrocephalus. In C. M. Bannister & B. Tew (Eds.), *Current concepts in Spina Bifida and hydrocephalus* (pp. 193-201). New York: Cambridge University Press.
- Brewer, V. R., Fletcher, J. M., Hiscock, M., & Davidson, K. C. (2001). Attention processes in children with shunted hydrocephalus versus attention deficit-hyperactivity disorder. *Neuropsychology*, 15, 185-198.
- Buffart, L. M., Roebroek, M. E., Rol, M., Stam, H. J., & van den Berg-Emons, R. J. G. on behalf of the Transition Research Group South-West Netherlands. (2008). *Journal of Rehabilitation Medicine*, 40, 70-75.

- Buran, C. F., Sawin, K. J., Brei, T. J., Fastenau, P. S. (2004). Adolescents with myelomeningocele: Activities, beliefs, expectations, and perceptions. *Developmental Medicine & Child Neurology*, 46, 244-252.
- Burmeister, R., Hannay, H. J., Fletcher, J. M., Boudousquie, A., & Dennis, M. (2005). Attention and executive functions in children with spina bifida meningomyelocele. *Child Neuropsychology*, 11, 265-284.
- Cavell, T. A. (1990). Social adjustment, social performance, and social skills: A tri-component model of social competence. *Journal of Clinical Child Psychology*, 19, 111-122.
- Cicchetti, D. & Bukowski, W. M. (1995). Developmental processes in peer relations and psychopathology. *Development and Psychopathology*, 7, 587-589.
- Charney, E. (1992). Neural tube defects: Spina bifida and meningomyelocele. In M. Batshaw & Y. Perret (Eds.), *Children with disabilities: A medical primer* (3rd ed., pp. 471-488). Baltimore: Brookes.
- Clancy, C. A., McGrath, P. J., & Oddson, B. E. (2005). Pain in children and adolescents with spina bifida. *Developmental Medicine and Child Neurology*, 47, 27-34.
- Centers for Disease Control and Prevention (2008). QuickStats: Spina bifida and anencephaly rates—United States, 1991, 1995, 2000, and 2005. *Morbidity and Mortality Weekly Report*, 57, 15.
- Centers for Disease Control and Prevention. (1999). Youth risk behavior surveillance system: 1999 youth risk behavior survey. Retrieved 08/03, 2000 from <http://www.cdc.gov/nccdphp/dash/yrebs/survey99.htm>.
- Centers for Disease Control and Prevention. (n.d.). Healthy Weight: Children's BMI Tool for Schools. Retrieved 08/13, 2011 from http://www.cdc.gov/healthyweight/assessing/bmi/childrens_bmi/tool_for_schools.html.
- Cicchetti, D. & Bukowski, W. M. (1995). Developmental processes in peer relations and psychopathology. *Development and Psychopathology*, 7, 587-589.
- Claar, R. L. & Walker, L. S. (2006). Functional assessment of pediatric pain patients: Psychometric properties of the functional disability inventory. *Pain*, 121, 77-84.
- Cohen, J. (1992). A power primer. *Psychological Bulletin*, 112, 155-159.

- Cohen, L. L., Lemanek, K., Blount, R. L., Dahlquist, L. M., Lim, C. S., Palermo, T. M., McKenna, K. D., & Weiss, K. E. (2008). Evidence-based assessment of pediatric pain. *Journal of Pediatric Psychology, 33*, 939-955.
- Cole, D.A., Gondoli, D.M., & Peeke, G. (1998). Structure and validity of parent and teacher perceptions of children's competence: A multitrait-multigroup investigation. *Psychological Assessment, 10*, 241-249.
- Culbertson, J. L. (1999). Research methods with children. In P. C. Kendall, J. N. Butcher, & G. N. Holmbeck (Eds.), *Handbook of Research Methods in Clinical Psychology*. New York: John Wiley & Sons.
- Cunningham, S. D., Thomas, P. D., & Warschausky, S. (2007). Gender differences in peer relations of children with neurodevelopmental conditions. *Rehabilitation Psychology, 52*, 331-337.
- Dahl, M., Ahlsten, G., Norrlin, B. S., Strinnholm, M., & Winberg, A. (2000). Self-care skills in young children with myelomeningoceles. *European Journal of Pediatric Surgery, 10*, S52-S53.
- De Los Reyes, A. & Kazdin, A. (2005). Informant discrepancies in the assessment of childhood psychopathology: A critical review, theoretical framework, and recommendations for further study. *Psychological Bulletin, 131*, 483-509.
- Dennis, M., Edelstein, K., Hetherington, R., Copeland, K., Frederick, J., Blaser, S. E., Kramer, L. A., Drake, J. M., Brandt, M., & Fletcher, J. M. (2004). Neurobiology of perceptual and motor timing in children with spina bifida in relation to cerebellar volume. *Brain, 127*, 1292-1301.
- Eccles, J. S. (2004). Schools, academic motivation, and stage-environment fit. In R. M. Lerner & L. Steinberg (Eds.), *Handbook of Adolescent Psychology* (2nd ed.; pp. 125-153). Hoboken, NJ: John Wiley & Sons.
- Ellerton, M., Stewart, M. J., Ritchie, J. A., & Hirth, A. M. (1996). Social support in children with a chronic condition. *Canadian Journal of Nursing Research, 28*, 15-36.
- Ellis, D. A., Templin, T. N., Naar-King, S., & Frey, M. A. (2008). Toward conceptual clarity in a critical parenting construct: Parental monitoring in youth with chronic illness. *Journal of Pediatric Psychology, 33*, 799-808.
- Farmer, J. E. & Deidrick, K. K. (2006). Introduction to childhood disability. In J. E. Farmer, J. Donders, & S. Warschausky (Eds.), *Neurodevelopmental Disabilities:*

Clinical Research and Practice (pp. 3-20). New York: Cambridge University Press.

- Flato, B., Aasland, A., Vinje, O., & Forre, O. (1998). Outcomes and predictive factors in juvenile rheumatoid arthritis and juvenile spondyloarthritis. *Journal of Rheumatology*, *25*, 366-375.
- French, S. A., Story, M., & Perry, C. L. (1995). Self-esteem and obesity in children and adolescents: A literature review. *Obesity Research*, *3*, 479-490.
- Friedman, D., Holmbeck, G.N., Jandasek, B., Zukerman, J., & Abad, M. (2004). Parent functioning in families of preadolescents with spina bifida: Longitudinal implications for child adjustment. *Journal of Family Psychology*, *18*, 609-619.
- Friedman, D., Bryant, F. B., & Holmbeck, G. N. (2007). Testing the factorial invariance of the CBCL Somatic Complaints Scale as a measure of internalizing symptoms for children with and without chronic illness. *Journal of Pediatric Psychology*, *32*, 512-516.
- Fuggle, P. Shand, P. A. X., Gill, L. J., Davies, S. C. (1996). Pain, quality of life, and coping in sickle cell disease. *Archives of Diseases in Childhood*, *75*, 199-203.
- Gil, K. M., Williams, D. A., Thompson, R. J., & Kinney, T. R. (1991). Sickle cell disease in children and adolescents: The relation of child and parent pain coping strategies to adjustment. *Journal of Pediatric Psychology*, *16*, 643-663.
- Griffiths, L. J., Wolke, D., Page, A. S., & Horwood, J. P. (2006). Obesity and bullying: Different effects for boys and girls. *Archives of Disease in Childhood*, *91*, 121-125.
- Hansen, D. M., Larson, R. W., Dworkin, J. B. (2003). What adolescents learn in organized activities: A survey of self-reported developmental experiences. *Journal of Research on Adolescence*, *13*, 25-55.
- Hayes, S. C., Strosahl, K., & Wilson, K. G. (1999). *Acceptance and commitment therapy: An experiential approach to behavior change*. New York: Guilford.
- Hirst, M. (1989). Patterns of impairment and disability related to social handicap in young people with cerebral palsy and spina bifida. *Journal of Biosocial Science*, *21*, 1-12.
- Holler, K. A., Fennell, E. B., Crosson, B., Boggs, S. R., & Mickle, J. P. (1995). Neuropsychological and adaptive functioning in younger versus older children shunted for early hydrocephalus. *Child Neuropsychology*, *1*, 63-73.

- Hollingshead, A. A. (1975). *Four factor index of social status*. Unpublished manuscript, Yale University, New Haven, CT.
- Holmbeck, G. N. (1997). Toward terminological, conceptual, and statistical clarity in the study of mediators and moderators: Examples from the child-clinical and pediatric psychology literatures. *Journal of Consulting and Clinical Psychology, 65*, 599-610.
- Holmbeck, G. N. (2002a). A developmental perspective on adolescent health and illness: An introduction to the special issues. *Journal of Pediatric Psychology, 27*, 409-415.
- Holmbeck, G. N. (2002b). Post-hoc probing of significant moderational and mediational effects in studies of pediatric populations. *Journal of Pediatric Psychology, 27*, 87-96.
- Holmbeck, G. N., Shapera, W. E., & Hommeyer, J. S. (2002). Observed and perceived parenting behaviors and psychosocial adjustment in preadolescents with spina bifida. In B. K. Barber (Ed.), *Intrusive Parenting: How Psychological Control Affects Children and Adolescents* (pp. 191-234). Washington, DC: American Psychological Association.
- Holmbeck, G. N., Zebracki, K., Johnson, S.Z., Belvedere, M., & Schneider, J. (2007a). *Child-Peer Interaction Macro-Coding Manual*. Unpublished manual, Loyola University of Chicago.
- Holmbeck, G. N., Zebracki, K., Johnson, S.Z., Belvedere, M., & Schneider, J. (2007b). *Parent-Child Interaction Macro-Coding Manual*. Unpublished manual, Loyola University of Chicago.
- Holmbeck, G. N., DeLucia, C., Essner, B. Kelly, L., Zebracki, K., Friedman, D., et al. (under review). Trajectories of psychosocial adjustment in adolescents with spina bifida: A six-year four-wave longitudinal follow-up. *Journal of Consulting and Clinical Psychology*.
- Holmbeck, G. N. & Faier-Routman, J. (1995). Spinal lesion level, shunt status, family relationships, and psychosocial adjustment in children and adolescents with spina bifida myelomeningocele. *Journal of Pediatric Psychology, 20*, 817-832.
- Holmbeck, G. N., Westhoven, V. C., Shapera Phillips, W., Bowers, R., Gruse, C. & Nikolopoulos, T, et al. (2003). A multimethod, multi-informant, and multidimensional perspective on psychosocial adjustment in preadolescents with spina bifida. *Journal of Consulting and Clinical Psychology, 71*, 782-796.

- Holmbeck, G. N., Johnson, S. Z., Wills, K. E., McKernon, W., Rose, B., Erklin, S., et al. (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*, 96-110.
- Hommeyer, J. S., Holmbeck, G. N., Wills, K. E., & Coers, S. (1999). Condition severity and psychosocial functioning in pre-adolescents with spina bifida: Disentangling proximal functional status and distal adjustment outcomes. *Journal of Pediatric Psychology, 24*, 499-509.
- Ilowite, N. T., Walco, G. A., & Pochaczewsky, R. (1992). Assessment of pain in patients with juvenile rheumatoid arthritis: Relation between pain intensity and degree of joint inflammation. *Annals of the Rheumatic Diseases, 51*, 343-346.
- Kaczynski, K. J., Claar, R. L., & Logan, D. E. (2009). Testing gender as a moderator of associations between psychosocial variables and functional disability in children and adolescents with chronic pain. *Journal of Pediatric Psychology, 34*, 738-748.
- Kashikar-Zuck, S., Goldschneider, K. R., Powers, S. W., Vaught, M. H., & Hershey, A. D. (2002). Depression and functional disability in chronic pediatric pain. *Clinical Journal of Pain, 17*, 341-349.
- Kasser, S. L. & Lytle, R. K. (2005). *Inclusive physical activity: A lifetime of opportunities*. Champaign, IL: Human Kinetics.
- Kazdin, A. E. (1999). Overview of research design issues in clinical psychology. In P. C. Kendall, J. N. Butcher, & G. N. Holmbeck (Eds.), *Handbook of Research Methods in Clinical Psychology*. New York: John Wiley & Sons.
- Kovacs, M. (1992). *Children's depression inventory—manual*. North Tawonda, NY: Multi-Health Systems.
- Kupersmidt, J. B., Coie, J. D., & Dodge, K. A. (1990). The role of poor peer relationships in the development of disorder. In S. R. Asher & J. D. Coie (Eds.), *Peer rejection in childhood* (pp. 274-305). New York: Cambridge University Press.
- Kuczumarski, R. J., Ogden, C. L., Guo, S. S., et al. (2000). CDC growth charts for the United States: Methods and development. National Center for Health Statistics. *Vital Health Stat 11*(246).
- La Greca, A. (1990). Social consequences of pediatric conditions: Fertile area for future investigation and intervention. *Journal of Pediatric Psychology, 15*, 285-307.

- La Greca, A. M., Auslander, W. F., Greco, P., Spetter, D., Fisher, E. B., & Santiago, J. V. (1995). I get by with a little help from my family and friends: Adolescents' support for diabetes care. *Journal of Pediatric Psychology, 20*, 449-476.
- La Greca, A. M., Prinstein, M. J., & Fetter, M. J. (2001). Adolescent peer crowd affiliation: Linkages with health-risk behaviors and close friendships. *Journal of Pediatric Psychology, 26*, 131-143.
- La Greca, A. M., Bearman, K. J., & Moore, H. (2002). Peer relations of youth with pediatric concerns and health risks: Promoting social support and healthy lifestyles. *Developmental and Behavioral Pediatrics, 23*, 271-280.
- La Greca, A. M., & Schuman, W. B. (1999). Research methods in pediatric psychology. In P. C. Kendall, J. N. Butcher, & G. N. Holmbeck (Eds.), *Handbook of Research Methods in Clinical Psychology*. New York: John Wiley & Sons.
- Larsson, B. & Sund, A. M. (2007). Emotional/behavioral, social correlates, and one-year predictors of frequent pains among early adolescents: Influences of pain characteristics. *European Journal of Pain, 11*, 57-65.
- Lavigne, J., & Faier-Routman, J. (1992). Psychological adjustment to pediatric physical disorders: A meta-analytic review. *Journal of Pediatric Psychology, 12*(2), 133-157.
- Leibold, S. (1994). Achieving and maintaining body systems integrity and function: Personal care skills. In D. Lollar (Ed.), *Preventing Secondary Conditions Associated with Spina Bifida and cerebral Palsy* (pp.87-94). Washington, D. C.: Spina Bifida Association of America.
- Lemanek, K., Horowitz, W., Ohene-Frempong, K. (1994). A multi-perspective investigation of social competence in children with sickle cell disease. *Journal of Pediatric Psychology, 19*, 443-456.
- Liou, T-H., Pi-Sunyer, X., & Laferrere, B. (2005). Physical disability and obesity. *Nutrition Reviews, 63*, 321-331.
- Liusuwan, A., Widman, L., Abresch, R. T., & McDonald, C. M. (2004). Altered body composition affects resting energy expenditure and interpretation of body mass index in children with spinal cord injury. *The Journal of Spinal Cord Medicine, 27*, S24-S28.
- Marge, T. (1994). Toward a state of well being: Promoting healthy behaviors to prevent secondary conditions. In D. Lollar. (Ed.), *Preventing Secondary Conditions*

Associated with Spina Bifida and Cerebral Palsy (pp. 87-94). Washington, D. C: Spina Bifida Association of America.

- Mei, Z., Grummer-Strawn, L. M., Pietrobelli, A., Goulding, A., Goran, M. I., & Dietz, W. H. (2002). Validity of body mass index compared with other body-composition screening indexes for the assessment of body features in children and adolescents. *American Journal of Clinical Nutrition*, 75, 978-985.
- Meijer, S. A., Sinnema, G., Bijstra, J. O., Mellenbergh, G. J., & Wolters, W. H. G. (2000). Social functioning in children with chronic illness. *Journal of Child Psychology and Psychiatry*, 41, 309-317.
- Nassau, J. H. & Drotar, D. (1997). Social competence among children with central nervous system-related chronic health conditions: A review. *Journal of Pediatric Psychology*, 22, 771-793.
- Neumark-Sztainer, D., Falkner, N., Story, M., Perry, C., Hannon, P. J., & Mulert, S. (2002). Weight-teasing among adolescents: Correlations with weight status and disordered eating behaviors. *International Journal of Obesity*, 26, 123-131.
- Neumark-Sztainer, D., Story, M., & Faibisch, L. (1998). Perceived stigmatization among overweight African American and Caucasian adolescent girls. *Journal of Adolescent Health*, 23, 264-270.
- Newcomb, A. F. & Bagwell, C. L. (1998). The developmental significance of children's friendship relations. In W. M. Bukowski, A. F. Newcomb, & W. W. Hartup (Eds.), *Company they keep: Friendship in childhood and adolescence* (pp. 289-321). New York: Cambridge University Press.
- Norrin, S., Strinnholm, M., Carlsson, M., & Dahl., M. (2003). Factors of significance for mobility in children with myelomeningocele. *Acta Paediatrica*, 92, 204-210.
- Oddson, B. E., Clancy, C. A., & McGrath, P. J. (2006). The role of pain in reduced quality of life and depressive symptomology in children with spina bifida. *The Clinical Journal of Pain*, 22, 784-789.
- Padua, L. et al. (2002). Health-related quality of life and disability in young patients with spina bifida. *Archives of Physical Medicine and Rehabilitation*, 83, 1384-1388.
- Palermo, T. N., Witherspoon, D., Valenzuela, D., & Drotar, D. (2004). Development and validation of the Child Activity Limitations Interview: A measure of pain-related functional impairment in school-age children and adolescents. *Pain*, 109, 461-470.

- Palermo, T. M. (2000). Impact of recurrent and chronic pain on child and family daily functioning: A critical review of the literature. *Developmental and Behavioral Pediatrics, 21*, 58-69.
- Palermo, T. M. & Chambers, C. T. (2005). Parent and family factors in pediatric chronic pain and disability: An integrative approach. *Pain, 119*, 1-4.
- Palisano, R., Rosenbaum, P., Walter, S., Russell, D., Wood, E., & Galuppi, B. (1997). Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Developmental Medicine & Child Neurology, 39*, 214-223.
- Palisano, R., Rosenbaum, P., Walter, S., Bartlett, D., & Livingston, M. (2007). Gross Motor Classification System, Expanded and Revised. Unpublished manuscript, McMaster University, Hamilton, ON, Canada.
- Parker, J. G., & Asher, S. R. (1993). Friendship and friendship quality in middle childhood: Links with peer group acceptance and feelings of loneliness and social dissatisfaction. *Developmental Psychology, 29*, 611-621.
- Perquin, C. W., Hazebroek-Kampschreur, A. A. J. M., Hunfeld, J. A. M., Bohnen, A. M., van Suijlekom-Smit, L. W. A., Passchier, J., et al. (2000). Pain in children and adolescents: A common experience. *Pain, 87*, 51-58.
- Peterson, C. C. & Palermo, T. P. (2004). Parental reinforcement of recurrent pain: The moderating impact of child depression and anxiety on functional disability. *Journal of Pediatric Psychology, 29*, 331-341.
- Reiter-Purtill, J. & Noll, R. B. (2003). Peer relationships of children with chronic illness. In M. C. Roberts (Ed.), *Handbook of Pediatric Psychology* (3rd ed., pp. 176-198). New York: Guilford.
- Reiter-Purtill, J., Waller, J. M., & Noll, R. B. (2009). Empirical and theoretical perspectives on the peer relationships of children with chronic conditions. In M. C. Roberts, & R. G. Steele (Eds.), *Handbook of Pediatric Psychology*. New York: Guilford Press.
- Rimmer, J. H., Rowland, J. L., & Yamaki, K. (2007). Obesity and secondary conditions in adolescents with disabilities: Addressing the needs of an underserved population. *Journal of Adolescent Health, 41*, 224-229.
- Robin, A. L., & Foster, S. L. (1989). *Negotiating parent-adolescent conflict: A behavioral-family systems approach*. New York: Guilford.

- Roth-Isigkeit, A., Thyen, T., Stoven, H., Schwarzenberger, J., & Schmucker, P. (2005). Pain among children and adolescents: Restrictions in daily living and triggering factors. *Pediatrics, 115*, 152-162.
- Rowe, D. E. & Jadhav, A. L. (2008). Care of the adolescent with spina bifida. *The Pediatric Clinics of North America, 55*, 1359-1374.
- Sandler, A. (1997). *Living with Spina Bifida: A Guide for Families and Professionals*. Chapel Hill, NC: The University of North Carolina Press.
- Schoenmakers, M. A. G. C., Gulmans, V. A. M., Gooskens, R. H. J. M., Pruijs, J. E. H., Helders, P. J. M. (2005). Spinal fusion in children with spina bifida: Influence on ambulation level and functional abilities. *European Spine Journal, 14*, 415-422.
- Schuman, W. B. & La Greca, A. M. (1999). Social correlates of chronic illness. In R. T. Brown (Ed.), *Cognitive Aspects of Chronic Illness in Children* (pp. 289-311). New York: Guilford.
- Scott, M. A., Fletcher, J. M., Brookshire, B. L., Davidson, K. C., Landry, S. H., Bohan, T. C., & Francis, D. J. (1998). Memory functions in children with early hydrocephalus. *Neuropsychology, 12*, 578-589.
- Simeonsson, R. J., McMillen, J. S., & Huntington, G. S. (2002). Secondary conditions in children with disabilities: Spina bifida as a case example. *Mental Retardation and Developmental Disabilities, 8*, 198-205.
- Simons, L. E., Claar, R. L., & Logan, D. L. (2008). Chronic pain in adolescence: Parental responses, adolescent coping, and their impact on adolescent's pain behaviors. *Journal of Pediatric Psychology, 33*, 894-904.
- Simpson, C. G., Swicegood, P. R. G., & Mark, D. (2006). Nutrition and fitness curriculum: Designing instructional interventions for children with developmental disabilities. *Teaching Exceptional Children, 38*, 50-53.
- Smetana, J. G., Yau, J., Restrepo, A., & Braeges, J. L. (1991). Adolescent-parent conflict in married and divorced families. *Developmental Psychology, 27*, 1000-1010.
- Sobel, M. E. (1982). Asymptotic confidence intervals for indirect effects in structural equation models. In S. Leinhardt (Ed.), *Sociological Methodology 1982* (pp. 290-312). Washington DC: American Sociological Association.
- Sobus, K. (2008, Fall). Ask the expert: Effectively managing pain. *Insights, 12*.

- Soper, D. S. (n.d.). *Free effect size calculator for multiple regression*. Retrieved from <http://www.danielsoper.com/statcalc/calc05.aspx>
- Spina Bifida Association of America. (2007). Ask the doctor: Adult back pain. Retrieved January 8, 2009 from http://www.spinabifidaassociation.org/site/c.liKWL7PLLrF/b.3074327/k.7A9A/Adult_Back_Pain.htm.
- Spina Bifida Association of America. (n.d.). Fact Sheets: Obesity. Retrieved October 28, 2009 from <http://www.spinabifidaassociation.org/site/c.liKWL7PLLrF/b.2700287/k.C25F/Obesity.htm>.
- Spirito, A., DeLawyer, D. D., & Stark, L. J. (1991). Peer relations and social adjustment of chronically ill children and adolescents. *Clinical Psychology Review, 11*, 539-564.
- Stellman-Ward, G. R., Bannister, C. M., Lewis, M. A., & Shaw, J. (1997). The incidence of chronic headache in children with shunted hydrocephalus. *European Journal of Pediatric Surgery, 7*, 12-14.
- Stevens, S. E., Steele, C. A., Jutai, J. W., Kalnins, I. V., Bortolussi, J. A., & Biggar, D. (1996). *Journal of Adolescent Health, 19*, 157-164.
- Tabachnick, B. & Fidell, L. (2006). *Using Multivariate Statistics* (5th Ed.). Boston: Allyn & Bacon.
- Thomasgard, M., Metz, W.P., Edelbrock, C., & Shonkoff, J. (1995). Parent-child relationship disorders: Part I. Parental overprotection and the development of the Parent Protection Scale. *Journal of Developmental and Behavioral Pediatrics, 16*, 244-250.
- Turk, D. C. & Monarch, E. S. (2002). Biopsychosocial perspective on chronic pain . In D. C. Turk & R. J. Gatchel (Eds.), *Psychological Approaches to Chronic Pain Management: A Practitioner's Handbook*. (2nd Ed.). New York: Guilford.
- Van Slyke, D. A. & Walker, L. S. (2006). Mothers' responses to adolescent's pain. *Clinical Journal of Pain, 22*, 387-391.
- Varni, J. W., Setoguchi, Y., Rappaport, L. R., & Talbot, D. (1992). Psychological adjustment and perceived social support in children with congenital/acquired limb deficiencies. *Journal of Behavioral Medicine, 15*, 31-44.

- Vinck, A., Maassen, B., Mullaart, R., & Rotteveel, J. (2006). Arnold-Chiari-II malformation and cognitive functioning in spina bifida. *Journal of Neurology, Neurosurgery, & Psychiatry*, 77, 1083-1086.
- Walker, L. S. & Greene, J. W. (1991). The functional disability inventory: Measuring a neglected dimension of child health status. *Journal of Pediatric Psychology*, 16, 39-58.
- Walker, L. S., Levy, R. L., & Whitehead, W. E. (2006). Validation of a measure of protective parent responses to children's pain. *Clinical Journal of Pain*, 22, 712-716.
- Wallander, J. L., Feldman, W. S., & Varni, J. W. (1989). Physical status and psychosocial adjustment in children with spina bifida. *Journal of Pediatric Psychology*, 14, 89-102.
- Walters, A. S. & Williamson, G. M. (1999). The role of activity restriction in the association between pain and depression: A study of pediatric patients with chronic pain. *Children's Health Care*, 28, 33-50.
- Wechsler, D. (1999). *WASI: Wechsler Abbreviated Scale of Intelligence Manual*. San Antonio, Texas: Harcourt Assessment, Inc.
- Wicksell, R. K., Melin, L., Lekander, M., & Olsson, G. L. (2009). Evaluating the effectiveness of exposure and acceptance strategies to improve functioning and quality of life in longstanding pediatric pain: A randomized controlled trial. *Pain*, 141, 248-257.
- Wilson, S., Washington, L. A., Engel, J. M., Ciol, M. A., & Jensen, M. P. (2006). Perceived social support, psychological adjustment, and functional ability in youths with physical disabilities. *Rehabilitation Psychology*, 51, 322-330.

VITA

Bonnie Essner was born in Cape Girardeau, Missouri and raised in nearby Kelso, Missouri. She received a bachelor's of science degree in psychology, with a minor in fine arts, and graduated magna cum laude from Loyola University Chicago in 2000. She worked as a research associate at Children's Memorial Hospital in Chicago, Illinois for two years and returned to Loyola University Chicago for graduate study in 2006. As a graduate student, she was involved in research led by Dr. Grayson Holmbeck, which investigated psychosocial development of youth with spina bifida during the transition to adolescence. She completed her graduate and doctoral research under the mentorship of Dr. Holmbeck.

Ms. Essner's clinical work during her graduate education involved neuropsychological evaluation of children and adolescents; psychotherapy with children, adolescents, young adults, and their families; and pediatric consultation-liaison assessment and intervention with youth in inpatient medical settings outpatient medical and multidisciplinary clinics. She completed her clinical psychology internship at the Ann and Robert H. Lurie Children's Hospital of Chicago. She is current a postdoctoral fellow in pediatric pain research at the Seattle Children's Hospital Research Institute, under the direction of Dr. Tonya Palermo.