2012

Agreement and Disagreement in Parent and Child Perceptions of Spina Bifida Medical Responsibilities During the Transition to Adolescence

Alexandra Psihogios
Loyola University Chicago

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

Part of the Psychology Commons

www.manaraa.com

LOYOLA UNIVERSITY CHICAGO

AGREEMENT AND DISAGREEMENT IN PARENT AND CHILD

PERCEPTIONS OF SPINA BIFIDA MEDICAL RESPONSIBILITIES

DURING THE TRANSITION TO ADOLESCENCE

A THESIS SUBMITTED TO

THE FACULTY OF THE GRADUATE SCHOOL

IN CANDIDACY FOR THE DEGREE OF

MASTER OF ARTS

PROGRAM IN CLINICAL PSYCHOLOGY

BY

ALEXANDRA M. PSIHOGIOS

CHICAGO, ILLINOIS

DECEMBER 2012

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER ONE

INTRODUCTION

As a result of rapid biological, cognitive, and social maturation during early adolescence, the nature of close relationships often change during this critical stage of development (Collins, Laursen, Mortensen, Luebker & Ferreira, 1997). During this time, a child begins to assume new roles and family relationships are reorganized to support these developments (Hill, Bromell, Tyson & Flint, 2007). Considering the changes that characterize early adolescence, it is not surprising that there are significant differences in how parents and their children perceive the child's course of autonomy-related development. Autonomy has been defined as an interpersonal and developmental process in which an adolescent behaves with increasing independence within a family context (Hill, Bromell, Tyson & Flint, 2007). The development of autonomy is considered a fundamental component of healthy adolescent growth (Friedman, Holmbeck, DeLucia, Jandasek & Zebracki, 2009). Perceived decision-making autonomy refers to the extent to which a parent or child believes that he or she is in control of making decisions about a responsibility (e.g. doing chores or adhering to medical regimen; Miller & Drotar, 2003) According to Holmbeck's (1996) model of parent-child relational change during adolescence, changes in the adolescent's development may prompt discrepancies between parent and child views of autonomy. These disagreements may occur because rapid

1

physical and psychological changes make it difficult for parents to track changes in their adolescents' abilities, and because these changes promote new expectations that may or may not be developmentally appropriate. Therefore, from a developmental perspective, disagreements over perceived independence may be caused by child autonomy seeking and may result in conflict if left unresolved (Butner et al., 2009; Greenley, Holmbeck & Rose, 2006). Considering that children with chronic illnesses may have to manage more independence-related issues than typically developing children during the transition to adolescence (e.g. by beginning to independently monitor medical regimen), parents and children with chronic illnesses may be more likely to exhibit such disagreements. Informant disagreements over perceived decision-making autonomy are important to study in healthy and pediatric populations because they may be associated with positive or risky health-related behaviors (Holmbeck, 2002; Anderson et al., 2009; Butner et al., 2009).

Though parent-child disagreements have been associated with increased family conflict, they are often considered a normative and beneficial process of growth (Butner et al., 2009; Holmbeck 1996). For example, when parents and children have different expectations about individual or family functioning, conflict may prompt realignments toward age-appropriate expectations, thereby reducing the discrepancies (Collins et al., 1997). However, when families fail to resolve conflicts, inconsistencies may persist and be exacerbated (Anderson, Auslander, Jung, Miller & Santiago, 1990; Anderson et al., 2009). It has been proposed that high levels of differing perceptions within parent-child dyads may reflect maladaptive interaction styles and could predict negative behavioral or psychological functioning (De Los Reyes, Goodman, Kliewer & Reid- Quinones, 2008).

For instance, it has been found that parent-child disagreements predict subsequent child internalizing problems and level of social competence (Guion, Mrug & Windle, 2009).

This issue is particularly relevant for developing adolescents with chronic conditions, as parents typically shift responsibility for medical tasks to their child during early adolescence (Anderson et al., 1990; Stepansky, Roache, Holmbeck & Schultz, 2009). In pediatric populations, research suggests that parent-child disagreement regarding perceived adolescent autonomy may be associated with family conflict (Miller & Drotar, 2003) and poorer medical adherence (Anderson et al., 2009; Butner et al., 2009). Furthermore, research suggests that family conflict typically emerges when there are negotiations about who is responsible for certain tasks (Smetana, Campione-Barr, & Metzger, 2006). Although mothers and adolescents with spina bifida have demonstrated differences in their perceptions of adolescent autonomy development (Sawin et al., 2006; Devine et al., 2011), less is known about the relationship between mother-child disagreements and negative outcomes in this population. Considering that lifelong healthcare behaviors are often established and consolidated during adolescence, gaining insight into the relationships between parent-child perceptions of adolescent autonomy, family conflict, and medical adherence is essential.

The purpose of this study was to examine the validity of informant discrepancies by evaluating levels of mother-child agreement and disagreement in perceived decision-making autonomy in relation to family conflict and medical adherence. Specifically, mother-child dyadic agreement and disagreement regarding who takes responsibility for spina bifida medical tasks was studied at one time point, when youth were between the ages of 8 to 15 years old. Though a few studies have evaluated discrepant beliefs in

pediatric populations (e.g. Miller & Drotar, 2003; Anderson et al., 2009; Butner et al., 2009; Devine et al, 2011), no studies have investigated mother-child differences in perceived control over spina bifida- related medical tasks. Furthermore, few studies have evaluated different types of parent-child agreement and disagreement (Devine et al., 2011). This study chose to evaluate agreement levels, in addition to disagreement levels, as agreement over perceived decision-making autonomy represents a reliable assessment of whether the child, parent, or both the child and the parent, possess significant decision-making autonomy over spina bifida medical responsibilities. The study of parent-child agreement and disagreement over medical responsibilities is especially relevant for individuals with spina bifida, as these individuals tend to exhibit delays in autonomy development (Friedman et al., 2009). Moreover, the relationbetween parents and children with spina bifida appears to be unique, as parents are more likely to be psychological controlling or intrusive because they perceive their child as vulnerable (Holmbeck et al., 2002a). Considering these characteristics, it was expected that parents and children with spina bifida may not consistently agree on the sharing of disease responsibilities.

For this study, three types of agreement and two types of disagreement were analyzed (see Figure 1). Mother-child dyads may have agreed that responsibility belonged to the child, that the responsibility was shared, or that the responsibility belonged to the parent. Mother-child dyads may have disagreed because each family member reported being responsible for the task (e.g. child reported that the responsibility belonged to the child and parent reported that the responsibility belonged to the parent) or dyads may have disagreed because each family member reported that the other family

member was in charge (e.g. child reported that the responsibility belonged to the parent

and parent reported that the responsibility belonged to the child).

Figure 1: Levels of Agreement and Disagreement Based on Child and Mother Reports of
Medical Responsibilities

		Parent Report		
		Child Responsibility	Equal Responsibility	Parent Responsibility
Child Report	Child Responsibility	1 Agree, Child Responsible	2	3 Disagree, "Both report being responsible"
	Equal Responsibility	4	5 Agree, Shared Responsibility	6
	Parent Responsibility	7 Disagree, "Both report that someone else is in charge"	8	9 Agree, Parent Responsible

In addition to measuring levels of agreement and disagreement within mother-

child dyads, outcomes of agreements and disagreements were also studied (i.e., family

conflict and medical adherence). For this study, conflict was chosen as a potential

outcome because research suggests that families who have discrepant perceptions of child

autonomy exhibit high levels of conflict (Holmbeck & O'Donnell, 1991; Miller & Drotar,

2003), possibly due to child autonomy-seeking (Collins et al., 1997)Although research

suggests that adolescents tend to believe that they are more independent than parents do (Dekovic, Noom & Meeus, 1996), adolescents with spina bifida have been found to be less self-reliant than typically developing peers (Holmbeck et al., 2003). Therefore, adolescents with spina bifida may be reluctant to manage spina bifida care independently, despite parental encouragement to do so. Thus, it was expected that both types of disagreements would be present in this population and would be associated with increased family conflict. Conversely, it was expected that mother-child agreement would be associated with decreased family conflict; high levels of such agreements may suggest that mothers and adolescents are "on the same page" about who is responsible for certain medical tasks.

Research with pediatric populations also suggests that parent-child disagreements about child autonomy are associated with poorer medical outcomes (Butner et al., 2009; Anderson et al., 2009). Considering that disagreements over the management of spina bifida may have direct implications for treatment (e.g., if neither mother nor child assumes responsibility for a medical task then the medical task may not be completed), it was expected that high levels of mother-child disagreement would be associated with poorer medical adherence. On the other hand, it was expected that mother-child agreement would be associated with higher medical adherence.

This study proposed a meditation model (see Figure 2) to examine whether family conflict explains, in part, the relationship between mother-child agreement/disagreement in perceived decision-making autonomy and medical adherence outcomes. Finally, a moderation model (see Figure 3) was tested to examine the effects of

agreement/disagreement levels and family conflict on medical adherence outcomes. To

this researcher's knowledge, these relations have not been previously analyzed.

Figure 2: Mediation Model for Mother-Child Agreement/Disagreement Predicting Family
Conflict and Medical Adherence
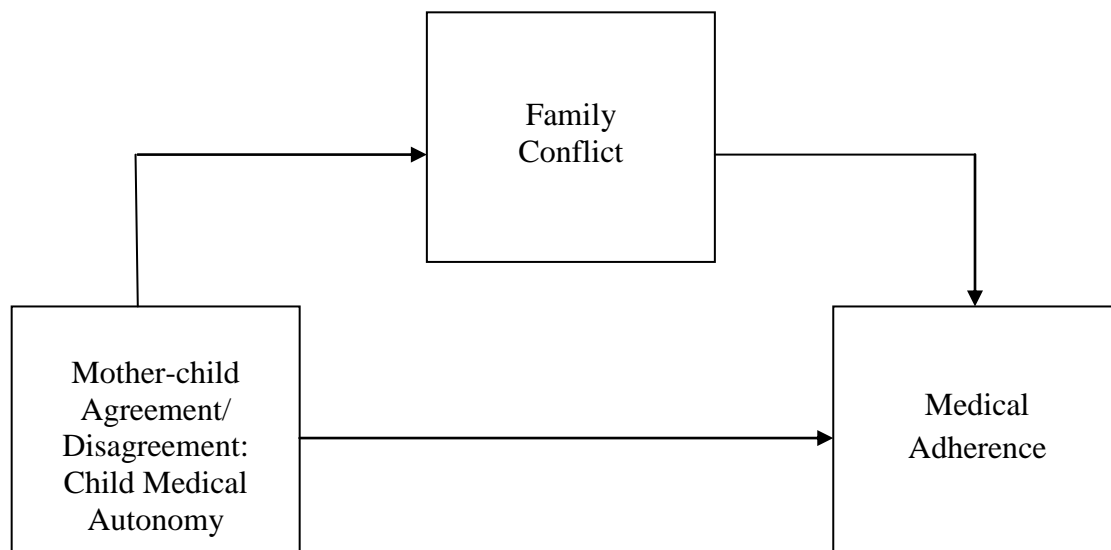
Figure 3: Moderation Model for Predicting Medical Adherence from Mother-Child Agreement/Disagreement and Family Conflict
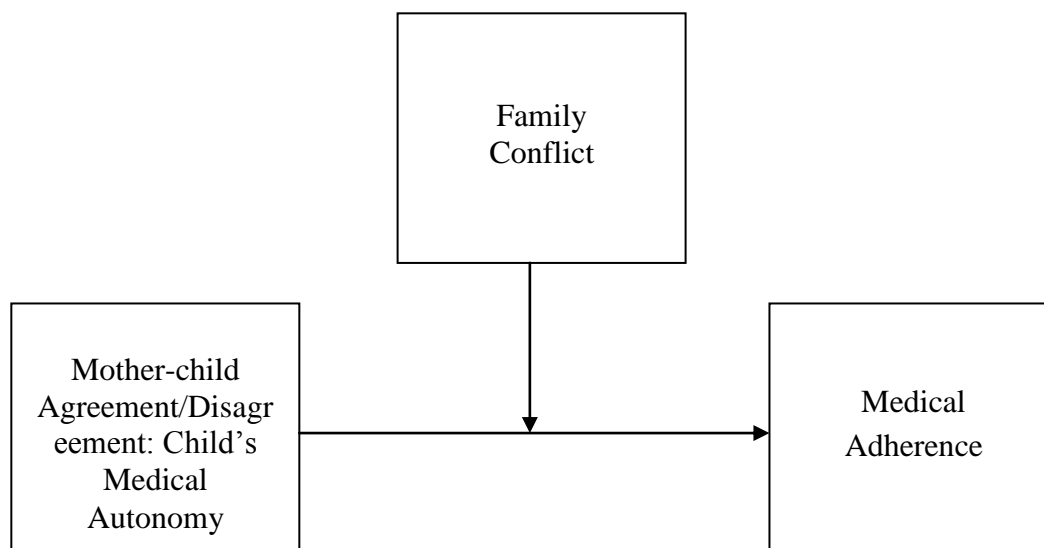
The following sections will include a review of the current literature regarding the hypotheses of this study. A background of spina bifida will be provided, followed by a description of the transition of medical regimen from parent to child, the importance of measuring agreement levels in pediatric populations, and methods of measuring informant agreement and disagreement. Hypotheses that are consistent with this background literature will then be presented. The methods of the current study will be reviewed including descriptions of the data collection process and measures used. Finally, results will be reported and conclusions, clinical implications, and future directions will be discussed.

CHAPTER TWO

REVIEW OF THE RELEVANT LITERATURE

Background: Spina Bifida and Medical Care

Spina bifida is one of the most common birth defects, occurring in roughly 3 out of every 10,000 live births (Centers for Disease Control and Prevention, 2011) and is caused by the failed closure of the neural tube during pregnancy (Sarwark, 1996). Individuals with spina bifida face a multitude of challenges, including cognitive, orthopedic, urinary, and bowel difficulties. Individuals with spina bifida may have below average cognitive abilities (e.g. deficits in abstract reasoning, attention, and visual perception and visual motor integration) and often require braces or wheelchairs to ambulate (Sandler, 2010). Cognitive and orthopedic impairments pose major challenges to the development of independent living skills, including autonomous medical adherence. Typically, individuals with spina bifida are required to take medications, learn how to self-catheterize, follow a specific bowel program, and perform skin checks and pressure relief exercises.

According to self-determination theory, the need for autonomy must be satisfied to reach optimal functioning and growth (Ryan & Deci, 2000). The transition to adolescence is considered an important time period for such development (Holmbeck, 2002a). For children with chronic health conditions, the transition to adolescence is often

9

characterized by increased responsibilities for medical care. For instance, it has been found that parents of children with diabetes (Anderson et al., 1997) and cystic fibrosis (Modi et al., 2008) transfer medical responsibilities to children during early adolescence. Similarly, Stepansky and colleagues (2009) found that adolescents with spina bifida also are granted increasing responsibility for medical regimens over time (specifically, for catheterization and one's bowel program). By the time children with spina bifida are 12-13 years old, most children have obtained at least partial responsibility for catheterization and bowel programs.

Despite these gains, it has also been observed that children with spina bifida tend to achieve lower overall levels of autonomy during adolescence compared to typically developing children (Davis, Shurtleff, Walker & Seidel, 2006; Friedman et al., 2009). The transfer of disease responsibilities from parent to child may be particularly difficult because children with spina bifida tend to be less self-reliant, less likely to make independent decisions, and more passive in family interactions (Holmbeck et al., 2003, Blum , Resnick, Nelson & St Germaine, 1991). Cognitive deficits and parental intrusiveness could also influence how the medical regimen is transferred (Holmbeck et al., 2002a). For example, a parent may perceive their child as more vulnerable because of their spina bifida and be less likely to encourage independent medical care (Thomasgard & Metz, 1995; Holmbeck et al., 2002a). Taken together, the successful transfer of responsibility for medical tasks may be especially challenging because mother and child characteristics may undermine aspects of effective communication.

The Importance of Measuring Informant Disagreements

In the past few decades, a rich assortment of valid and reliable measurement tools have been developed to assess aspects of child and adolescent psychological functioning. It has been proposed that the best practices for evidence-based assessments involve the use of such measures, as well as multiple informants (Hunsley & Mash, 2007). Especially when assessing children, multiple reporters (e.g. child, parent, or teacher reports) are utilized to understand functioning in different contexts (De Los Reyes, 2011). Despite the advances in child assessment, a pervasive issue has been the lack of agreement among parents, children and teachers among all aspects of child psychopathology, as well as family dynamics (Rutter & Srouffe, 2000). Indeed, correlations between reporters on measures are typically in the low to moderate range (Achenbach, McConaughy, & Howell, 1987; Hope et al., 1999).

However, it is not yet well understood why multiple informants provide inconsistent ratings when reporting on the same behaviors (De Los Reyes, Goodman, Kliewer & Reid-Quinones, 2008). It has been hypothesized that disagreements between informants are influenced by how well reporters remember information, how candid they are, the context in which the behavior occurs, and whether the behavior is directly observed or inferred (Achenbach, 2006). It has also been suggested that children may be more likely to report on how they are feeling now or what they are doing now, as opposed to how they typically feel or what they typically do (Rutter & Srouffe, 2000). On the other hand, parents are more likely to compare their child with their other children or with other children they know, and these contrasts may influence their reports. Despite

these explanations, little research has been devoted to studying the causes or correlates of informant discrepancies.

It has been argued that more research is needed to understand what informant disagreements mean, and if measuring disagreements is a useful strategy when conducting research (De Los Reyes, 2011). Most research on informant disagreements have focused on the characteristics of the informants providing ratings of child behaviors (e.g. parent or teacher characteristics) or on the characteristics of the child (De Los Reyes & Kazdin, 2005). For instance, parental levels of depression have been associated with discrepancies between mothers' ratings and the ratings of other informants (e.g. child, teachers; Chi & Hinshaw, 2002; Youngstrom, Loeber & Stouthamer-Loeber, 2000). Child characteristics such as age (Achenbach et al., 1987), ethnicity (Kaufman et al., 1980), socioeconomic status (Devine et al., 2011) have also been associated with informant disagreements. Although these studies have been informative, the mechanisms involved in parent-child agreement and disagreement remains poorly understood (Rutter & Srouffe, 2000).

Parent-child disagreements may also relate to family characteristics because they are important indicators of how a system is functioning (Anderson et al., 2009). For example, differences between mother and child perceptions may relate to stressful home environments and family conflict (De Los Reyes & Kazdin, 2005). It has been suggested that disagreements are caused by child autonomy-seeking and may be resolved through the ensuing family conflict (Collins et al., 1997).. Indeed, the relationship between parent-child disagreements and conflict has been observed across a variety of populations (e.g., youth with anxiety, externalizing disorders, and diabetes) and measurement devices

(e.g., structured interviews and questionnaires; Grills & Ollendick, 2002; De Los Reyes & Kazdin, 2006; Miller & Drotar, 2003; Holmbeck & O'Donnell, 1991), suggesting a link between family conflict and parent-child disagreements in both pediatric and non-pediatric populations.

For pediatric populations, disagreements surrounding medical responsibilities may become more salient during early adolescence because the responsibility for managing disease responsibilities begins to shift from parent to child during this period of development (Anderson et al., 2009). For instance, when parents and children each report that the other family member is responsible for the management of medical tasks, this may indicate that communication in families about medical management has not kept pace with the shifting of responsibilities from parent to child (Anderson et al., 1990). These disagreements may have long term implications on the child's development of independence with his or her medical treatments, as well as the child's ability to adhere to medical recommendations properly. However, few studies have evaluated parent-child disagreements in pediatric populations, and even fewer have researched disagreements surrounding the sharing of medical responsibilities. Butner et al. (2009) found that greater discrepancies in parent-child perceptions of adolescent competence and independence were associated with poorer diabetes outcomes. Also, Anderson et al. (2009) found a relationship between parent-child agreement around responsibility sharing and glycemic control for young adolescents with diabetes. However, Miller and Drotar (2003) found that parent-child discrepancies were not significantly related to adherence to the diabetes treatments. Thus, more research is needed to understand the implications of parent-child discrepancies in perceived decision-making autonomy.

To this researcher's knowledge, outcomes of disagreements surrounding perceptions of responsibilities for medical care have not been studied in spina bifida populations. However, one study has evaluated disagreements in mother-adolescent reports over responsibilities for non-medical tasks (e.g. what time the adolescent has to be home; Devine et al., 2011). This study found that adolescents with spina bifida were less likely to agree with their mother's about responsibilities, as compared to typically developing peers. Moreover, disagreements occurred more frequently in younger adolescents from lower socioeconomic backgrounds. Another study found that parents and adolescents with spina bifida had differing perceptions of future expectations, family functioning, and developmental competencies (e.g. decision-making, household responsibilities and self-management; Sawin et al., 2006). It appears that young adolescents with spina bifida are not always in agreement with parents about their medical and non-medical responsibilities, although more research is needed to understand how disagreements impact family functioning and medical adherence.

<div align="center">Measuring Levels of Agreement and Disagreement</div>

To take informant disagreements into account, researchers frequently select an optimal informant or integrate reports using various combinational methods (Holmbeck, et al., 2002b; De Los Reyes & Kazdin, 2005). The optimal informant approach involves selecting one person as the best reporter because of the environmental context that he or she operates in (e.g. teachers are considered the best for reporting on classroom behavior). Though the optimal informant approach is often utilized in research, it may be problematic because research suggests that both parents and children offer unique, meaningful perceptions of behavior (Achenbach, 2006).

Since it is not always possible to accurately select an optimal informant, other combinational methods have been used to handle multisource data (Holmbeck et al., 2002b). For instance, researchers may examine informant reports separately, combine data across sources by summing (e.g., collapsing across informants) or combine data through latent variable modeling (e.g., where the common variance between reporters is considered to be true construct variance and unshared variance is considered to be error variance).

An alternative to the optimal informant or combinational approach is to examine informant disagreements as variables of interest. Rather than attributing divergent perspectives to measurement error or the belief that one informant is more accurate than the other, disagreements can be examined as predictors or outcomes. For instance, difference scores (e.g., a score from a child self-report measure subtracted from a score on a mother self-report measure) is one method of calculating discrepancies. Once calculated, the difference score may be related to aspects of psychological functioning. However, difference scores may be problematic because different types of mother-child dyads can yield the same score (e.g., dyads that are in high agreement that parents are responsible for healthcare management may yield the same difference score as dyads that are in high agreement that children are responsible). Holmbeck et al. (2002b) recommended other methods for evaluating disagreements such as isolating congruence and incongruence groups (e.g., mother-high/adolescent-high, mother-high/adolescent-low, mother-low/adolescent-high, and mother-low/adolescent-low) by median spilt and then evaluating whether the groups differ in important areas of functioning.

Devine and colleagues (2011) adopted a more fine-grained methodology for examining mother-adolescent agreement and disagreement in reports on a non-medical decision-making questionnaire. Specifically, mother and adolescent responses to each item were placed into 1 of 16 cells (four possible child responses and four possible mother responses). For instance, if a mother indicated that she had complete responsibility for a given task and the child agreed, the dyad would be assigned to cell '1' for that item. The 16 combinations were then collapsed into four categories to show who was responsible for a task (e.g., Agree- Mother, Agree- Adolescent, Disagree-Self, and Disagree-Other). For each participating dyad, the proportion of the total responses that fell into each of the four categories was calculated. A similar methodology will be adopted for this study in evaluating mother-adolescent agreement and disagreement over who is responsible for each of 34 spina bifida medical tasks.

The Current Study

Across various pediatric populations, it has been observed that optimal medical care during adolescence occurs when parents and children communicate effectively and collaboratively deal with problems surrounding medical management (Wiebe et al., 2005). Levels of agreement and disagreement may be important indicators of how families are negotiating a child's transition to adolescence, increased need for independence, and the transfer of medical responsibilities from parent to child. While informant disagreements have been observed across different informants, behaviors, and assessment tools, more research is needed to understand why disagreements exist and how they relate to outcomes of interest (De Los Reyes & Kazdin, 2005). Thus, a goal of

this study was to examine the validity of evaluating informant disagreements when conducting research in spina bifida populations.

Although past research has examined informant characteristics as correlates of informant discrepancies, findings have been mixed, and there is not yet a clear understanding as to why discrepancies occur. It has been recommended that the mechanisms involved in informant agreement and disagreement deserve further study by testing specific hypotheses (Rutter & Srouffe, 2000). Another limitation of past research has been focusing on informant discrepancies (e.g. by calculating difference scores) rather than exploring different types of dyadic agreement and disagreement (e.g. full agreement that the mother is responsible for a task compared to full agreement that the child is responsible). Finally, relatively little attention has been given to the relationship between agreement and disagreement levels, family characteristics, and medical adherence in pediatric populations.

To address these limitations, this study examined the relationships between mother-child agreement and disagreement, family conflict, and medical adherence in families of youth with spina bifida. Since research suggests that preadolescents are more likely to have conflicts with parents over rule-governed issues than older adolescents (Smetana, 1989) and responsibility for spina bifida medical responsibilities are typically transferred from parent to child during this time (Stepansky et al., 2010), this study focused on preadolescence. Mother and child reports on a sharing of spina bifida responsibilities questionnaire were assessed and mother-child agreement and disagreement levels were calculated based on the methodology outlined by Devine and colleagues (2011). Since it has been suggested that mothers are more likely to provide

consistent information about their child's behavior compared to other informants (e.g., fathers, teachers and peers: De Los Reyes & Kazdin, 2005), father reports were not utilized for this study. As previously discussed, mother-child disagreements over the sharing of spina bifida responsibilities were expected to result in increased family conflict and poorer medical adherence (see Figure 2). Similarly, mother-child agreements were expected to result in lower family conflict and higher medical adherence.

Although past research suggests that informant discrepancies are related to family conflict in non-pediatric samples (Grills & Ollendick, 2002; De Los Reyes & Kazdin; 2006), less is known about this relationship in a pediatric populations. Furthermore, few studies have investigated agreements and disagreements in perceptions of medical autonomy. This study attempted to address this limitation by investigating the effects of mother-child agreement and disagreement over perceived medical autonomy on family conflict. In the current study, family conflict was evaluated from three different perspectives: mother report of conflict with the child, child report of conflict with parents, and observations of family conflict. This study expanded on the work of Coakley and colleagues (2002) by evaluating different perspectives on conflict. Thus, an advantage of this study was the use of multiple informants.

As responsibilities for medical tasks gradually shift from parent to child, ongoing communication within the family is needed to promote adherence behaviors. In fact, past research suggests that family communication, especially surrounding issues of disease management, is related to better adherence outcomes (Rapoff, 2010). Furthermore, greater family involvement and shared responsibility has been associated with better adherence for children with diabetes (Helgeson, Siminerio, Escobar, & Becker, 2008) and

HIV (Martin et al., 2007). Thus, mother-child disagreement in reports of who is responsible for spina bifida medical tasks may denote a lack of communication and was expected to result in poorer medical adherence. On the other hand, mother-child agreement may indicate effective communication and was expected to result in higher medical adherence. In the current study, medical adherence was evaluated based on mother report of medical adherence. In general, parent reports of medical adherence have been relatively accurate across a variety of pediatric conditions (Quittner et al., 2008).

It has been suggested that conflicts between parents and children during early adolescence may mark a developmental transition in which children are striving for more autonomy (Butner et al., 2009; Greenley, Holmbeck & Rose, 2006). While previous research in pediatric populations suggests that disagreements between parents and children over autonomy-related issues may result in poorer medical adherence (Butner et al., 2009; Anderson et al., 2009) other studies have not supported this finding (Miller & Drotar, 2003). Although disagreements over perceived decision-making autonomy may relate to differing perceptions of child autonomy, disagreements may also be the result of a number of other variables (e.g. misunderstanding the questionnaire, inattention, or fatigue). Despite this possibility, it was expected that family conflict will mediate the relationship between parent-child discrepancies in perceptions of the child's medical autonomy and medical adherence. That is, if parents and children disagree about who is responsible for spina bifida medical tasks, and these disagreements cause conflict, families may be less adherent to treatments because of differing perceptions of child autonomy levels. On the other hand, if parents and children disagree about who is

responsible and conflict is not present, disagreements are less likely to affect adherence because these disagreements may be due to various types of measurement error.

Finally, it was hypothesized that family conflict would moderate the relationship between mother-child disagreement and medical adherence. That is, the relationship between mother-child disagreements and poor medical adherence would depend on the presence of low or high family conflict. For families with high levels of conflict, it was expected that the relationship between informant disagreements and poor medical adherence would be stronger than for families with low levels of conflict.

Study Hypotheses

<u>Hypothesis 1</u>. Both types of mother-child disagreements (e.g. "Both report being responsible" and "Both report that someone else is in charge") were expected to result in family conflict. Similarly, mother-child agreements (e.g. "Agree, child responsible", "Agree, both responsible", and "Agree, parent responsible") were expected to be negatively related to family conflict.

<u>Hypothesis II</u>. Mother-child disagreements were expected to result in lower levels of medical adherence. Conversely, mother-child agreements were expected to result in higher levels of medical adherence.

<u>Hypothesis III</u>. Family conflict was expected to mediate associations between mother-child agreement/disagreement and medical adherence. Although mother-child disagreements were expected to be associated with poorer medical adherence, it was expected that the relation between disagreements and medical adherence would be significantly reduced when controlling for conflict. Similarly, the relation between

mother-child agreement and higher medical adherence would be significantly reduced when controlling for conflict.

Hypothesis IV. Family conflict was expected to moderate associations between mother-child agreement and disagreement and medical adherence. That is, the relationship between mother-child agreement/disagreement levels and medical adherence would depend on the presence of low or high family conflict.

CHAPTER THREE

METHODS

Participants

Participants were part of a larger longitudinal study at Loyola University Chicago examining family, psychosocial, and neurocognitive functioning among children with spina bifida (Devine et al., 2010). This study focused exclusively on data regarding disease management and family conflict in families of children with spina bifida at Time 1, when youth were between the ages of 8 and 15. Families of children with spina bifida were recruited from four hospitals and a statewide spina bifida association in the Midwest. Inclusion criteria consisted of: (1) diagnosis of spina bifida (types included myelomeningocele, lipomeningocele, myelocystocele); (2) age eight to 15 years at time 1; (3) ability to speak and read English or Spanish; (4) involvement of at least one primary caregiver; and (5) residence within 300 miles of lab (to allow for home visits for data collection). During recruitment, 246 families who met inclusion criteria were approached. Of the original 246 families, 163 families agreed to participate but 21 of those families were not able to be contacted or later declined, and two families did not actually meet inclusion criteria. The final participants included 140 families of children with spina bifida (53.6% female; *M* age = 11.40). Demographic information is provided

22

in Table 1. Children of families who declined participation did not differ from those who accepted participation with respect to type of spina bifida (e.g. myelomeningocele or other), $\chi^2 (1) = .000$, $p > .05$, shunt status, $\chi^2 (1) = .003$, $p >. 05$, or occurrence /nonoccurrence of shunt infections, $\chi^2 (1) = 1.08$, $p > .05$.

Table 1: Child Demographic Information for the Original Sample at Time 1

Characteristic	Child with Spina Bifida n = 140
Age M (SD)	11.40 (2.48)
Gender:	
% Male	46.4
% Female	53.6
Ethnicity:	
% White	53.6
% Hispanic	27.9
% African American	12.9
% Other	5.7
Hollingshead SES, M (SD)	39.7 (15.9)

Child medical information about their physical status was gathered from their medical chart (medical chart release was obtained during the home visit) and from a mother questionnaire. Of the 140 participants, medical chart review indicated that 87.9% had a diagnosis of myelomeningocele, 8.3% lipomeningocele, and 3.8% other. Additionally, over half of the children had spinal lesions in the lumbosacral or lumbar spinal regions (62.9%), 19.0% were sacral, and 18.1% thoracic. Also, 80.3% of the children had a shunt. Mother questionnaire data indicated that 81.1% of the children used braces to ambulate and 61.4% used a wheelchair.

As a part of the study, each family was asked to invite a peer to participate. Inclusion criteria for peers were (1) age six to 17 years at time 1, and (2) ability to speak and read English or Spanish. Families were also asked to invite a peer that was not related to the subject and who was within two years of the child's age, though peers that did not meet these criteria were not excluded from the study. One hundred twenty-one families (86%) identified a peer within the inclusionary age range. Since this study focuses on family dynamics and medical-related information, data obtained from peers will not be utilized in the current study.

Design and Procedure

Data were collected by trained undergraduate and graduate student research assistants over the span of two home visits that each lasted about 3 hours. Families and peers who completed all parts of the study received monetary compensation ($150 for families, $50 for peers) and gifts (e.g. t-shirts and pens). For participant families, informed consent from parents and assent from children were obtained prior to the start of the first home visit at the participant's house. For peers, informed consent from parents

and assent from children were obtained prior to the start of the second home visit at the participant's house. Parents of participants were asked to complete release of information forms to allow for additional data collection from teachers, health professionals and medical charts.

During the first home visit, children with spina bifida and their parents independently completed questionnaires. To maintain confidentiality, family members were asked to fill out questionnaires separately. If needed, research assistants read the questionnaires out loud to the child to ensure that he/she understood the questions. Likert scale responses on a laminated card were also available for the child to use in selecting desired responses.

Families also participated in audio- and video-taped structured interaction tasks. The videotaped interactions consist of four structured tasks: (1) an interactive game, (2) discussion of two age-appropriate vignettes about social situations, (3) discussion of transferring disease-specific responsibilities to the child, and (4) discussion of family conflict issues that were frequently endorsed in on questionnaires (Smetana, Yau, Restrepo, & Braeges, 1991). The last three tasks were counterbalanced for each family.

First, parents and children were asked to play the game "Uno-Stacko". A research assistant explained the rules to the family and then provided a laminated card of the rules for reference. Families were instructed to play until someone won.

For the discussion of two age-appropriate vignettes, families were given two cards that contained two short stories and were asked to answer a series of questions together about the stories. Specific cards were given to families based on child gender (e.g., male children were given stories with male characters). In one story, a child with spina bifida

had to attend a new school where the other children do not know him/her or that he/she has spina bifida. In the other story, a child discovers his/her friend does not want to spend time with him/her. Families were asked to read each story out loud, and then discuss all of the questions together in order. Examples of questions included: "How do you think [the character] is feeling?", "Should [the character] tell anyone about his spina bifida" and "If something like this were to happen to you in the future, what would you do?" Families were given 10 minutes to complete this task.

For the discussion of the sharing of spina bifida responsibilities, families were asked to identify one spina bifida related responsibility that is currently managed by the parent but for which the child will have to take responsibility in the future. After identifying this responsibility, families were asked to discuss how the transfer of this responsibility will take place (e.g., how it will be done and by when it will need to be done). If families were unable to identify a spina bifida responsibility, they were asked to think of other responsibilities that will need to shift from the parent to the child. Families were given five minutes to complete this task.

Prior to the conflict task, families were asked to complete part of their questionnaires, including the Parent-Adolescent Conflict Scale (PAC; Robin & Foster, 1989). Mother, father, and child reports on this questionnaire were examined and scored by a research assistant. Scores were computed for each item by multiplying conflict frequency by intensity. Items with the five highest scores across respondents were selected for the conflict task. The family was then given 10 minutes to discuss three of these five issues (considered to be "hot" topics; Smetana et al., 1991).

During the first home visit, neuropsychological testing of the child was also done. Assessments of the child's IQ, executive functioning, motor functioning, and nonverbal accuracy (i.e., where one was required to identify emotions based on pictures and voices) were conducted. Finally, families were asked to select a peer to participate in the second home visit if one had not already been identified.

Data from the second home visit was not analyzed for this study. During this visit, the child and peer individually completed questionnaires and audio-taped interviews about general friendship characteristics and the specific friendship of the participating target child and peer. Target children and peers engaged in video-taped structured interaction tasks.

Measures

Agreement and disagreement for spina bifida responsibilities: The Sharing of Spina Bifida Management Responsibilities (SOSBMR), an adaptation from the Diabetes Family Responsibility Questionnaire (DFRQ; Anderson et al., 1990) was utilized to examine mother-child agreement and disagreement over who takes primary responsibility for spina bifida medical tasks at Time 1. The SOSBMR consists of 34- items that describe spina bifida or general health-related tasks that are relevant to children with spina bifida (e.g. "Remembering to catheterize regularly, every 2-4 hours"). This measure consists of several domains: health appointments, communication about SB, medications, general needs and self-care, ambulation, skin care, catheterization, bowel management, and exercise and diet. Parents and children independently rated who was primarily responsible for each task (e.g. Parent, Child, Equal, or Not Applicable). This measure

was found to have acceptable alphas in the current study (α =.89 for mothers and α =.90 for children). For this study, mother and child SOSMBR responses were evaluated at the item level. Disagreements between father and child SOSBMR reports were not investigated.

Levels of agreement and disagreement were calculated by using the procedure outlined by Devine and colleagues (2011). Mother and child responses were compared at the item level and responses from each dyad were placed in 1 of 9 combinations (see Figure 1). To accomplish this, new variables were created for each of the nine possible agreement/disagreement levels for each of the 34 items on the SOSBMR. If dyads fulfilled the response criteria (e.g. a mother gave the item a "1" and a child gave the item a "1"), one of the newly created variables would be assigned a 1). For instance, if mothers and children both stated that the child was responsible for the task, the dyad would receive a '1' in cell 1 of Figure 1. After dyad's responses on each of the 34 items were analyzed in this way, the total number of responses in each of the nine matrix boxes was summed. The proportion of responses in each category was calculated by dividing the total number of responses from one category by the total number of responses in all nine categories (maximum number of responses = 34). The proportion of responses in each category was calculated to control for the number of items answered. In this way, "not applicable" responses or skipped items did not affect mother-child total agreement and disagreement scores. For this study, categories of full agreement or disagreement were utilized (i.e. cells 1, 3, 5, 7, and 9 in Figure 1). The remaining four categories (i.e., cells 2, 4, 6, and 8) were not analyzed, as the disagreements in these categories were less profound. For instance, a response in cell 2 would indicate that the mother marked item

as shared responsibility and the child marked the item as child responsibility. Though this represents a disagreement over how involved the mother is in the task (e.g., partial or no involvement), the dyad also agreed that the child is responsible to some extent (e.g., partial or total involvement). Thus, these types of disagreements were less severe than the categories of full disagreement and were not utilized in this investigation.

Family Conflict (Questionnaire data): Family conflict was assessed in two ways: through the use of Time 1 questionnaire data and coded family interactions from a videotape. Additionally, since past research suggests that parents and children do not always interpret family conflict in the same way (Smetana, 1989), both mother and child questionnaire data were utilized.

The Parent-Adolescent Conflict scale (PAC), a brief version of the Issues Checklist (IC; Robin & Foster, 1989) was separately completed by mothers and children at the first time point. The PAC broadly measures conflict by asking informants to respond to 15 potential conflict issues that are commonly discussed in all families during adolescence (e.g. whether or not the child does chores around the house) and 10 potential conflict issues that are typically discussed in families of children with spina bifida (e.g. how he/she does his/her catheterization). For each issue, respondents are asked to indicate whether or not the issue was discussed in the past 2 weeks. If the issue had been discussed, respondents are asked how many times the issue was discussed and how intense those conversations were. Intensity is rated on a Likert scale (ranging from "calm" to "angry"). Items on the PAC are organized into two subscales: medical conflict and non-medical conflict. Alpha coefficients are not available for this measure, as each

family member only answers items that they have personally discussed and each respondent does not answer every item.

Family Conflict (Observational data): This study also investigated family conflict by evaluating family interaction tasks from Time 1. Each interaction task was coded by a trained undergraduate or graduate research assistant, using the Family Interaction Macro-coding System (FIMS; Holmbeck et al., 2007) an adaptation of the coding system developed by Smetana et al. (1991). Research assistants received approximately 10 hours of training prior to coding the video tapes. Training included the coding of previously coded interactions and discussing each code with an expert coder. Coders are instructed to view one interaction at a time and then rate the interaction on a variety of dimensions. The FIMS consists of 113 separate codes that are grouped into 6 domains: interaction style, conflict, affect, control, parental behaviors and collaborative problem solving, and summary family measures. Acceptable interrater reliabilities have been found for FIMS subscales (reliability coefficients ranging from .53 to .90 for parental scores and .46 to .87 for family-level scores). For this project, the broad family conflict dimension across all four tasks was utilized. This measure was found to have acceptable internal consistency for this study ($\alpha = .73$).

Medical Adherence: The Spina Bifida Self-Management Profile (SBSMP; Wysocki & Gavin, 2006) was used to measure adherence to spina bifida medical treatments at Time 1. The SBSMP is a 14-item, structured interview that addresses seven dimensions of spina bifida medical regimen, including appointment keeping, bowel control program, skin and wound care, exercise, medications, clean intermittent catheterization, and dealing with urinary tract infections. When developing this measure,

item content, wording, and scoring was developed based on a consultation with Dr. Wysocki (the developer of the original version of this measure for youth with type 1 diabetes). For this study, the SBSMP was administered as a questionnaire rather than an interview and mother responses were evaluated. Total scores were transformed into z-scores because scales varied for each item (e.g. 4, 5 and 6-point scales). Due to a low number of participants completing each individual item (i.e., parents selecting "not applicable" for certain items), scale reliability was unable to be computed.

Child's Cognitive Ability: The Wechsler Abbreviated Scale of Intelligence (WASI; Wechsler, 1999) was used as a measure of child cognitive ability at time 1. In this investigation, child cognitive ability was controlled for, as cognitive ability may influence the child's ability to understand and respond to questionnaire measures accurately. The WASI consists of a vocabulary subtest and a matrix reasoning subtest. The vocabulary subtest is similar to the Vocabulary subtests of the Wechsler Intelligence Scale for Children (WISC-III) and the Wechsler Adult Intelligence Scale (WAIS-III), with the exception that the WASI subtest includes low-end picture items. The WASI vocabulary subtest is used to measure child's expressive vocabulary and verbal knowledge. Additionally, it is an adequate measure of crystallized and general intelligence. The average internal consistency reliability coefficient for children 6-16 years old was .89. The matrix reasoning subtest is similar to the Matrix Reasoning subtest of the WAIS-III. This subtest is a visual information processing/abstract reasoning task that requires the examinee to process and organize 34 visual patterns with shapes. Matrix Reasoning is a measure of nonverbal fluid reasoning and general

intellectual ability. The average internal reliability coefficient for children 6-16 years old was .92.

Spina bifida severity: In spina bifida, the following variables are often used to assess severity: lesion level (i.e., sacral, lumbar, thoracic), type of spina bifida (i.e., myelomeningocele, meningocele, lipomeningocele), shunt status, total number of shunt surgeries, and ambulation method (e.g., braces, wheelchair, no ambulation method; Hommeyer, Holmbeck, Wills, & Coers, 1999). As lesion level has been associated with different independence outcomes in young adults with spina bifida (Verhoef et al., 2007), lesion level was controlled for in this study. Medical chart data was used to assess lesion level.

Demographics: Parents of children with spina bifida completed a questionnaire that assessed a variety of demographic factors about themselves, their child, and their family. Information about the parent included: relationship to child, marital status, education, employment status and income. Information about the child included: date of birth, race/ethnicity, school, and grade. Information about the family included: family medical history and the number and relation of people living in the home. The Hollingshead Four Factor Index of socioeconomic status was used to assess socioeconomic status (SES), based on parents' education and occupation (Hollingshead, 1975). Higher scores indicated higher SES. Due the large age range of the children in this study (i.e., children between the ages of 8 to 15), child age was controlled in this investigation

CHAPTER FOUR

RESULTS

Statistical Treatment

Regression analyses were used to test most of the hypotheses of this study. A power analysis was used to assess whether the sample size was appropriate for the following statistical analyses (Aiken & West, 1991; Cohen, 1992). Since this study focuses on mothers and children with spina bifida, power was computed based on the number of mother-child dyads who completed the SOSBMR at Time 1, N = 111. Assuming a power of .80, an alpha of .05, and an estimated R^2 of .15 (a medium effect size), a sample of 97 is required for the most complex analyses (6 predictors and a single outcome) (Cohen, 1992). Therefore, the current study has enough power to detect a medium effect size.

Preliminary Analyses

Medical and Non-medical Conflict

Prior to examining the main hypotheses of the study, the relationships between medical and non-medical conflict were examined separately for mother and child self-report. As measured by the PAC, child reported medical and non-medical conflict were significantly correlated, $r = .46$, $p = .00$. Mother reported medical and non-medical conflict were also significantly correlated, $r = .50$, $p = .00$.

33

Thus, medical and non-medical conflict scores were combined to form general measures of mother- and child reported conflict. Combined scores were used in all analyses examining mother or child self-reported family conflict

Evaluating Agreement and Disagreement Levels

Descriptive statistics were used to evaluate the average proportion of responses in each of the five categories of full agreement and disagreement. On average, the category with the highest proportion of responses was cell 9 (i.e. "Agree, mother responsible"), with 28.15% of responses. Cell 1 (i.e. "Agree, child responsible") received 16.74% of responses and cell 5 (i.e. Agreement that the responsibility is shared) received 12.01% of responses. Disagreement categories had the smallest proportion of responses, with 7.28% of responses in cell 7 (i.e. "Both report that someone else is in charge) and 2.28% of responses in cell 3 (i.e. "Both report being responsible").

The relationships between levels of full agreement or disagreement and continuous covariates (i.e., age and IQ) were also evaluated. Agreement that the child was responsible for medical tasks was positively correlated with age ($r = .48$, $p = .00$) and IQ ($r = .20$, $p = .03$). Agreement that the responsibility belonged to the mother was negatively associated with age ($r = -.48$, $p = .00$) and IQ ($r = -.21$, $p = .03$). However, agreement that the responsibility was shared was not associated with age ($r = .09$, $p > .05$) or IQ ($r = .17$, $p > .05$). Mother and child disagreement in cell 3 ("Both report being responsible") was also unrelated to age ($r = -.11$, $p > .05$) and IQ ($r = -.14$, $p > .05$). Mother and child disagreement in cell 7 ("Both reported that someone else is in charge) was negatively related to IQ ($r = -.26$, $p = .01$), but unrelated to age ($r = .09$, $p > .05$).

Hypotheses Testing

Hypothesis I

It was expected that both types of mother-child disagreements over the perceived

responsibility for spina bifida medical tasks (i.e., cells 3 and 7 in Figure 1) would be

related to family conflict. It was also expected that mother-child agreement (i.e., cells 1, 5

and 9 in Figure 1) would be negatively related to family conflict. To test the first

hypothesis, linear regression analyses were conducted. The predictors for the regression

analyses included child age, IQ, and lesion level (covariates) and mother-child

disagreement ("Both report being responsible" or "Both report that someone else is in

charge") or agreement (e.g. "Agree, child responsible", "Agree, both responsible", or

"Agree, parent responsible"). Lesion level was dummy coded so that individuals with

sacral lesions were compared to those with lumbar lesions and individuals with thoracic

lesions were compared to those with lumbar lesions. Agreement and disagreement

predictors were evaluated in separate regression analyses, yielding a total of 15

regression analyses (i.e., five levels of agreement/disagreement and three types of

conflict).

Mother Self-Report Conflict: For mother self-report of conflict on the PAC,

agreement that the child was responsible was nonsignificant ($B = .08$, $\beta = .03$, $t\,[106] =$

$.21$, $p > .05$), as was agreement that the mother was responsible ($B = -.28$, $\beta = .01$, $t\,[106]$

$= .11$, $p > .05$), and agreement that the responsibility was shared ($B = -.37$, $\beta = -.09$, t

$[106] = -.91$, $p > .05$). Disagreement in cell 3 ("Both report being responsible") was also

nonsignificant ($B = .86$, $\beta = .06$, $t\,[106] = .62$, $p > .05$), as was disagreement in cell 7

("Both report that someone else is in charge"; $B = .43$, $\beta = .08$, $t\,[106] = .73$, $p > .05$).

Child Self-Report Conflict: For child self-report of conflict on the PAC, agreement that the child was responsible (B = -.26, β = -.08, t [106] = -.66, p > .05), agreement that the mother was responsible (B = .23, β = .08, t [106] = .64, p > .05), and agreement that the responsibility was shared (B = -.21, β = -.05, t [106] = -.48, p > .05) did not predict conflict. Disagreement in cell 3 ("Both report being responsible") was also nonsignificant (B = -.22, β = -.02, t [106] = -.20, p > .05), as was disagreement in cell 7 ("Both report that someone else is in charge"; B = .67, β = .12, t [106] = 1.13, p > .05).

Observational Measures of Conflict: Agreement that the child was responsible (B = -.08, β = -.03, t [107] = -.26, p > .05) was unrelated to observations of family conflict, as was agreement that the mother was responsible (B = .04, β = .02, t [107] = .13, p > .05) and that the responsibility was shared (B = -.63, β = -.18, t [107] = -1.81, p > .05). Disagreement in cell 3 ("Both report being responsible"; B = 1.00, β = .11, t [107] = 1.16, p > .05) and disagreement in cell 7 ("Both report that someone else is in charge"; B = .62, β = .13, t [107] = 1.32, p > .05) were also nonsignificant. Therefore, the first hypothesis was not supported. Mother-child agreement and disagreement over the sharing of spina bifida medical responsibilities was not related to conflict of any type.

Hypothesis II

It was hypothesized that mother-child disagreement in perceived responsibility of spina bifida medical regimen would result in lower levels of medical adherence. It was also hypothesized that mother-child agreement would result in higher levels of medical adherence. To test the second hypothesis, linear regression analyses were conducted. The predictors for the regression analyses included child age, IQ, and dummy-coded lesion

level (covariates) and mother-child disagreement ("Both report being responsible" or "Both report that someone else is in charge") or agreement (e.g. "Agree, child responsible", "Agree, both responsible", or "Agree, parent responsible"). The dependent variable was mother-reported adherence to spina bifida medical regimen. All regressions were run separately for each disagreement or agreement variable.

It was found that agreement that the child was responsible for spina bifida medical tasks was significant (B = -.69, β = -.24, t [108] = -2.04, $p < .05$), suggesting that mother-child agreement that the child was responsible was associated with poorer medical adherence. However, agreement that the mother was responsible (B = .28, β = .11, t [108] = .91, $p > .05$) and that the responsibility was shared (B = .43, β = .11, t [108] = 1.14, $p > .05$) were nonsignificant. Disagreement in cell 3 ("Both report being responsible"; B = -.80, β = -.08, t [108] = -.85, $p > .05$) and disagreement in cell 7 ("Both report that someone else is in charge"; B = .24, β = .05, t [108] = .46, $p > .05$) were also nonsignificant. Although one of the regression analyses was significant (i.e., mother-child agreement that the child was responsible), the direction of the relationship was the opposite of what was expected. Furthermore, all other analyses were nonsignificant. Thus, the second hypothesis was not supported.

Hypothesis III

It was expected that family conflict would mediate associations between mother-child disagreements or agreements and medical adherence (see Figure 2). Although mother-child disagreements were expected to be associated with poorer medical adherence, it was expected that the relation between disagreements and medical adherence would be significantly reduced when controlling for conflict. In addition, the

relation between mother-child agreement and higher levels of medical adherence would be significantly reduced when controlling for conflict.

Proposed mediation models could not be tested in their entirety because levels of agreement and disagreement were unrelated to medical adherence, with the exception of mother-child agreement that the child was responsible (see hypothesis II). Additionally, the pathways between mother-child disagreement and agreement levels and family conflict were not supported (see hypothesis I). Linear regression analyses were conducted to determine whether the final pathway between family conflict and medical adherence was supported. The predictors for the regression analyses included child age, IQ, and dummy-coded lesion level (covariates) and family conflict (i.e. mother self-report, child self-report and an observational measure). The dependent variable was mother-reported adherence to spina bifida medical regimen. All regressions were run separately for each conflict variable.

It was found that mother self-report of family conflict was significantly related to medical adherence ($B = -.19$, $\beta = -.20$, t [113] = -2.22, $p < .05$). However, child self-report of family conflict was nonsignificant ($B = -.04$, $\beta = -.05$, t [111] = -.54, $p > .05$), as was the observational measure of family conflict ($B = -.06$, $\beta = -.05$, t [114] = -.57, $p > .05$). Thus, the final pathway of the mediational model was only significant for mother self-report of family conflict.

Hypothesis IV

It was hypothesized that family conflict would moderate associations between mother-child agreement and disagreement and medical adherence. That is, the relationship between mother-child agreement/disagreement levels and medical adherence

would depend on the presence of low or high family conflict. To test this hypothesis, procedures outlined by Aiken and West (1991) were followed for testing interactions using multiple regression. Specifically, the independent variables were centered (by subtracting the appropriate sample means) and centered predictors were used in the analyses. The predictors for the regressions were child IQ, age and dummy-coded lesion level (covariates), family conflict (mother self-report, child self-report or observational data), centered agreement or disagreement variables and the interaction term: Agreement/Disagreement x Conflict. The dependent variable was mother-reported medical adherence. All regressions were run separately for each conflict variable and each agreement or disagreement variable, yielding a total of 15 equations. If a significant moderation effect was found for any of the 15 interaction equations, then post-hoc analyses were conducted to test the nature of the interaction (Holmbeck, 2002).

Agreement, Child Responsible: For mother-self report of family conflict, it was found that the main effects of agreement that the responsibility belonged to the child and conflict were significantly related to medical adherence (see Table 2). The main effect of agreement remained significant when evaluating child-report of conflict and the observational measure of conflict as moderators. However, the main effects of child-report of conflict and the observational measure of conflict predicting medical adherence were not significant. The Agreement (Child) x Conflict (Mother Report) interaction was nonsignificant, as was the Agreement (Child) x Conflict (Child Report) interaction. A significant Agreement (Child) x Observational Conflict interaction was found ($B = 1.61$, $\beta = .24$, t [107] = 2.56, $p = .01$), suggesting that the relationship between agreement that

the child was responsible and medical adherence depends on the presence of high or low

family conflict.

Table 2: Regression Analyses for Hypothesis IV, Agreement (Child Responsible) x Conflict Predicting Spina Bifida Medical Adherence

Predictor	B	β	t	P
IV = Mother Self-report Conflict				
Covariate: Thoracic v. Lumbar	-.05	.22	2.25	.03*
Covariate: Sacral v. Lumber	-.20	-.15	-1.56	.12
Covariate: IQ	-.00	-.09	-.97	.34
Covariate: Age	-.00	-.01	-.09	.93
Agreement (Child Responsible)	-.71	-.25	-2.10	.04*
Conflict	-.18	-.19	-2.02	.05*
Agreement (Child Responsible) x Conflict	.88	.15	1.53	.13
IV = Child Self-report Conflict				
Covariate: Thoracic v. Lumbar	.34	.22	2.29	.02*
Covariate: Sacral v. Lumber	-.19	-.14	-1.48	.14
Covariate: IQ	-.00	.09	-.87	.39
Covariate: Age	-.00	-.02	-.15	.88
Agreement (Child Responsible)	-.69	-.23	-2.01	.05*
Conflict	-.03	-.04	-.39	.70
Agreement (Child Responsible) x Conflict	.09	.02	.18	.86
IV = Observational Measure of Conflict				
Covariate: Thoracic v. Lumbar	.35	.23	2.43	.02*
Covariate: Sacral v. Lumber	-.21	-.15	-1.59	.12
Covariate: IQ	-.00	-.09	-.88	.38
Covariate: Age	-.00	-.01	-.13	.90
Agreement (Child Responsible)	.68	-.23	-1.98	.05*
Conflict	-.10	-.09	-.93	.35
Agreement (Child Responsible) x Conflict	1.61	.24	2.56	.01*

* = significant

To evaluate the nature of the significant Agreement (Child) x Observational Conflict interaction, two variables were calculated to represent participant's one standard deviation above (i.e., high conflict) and below (i.e., low conflict) the mean of the observational measure of conflict (Aiken & West, 1991). Analyses were run in which the newly computed high and low conflict variables were separately entered into regression equations, replacing the original conflict variable. Simple slope tests revealed that agreement that the child was responsible was only related to medical adherence for families with low conflict, $B = -1.38$, $\beta = -.47$, $t(107) = -3.21$, $p = .00$. For families with high conflict, there was no relation between agreement that the child was responsible and medical adherence, $B = .07$, $\beta = .02$, $t(107) = .14$, $p > .05$. The results of the simple slope analyses suggest that the relationship between agreement levels and medical adherence depends on levels of family conflict (see Figure 5). Specifically, youth with the highest level of medical adherence had fewer agreements with their mothers that they were responsible and low family conflict.

Figure 4: Predicting medical adherence from agreement that child is responsible for SB medical tasks and observations of family conflict.

Agreement: Child Responsible
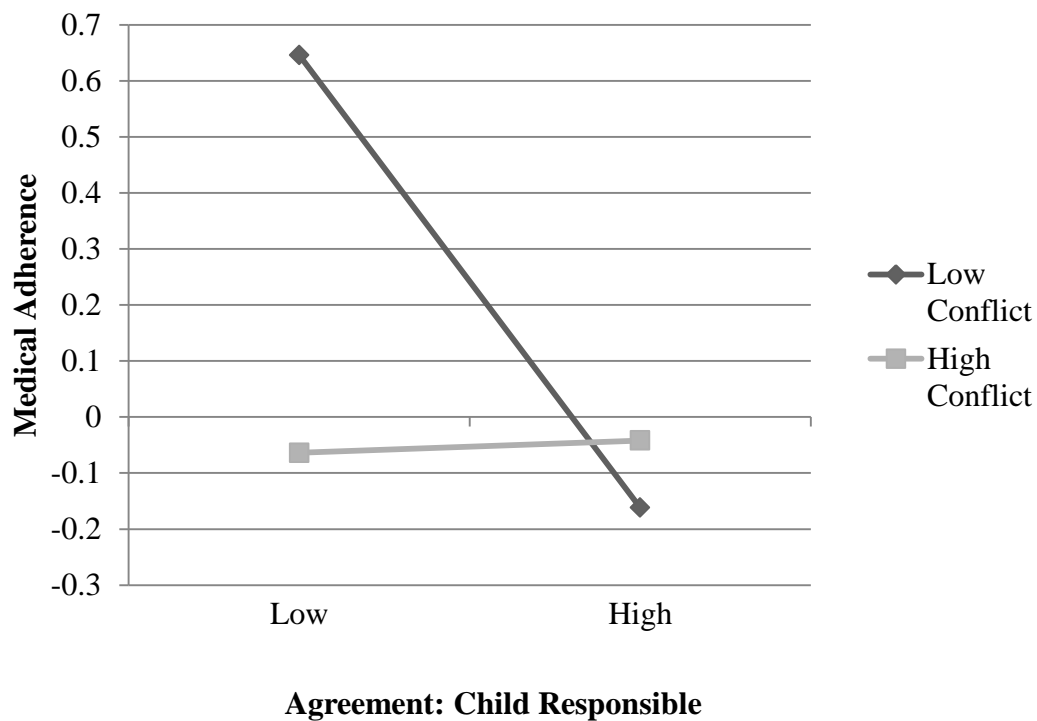
Low in conflict, β = -.468, p = .00.

Note. Negative values were observed because z-scores for medical adherence were utilized

Agreement, Parent Responsible: The main effect of agreement that the responsibility belonged to the mother was not related to medical adherence for any of the three moderation analyses (see Table 3). However, the main effect of conflict was significant for mother-report of conflict, though child-report and the observational measure were not significant. The Agreement (Parent) x Conflict (Child Report) interaction was also nonsignificant, as was the Agreement (Parent) x Observational Conflict interaction. A significant Agreement (Parent) x Conflict (Mother Report) interaction was found, suggesting that the relationship between agreement that the child was responsible and medical adherence depends on the presence of high or low mother-reported family conflict.

Table 3: Regression Analyses for Hypothesis IV, Agreement (Mother Responsible) x
Conflict Predicting Spina Bifida Medical Adherence

Predictor	*B*	β	*t*	*p*
IV = Mother Self-report Conflict				
Covariate: Thoracic v. Lumbar	.33	.22	2.25	.03*
Covariate: Sacral v. Lumber	-.20	-.15	-1.56	.12
Covariate: IQ	-.00	-.09	-.97	.34
Covariate: Age	-.00	-.01	-.09	.93
Agreement (Parent Responsible)	.28	-.11	-2.10	.37
Conflict	-.19	-.19	-2.02	.04*
Agreement x Conflict	-1.00	-.21	1.53	.04*
IV = Child Self-report Conflict				
Covariate: Thoracic v. Lumbar	.34	.22	2.29	.02*
Covariate: Sacral v. Lumber	-.19	-.14	-1.48	.14
Covariate: IQ	-.00	.09	-.87	.39
Covariate: Age	-.00	-.02	-.15	.88
Agreement (Parent Responsible)	.29	.11	.90	.37
Conflict	-.03	-.03	-.31	.76
Agreement x Conflict	.07	.02	.16	.87
IV = Observational Measure of Conflict				
Covariate: Thoracic v. Lumbar	.35	.23	2.43	.02*
Covariate: Sacral v. Lumber	-.21	-.15	-1.59	.12
Covariate: IQ	-.00	-.09	-.88	.38
Covariate: Age	-.00	-.01	-.13	.90
Agreement (Parent Responsible)	.29	.11	.93	.36
Conflict	-.10	-.09	-.88	.38
Agreement x Conflict	-.56	-.10	-1.08	.28

* = significant*

To evaluate the nature of the significant Agreement (Parent) x Conflict (Mother Report) interaction, two variables were calculated to represent participant's one standard deviation above (i.e., high conflict) and below (i.e., low conflict) the mean of mother-reported family conflict (Aiken & West, 1991). Analyses were run in which the newly computed high and low conflict variables were separately entered into regression equations, replacing the original conflict variable. Simple slope tests revealed that agreement that the mother was responsible was only related to medical adherence for families with low conflict, $B = .83$, $\beta = .33$, $t(106) = 2.08$, $p < .05$. For families with high conflict, there was no relation between agreement that the mother was responsible and medical adherence, $B = -.27$, $\beta = -.11$, $t(106) = -.68$, $p > .05$. The results of the simple slope analyses suggest that the relationship between agreement levels and medical adherence depends on levels of family conflict (see Figure 6). Specifically, families who have more agreement that parents are responsible for spina bifida medical regimen and low levels of conflict are the most adherent to spina bifida medical care.

Figure 5: Predicting medical adherence from agreement that mother is responsible for SB medical tasks and mother reported family conflict.

Agreement: Mother Responsible
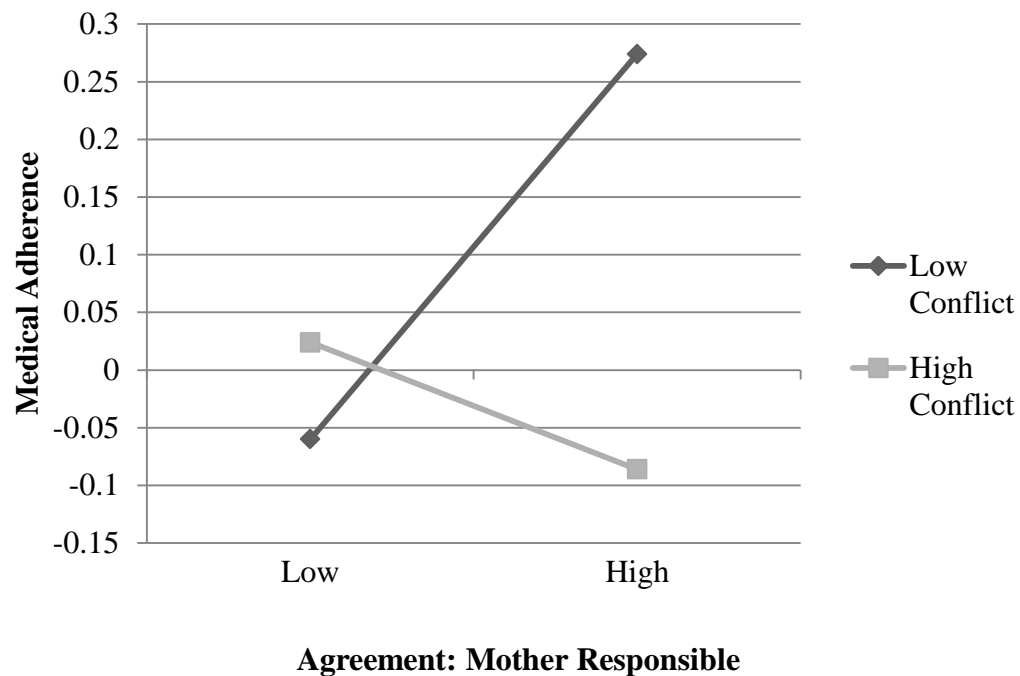
Low in conflict, $\beta = .325$, $p < .05$.

Note. Negative values were observed because z-scores for medical adherence were utilized

Agreement, Shared Responsibility: The main effect of agreement that the responsibility was shared was not related to medical adherence for all moderation analyses (mother-reported conflict as the moderator, $B = .33$, $\beta = .09$, t [106] = .88, $p >$ .05; child-reported conflict as the moderator, $B = .42$, $\beta = .11$, t [106] = 1.10, $p > .05$; observational measure of conflict as the moderator, $B = .41$, $\beta = .10$, t [107] = 1.06, $p >$ .05). However, the main effect of mother-reported conflict was significant ($B = -.19$, $\beta = -$ .19, t [106] = -2.04, $p < .05$). The main effect of child-reported conflict ($B = -.02$, $\beta = -$ .02, t [106] = -.20, $p > .05$) and the observational measure of conflict ($B = -.07$, $\beta = -.07$, t [107] = -.69, $p > .05$) were not significant. No interaction terms were significant when evaluating conflict moderating the relationship between agreement that the responsibility was shared and medical adherence (Agreement x Mother-Report Conflict, $B = .61$, $\beta = $ .08, t [106] = .86, $p < .05$; Agreement x Child-Report Conflict interaction, $B = -.15$, $\beta = -$ .02, t [106] = -.22, $p > .05$; Agreement x Observational Conflict, $B = .42$, $\beta = -.04$, t [107] = .43, $p > .05$).

Disagreement, "Both Report being Responsible": The main effect of disagreement in cell 3 did not predict medical adherence when evaluating mother-report of conflict as the moderator ($B = -.19$, $\beta = -.19$, t [106] = -2.04, $p > .05$), child-report of conflict as the moderator ($B = -.79$, $\beta = -.08$, t [106] = -.83, $p > .05$), or the observational measure of conflict as the moderator ($B = -.70$, $\beta = -.07$, t [107] = -.73, $p > .05$). Although the main effect of mother-reported conflict was significant ($B = .86$, $\beta = .06$, t [106] = .62, $p < .05$), child-report of family conflict ($B = -.02$, $\beta = -.03$, t [106] = -.27, $p > .05$) and the observational measure of conflict ($B = -.09$, $\beta = -.08$, t [107] = -.87, $p > .05$) were

not significantly related to medical adherence. The Disagreement x Mother-Report

Conflict interaction term was also nonsignificant (B = .88, β = .15, t [106] = 1.53, p >

.05), as was Disagreement x Observational Conflict interaction (B = -1.87, β = -.07, t

[107] = -.76, p > .05). However, the Disagreement x Child-Report Conflict interaction

approached significance (B = -3.20, β = -.17, t [106] = -1.71, p = .09).

 Disagreement, "Both Report Someone Else is in Charge": The main effect of

disagreement in cell 7 did not predict medical adherence when evaluating mother-report

of conflict as the moderator (B = .36, β = .07, t [106] = .46, p > .05), child-report of

conflict as the moderator (B = .26, β = .05, t [106] =.50, p > .05), or the observational

measure of conflict as the moderator (B = .33, β = -.06, t [107] = .63, p > .05). The main

effect of mother-reported conflict was significantly related to medical adherence (B = -

.19, β = -.19, t [106] = -2.04, p < .05), though the main effect of child-reported conflict (B

= -.03, β = -.03, t [106] = -.31, p > .05) and the observational measure of conflict (B = -

.03, β = -.03, t [106] = -.31, p > .05) were not significant. All Disagreement x Conflict

interactions were not significant: Disagreement x Mother-Report Conflict, B = .88, β =

.15, t [106] = 1.53, p < .05; Disagreement x Child-Report Conflict, B = .51, β = .05, t

[106] = .52, p > .05; Disagreement x Observational Conflict, B = -.65, β = -.05, t [107] =

-.48, p > .05.

<div align="center">Exploratory Analyses</div>

Curvilinear Analyses

 After examining the main hypotheses of this study, exploratory analyses were

conducted to determine whether the relationship between mother-child

agreement/disagreement and the dependent variables was curvilinear. Since the majority of the findings did not support a linear relationship between mother-child disagreement and conflict, or mother-child disagreement and medical adherence, curvilinear analyses were conducted to determine if a quadratic curvilinear effect was present. Possibly, mother-child disagreements over the child's autonomy with his or her medical care were adaptive to a point (as this allows parents and child to realign their perceptions to more age-appropriate expectations) but became maladaptive once disagreements reach a certain prevalence.

Each of the five variables of full agreement and disagreement were squared to test whether a quadratic curvilinear effect was present for mother-child agreement/disagreement and family conflict, and mother-child agreement/disagreement and medical adherence. Variables were entered the same way as they were for the main hypotheses of the study: the predictors included child age, IQ, and dummy-coded lesion level (covariates) and the squared agreement/disagreement term. The dependent variables were family conflict (i.e., mother self-report, child self-report and an observational measure) or medical adherence.

Significant curvilinear effects were not found for agreement/disagreement variables predicting medical adherence ($p > .05$), mother-reported family conflict ($p > .05$), child-reported family conflict ($p > .05$), or the observational measure of family conflict ($p > .05$). However, a quadratic curvilinear effect approaching statistical significance was found for the "Both report that someone else is in charge" disagreement predicting child-reported family conflict, $B = -7.07$, $\beta = -.44$, t [106] $= -1.82$, $p = .07$.

This negative quadratic curve suggests that too little or too much of the "Both report that someone else is in charge" disagreements results in poorer medical adherence.

T-Tests: SOSBMR Subscale and Total Scores

Although the primary focus of this study was to evaluate mother-child agreement and disagreement at the item level, another approach for assessing informant agreements and disagreements is to compare total or subscale scores. Paired samples t-tests were conducted to determine if SOSBMR total scores differed for mothers and children, as well as SOSBMR subscale scores (i.e., health appointments, communication about spina bifida, medications, general needs and self-care, ambulation, skin care, catheterization, bowel management, and exercise and diet).

Mother ($M = 1.76$) and child ($M = 1.97$) total scores on the SOSBMR were found to be significantly different, $t (111) = -5.42$, $p = .00$. That is, children rated themselves as more independent than their mother's rated their child's independence. Mother and child reports on particular subscales of the SOSBMR were also found to be statistically different, such as mother ($M = 1.11$) and child ($M = 1.25$) reports of responsibilities for appointment keeping ($t [107] = -3.03$, $p = .00$), mother ($M = 1.57$) and child ($M = 2.06$) reports of responsibilities for communication about spina bifida ($t [108] = -7.43$, $p = .00$), mother ($M = 1.38$) and child ($M = 1.75$) reports of responsibilities for medications ($t [105] = -4.93$, $p = .00$), mother ($M = 2.07$) and child ($M = 2.31$) reports of responsibilities for ambulation ($t [98] = -3.69$, $p = .00$), and mother ($M = 1.66$) and child ($M = 2.02$) reports of responsibilities for bowel management ($t [109] = -5.50$, $p = .00$). Across all of these domains, children rated themselves as more independent than mother's rated the children. Mother and child subscale scores were not significantly different for general

needs and self-care (t [103] = -.83, $p > .05$), skin care (t [101] = .02, $p > .05$),

catheterization (t [101] = -.79, $p > .05$), and exercise and diet (t [69] = -1.50, $p > .05$).

CHAPTER FIVE

DISCUSSION

Although informant disagreements have been observed across different informants, behaviors, and assessment tools, little is known about the implications of differing perspectives of child behavior on particular outcomes (De Los Reyes & Kazdin, 2005).This study attempted to address this limitation by examining mother-child agreement and disagreement over the sharing of spina bifida responsibilities in relation to family conflict and spina bifida medical adherence. Levels of mother-child agreement and disagreement about the child's independence with spina bifida medical responsibilities were examined during late childhood and early adolescence, as disagreements were expected to be present during this stage of development when parents begin to transfer medical responsibilities to their child (Anderson et al., 2009; Stepansky et al., 2010). This study expanded the current literature by investigating the implications of informant agreement and disagreement on outcomes of interest, utilizing a more fine-grained methodology for calculating mother-child agreement and disagreement at the item level (Devine et al., 2011), and employing a multi-method and multi-informant approach for evaluating the moderating and mediating role of family conflict on the relationship between mother-child agreement/disagreement and medical adherence.

52

Based on the small body of literature that has found associations between informant discrepancies and increased family conflict (e.g., Grills & Ollendick, 2002; Miller & Drotar, 2003) and poor medical adherence (Butner et al., 2009; Anderson et al., 2009), it was hypothesized that mother-child disagreements would relate to high level of family conflict (Hypothesis I) and poor medical adherence (Hypothesis II). On the other hand, high levels of mother-child agreement were expected to be associated with less family conflict and higher medical adherence, as communication in these families has kept up with the transfer of medical responsibilities from parent to child. It was also hypothesized that family conflict would mediate the relationship between mother-child agreement/disagreement levels and medical adherence (Hypothesis III). In other words, families who were unable to resolve disagreements effectively would be less likely to adhere to medical recommendations due to the ensuing conflict over divergent perspectives of child medical autonomy. Conversely, mother-child dyads with high levels of agreement would have less family conflict and therefore, higher medical adherence. It was also hypothesized that family conflict would moderate the relationship between mother-child agreement/disagreement levels and medical adherence. Mother-child dyads with high levels of disagreement and high levels of conflict were expected to have the poorest medical adherence, whereas dyads with high agreement levels and low conflict were expected to have the highest adherence to medical recommendations.

During this developmental period, 57.25% of responses fell into the categories of full agreement (i.e., agreement that the mother was responsible, agreement that the child is responsible, or agreement that the responsibilities are shared) and less than 10% of responses fell in the two categories of full disagreement (see Figure 1). Consistent with

spina bifida sample examined by Devine and colleagues (2011), the average scores for disagreement categories and the average score for the category of full agreement that the responsibility belonged to the child were small. Additionally, mother-child dyads were most likely to agree that the responsibility belonged to the mother. Exploratory analyses revealed that mother and child total scores and subscale scores on the measure were significantly different. Overall, youth viewed themselves as more independent than mothers did, as well as more independent in specific domains (i.e., communication about spina bifida, medications, ambulation, and bowel management responsibilities). These findings complement the results of Devine and colleagues (2011) by suggesting that mother-child disagreements surrounding child autonomy are salient for youth with spina bifida during early adolescence. Since early adolescence is typically characterized by the transition of medical responsibilities from parent to child (Stepansky et al., 2009), it is not surprising that youth with spina bifida and their mothers possessed differing perceptions of who was primarily responsible for specific medical tasks.

<div align="center">Mother-Child Disagreement</div>

Contrary to the main hypotheses of this study, mother-child disagreements over responsibilities for spina bifida medical tasks were not associated with any of the three measures of family conflict (i.e., mother report, child report, or the observational measure; Hypothesis I) or medical adherence (Hypothesis II). Furthermore, conflict did not mediate (Hypothesis III) or moderate (Hypothesis IV) the relationship between mother-child disagreements and medical adherence. Exploratory analyses revealed that curvilinear analyses were also nonsignificant, suggesting that there was neither a linear nor curvilinear relationship between mother-child disagreements and the outcomes of this

study. Contrasting past research that has found associations between parent-child disagreements over perceived child autonomy and family conflict (e.g., Holmbeck & O'Donnell, 1991; Miller & Drotar, 2003) and associations between parent-child disagreements over perceived child autonomy and diabetes medical adherence (Butner et al., 2009; Anderson et al., 2009), this study failed to replicate these findings.

Although youth with spina bifida generally viewed themselves as more independent than their mothers viewed them, varying perceptions of child medical autonomy did not relate to family conflict during this developmental period. It has been suggested that parent-child discrepancies in perceptions of adolescent autonomy are resolved through the confrontation and negotiation that takes place during family conflicts (Holmbeck & O'Donnell, 1991). For families of children with spina bifida, disagreements over medical responsibilities did not appear to be resolved this way. It is possible that the lack of association between mother-child disagreements and family conflict can be attributed to the unique dynamics between the child with spina bifida and his or her parents. For instance, characteristics of the child with spina bifida (i.e., passive, and less self-reliant and independent; Holmbeck et al., 2003) and mothers of children with spina bifida (i.e., intrusive; Holmbeck et al., 2002b) may prevent disagreements from escalating to conflict and negatively affecting medical adherence. Considering that youth with spina bifida tend to be more passive and withdrawn in family interactions (Holmbeck et al., 2003), these children may be less likely to seek autonomy from their parents by articulating their points of view. On the other hand, it has been found that mothers of youth with spina bifida view their child as vulnerable because of their illness (Thomasgard & Metz, 1995; Holmbeck et al., 2002b), and tend to be more intrusive than

mothers of typically developing children (Holmbeck et al., 2003). In light of these characteristics, it is possible that mothers of youth with spina bifida "pick up the slack" without confronting their child when the child fails to follow through on a certain medical responsibilities. Taken together, the dynamics between youth with spina bifida and their mothers may prevent disagreements over medical responsibilities from escalating to conflict, as youth are less likely to assert their needs for autonomy and mothers are less likely to push their child to accomplish tasks independently.

However, given the cross-sectional nature of this study, it is unclear whether the lack of conflict over differing perceptions of child medical autonomy is adaptive over time. For instance, parent-child disagreements over child autonomy and the ensuing conflict are thought to be a normal and beneficial process of growth (Butner et al., 2009; Holmbeck, 1996). In these cases, conflict can prompt realignments toward age-appropriate expectations, thereby reducing the discrepancies (Collins et al., 1997). However, when families fail to resolve conflicts, inconsistencies may persist and be exacerbated (Anderson et al., 1990; Anderson et al., 2009). For families of youth with spina bifida, disagreements over the sharing of spina bifida medical tasks may be unresolved due to the lack of conflict over these issues, and these disagreements may have long term negative effects on the adolescent's development. However, more research is needed to determine the longitudinal implications of mother-child disagreements on child development over time.

Similar to Miller and Drotar's findings in a population of adolescents with diabetes and their mothers (2003), mother-child disagreements were not related to adherence to treatment regimen. Miller and Drotar suggested that there may be a lack of

correspondence between perceptions of autonomy with medical tasks and adherence. Specifically, adherence relates to the actual performance of medical management tasks whereas perceptions of autonomy may not be directly linked to performance. For instance, a mother may decide when it is time for a child to catheterize, or consistently remind the child to do so, but the child may actually perform the task. The mother may view herself as primarily responsible for the task since she decides when it is time to catheterize, whereas the child may view him or herself as independent because he or she completes the procedure. Adherence refers to the performance of the task, regardless of who is making decisions about that task. Thus, although mothers and children may have differing perceptions over who is responsible for particular elements of the task, the performance of the medical task may not be negatively affected by divergent mother-child perceptions of child autonomy.

Mother-child disagreements were also unrelated to child age and IQ, with the exception of mother-child "Both report that someone else is responsible" disagreements. This type of disagreement was negatively correlated with child IQ, suggesting the children with lower intellectual abilities were more likely to nominate their parents as responsible, and parents were more likely to nominate their child as responsible. However, IQ was not universally associated with disagreements, suggesting that a lack of understanding of the questionnaire does not explain mother-child disagreements alone. It is possible that other factors explain the presence of disagreements, such a maternal depression (De Los Reyes et al., 2008). According to the depression-distortion hypothesis (Richters, 1992), informant's ratings of a child may be negatively biased by the informant's depression. The informant's depressed mood may make him or her more

likely to attend to, encode, and remember negative (as opposed to positive or neutral)

information regarding child behavior (De Los Reyes et al., 2008). However, this

hypothesis has yet to be studied in youth with spina bifida

<div style="text-align:center">Mother-Child Agreement</div>

Although the hypotheses about mother-child disagreement were not supported,

significant findings emerged for mother-child agreement over the management of spina

bifida medical tasks. While all three types of mother-child agreement (Figure 1) were not

directly related to family conflict (Hypothesis I), mother-child agreement was related to

medical adherence (Hypothesis II). Although it was expected that all three types of

mother-child agreement would be related to higher adherence, it was found that high

agreement that the responsibility belonged to the child was directly associated with poor

medical adherence. Significant interaction effects were also found, depending on who

was primarily responsible for the spina bifida responsibilities (i.e., parent or child;

Hypothesis IV). An Agreement (Child Responsible) x Conflict (Observational)

interaction was found, suggesting that medical adherence was the highest when mothers

and children had fewer agreements that the child was primarily responsible for medical

tasks and there was low family conflict (see Figure 5). Another moderation analysis

revealed that an Agreement (Parent Responsible) x Conflict (Mother Report) interaction

was also significant, suggesting that families who had more agreements that the

responsibility belonged to the parent and low levels of family conflict possessed the best

adherence to spina bifida medical tasks (see Figure 6). Similar to the analyses of mother-

child disagreement over the sharing of spina bifida medical responsibilities, the

mediational model (Hypothesis III) and exploratory curvilinear analyses were not

supported. Thus, although conflict moderated the relationship between informant

agreement and medical adherence, conflict did not mediate the relationship.

Taken together, adherence appears to be maximized when parents are primarily

responsible for spina bifida medical tasks and there are low levels of family conflict. This

finding is similar to the literature on the sharing of children's diabetes responsibilities,

which has consistently demonstrated that parental involvement in diabetes management is

associated with more favorable diabetes-related outcomes (Anderson et al., 1999; Ellis et

al., 2007; Helgeson, Reynolds, Siminerio, Escobar, & Becker, 2008; Wiebe et al., 2005;

Wysocki et al., 2006). For youth with spina bifida, parental involvement is also important

for successfully adhering one's medical regimen during preadolescence and early

adolescence.

As demonstrated by the interaction effects depicted in Figure 5 and Figure 6,

conflict was associated with low adherence for all families, regardless of who was

primarily responsible for the medical tasks. This finding is consistent with research that

has found a significant link between family conflict and poor medical adherence

(Jacobson et al., 1994; Miller & Drotar, 2003), including research on youth with spina

bifida (Stepansky et al., 2010). Although mother-child disagreements were not associated

with conflict during this developmental period, the presence of conflict placed a child at

increased risk for poor adherence and potentially poor health outcomes. However, it is

important to note that the main effect of conflict predicting medical adherence was only

significant for mother-reported conflict (i.e., child-reported conflict and the observational

measure of conflict were not significant). It could be that mothers' perceptions of family

conflict have the most important influence on medical adherence, as parents are primarily

responsible for the majority of spina bifida medical tasks during this time. When mothers perceive conflict in the family, the stress of the conflict may negatively impact a mother's ability to complete medical tasks effectively. On the other hand, when children perceive conflict in the family, medical adherence is less affected because they possess fewer medical responsibilities. As children begin to become more independent with medical tasks during adolescence, their perceptions of family conflict may have stronger implications on adherence behaviors. The main effect of the observational measure was not significantly related to medical adherence, though the observational measure moderated the relationship between agreement that the child was responsible and medical adherence (see above). Considering that families were observed for a short period of time, it is possible that the observational interactions did not elicit responses that are typical for that family. Social desirability may also have had an impact on the observational measure of family conflict, as interactions may be less likely to escalate to high levels of intense conflict due to the presence of the video and audio recorders.

Although it is clear that parental involvement is an important facet of spina bifida medical adherence during early adolescence, it is possible that this involvement may become maladaptive over time. Given that youth with spina bifida tend to lag behind typically developing youth in general independence development by approximately two years (Devine et al., 2011), and parents of youth with spina bifida are more likely to be psychologically controlling or intrusive because they perceive their child as vulnerable (Holmbeck et al., 2002b), parents may be less likely to encourage the practice and skills necessary for autonomous medical care. Thus, well-intentioned parenting behaviors may become maladaptive as the child's self-governance skills are diminished (Anderson &

Coyne, 1991). Although parental involvement was associated with higher adherence during this time point, not allowing children to be responsible for their medical care when they are older and developmentally able to do so may negatively impact adolescent autonomy development by encouraging an excessive dependence on parents (Stepansky et al., 2010). Thus, parental involvement in disease tasks may only be adaptive to the point in which youth are developmentally capable to manage their disease care independently. Further research is needed to evaluate the trajectories of medical autonomy development in youth with spina bifida in relation to the adolescent's developmental level and parenting characteristics.

<center>Limitations and Future Directions</center>

There are several limitations of the current study that should be addressed in future work. Consistent with other studies of pediatric populations, the sample size in this study was relatively small. The small sample size limited the statistical power of the analyses and the likelihood of detecting smaller effects. Another limitation of this study was that the majority of the population was Caucasian. Given the higher rates of spina bifida within the Hispanic population (Lary & Edmonds, 1996), there was an increased effort to include Hispanic, Spanish-speaking youth with spina bifida in this study. For instance, recruitment procedures, questionnaires, tasks, and letters to families were translated to Spanish, and Spanish-speaking research assistants recruited and collected data from Spanish-speaking families. These accommodations allowed for higher rates of Hispanics in this study (28%) compared to other studies investigating youth with spina bifida (e.g., Holmbeck et al., 2003). However, 54% of the sample was Caucasian which limits the generalizability of study findings to other ethnic groups. Future research should

continue to strive for a more representative sample of Spanish-speaking families, as well as other ethnic groups (e.g., African Americans). Third, the sample of this study was limited to one illness group. Although there are several advantages to conducting research with a single illness group (e.g., children with different illnesses may not demonstrate the same difficulties; Holmbeck et al., 2003), this methodology limits the degree to which we can generalize our findings to other chronic illness groups. Fourth, this study did not include fathers to evaluate father-child or father-mother differences in perceptions of the child's independence with medical tasks. As fathers may offer unique perceptions of how the transfer of medical responsibilities is going in the family, it is recommended that future research include father data.

Another limitation of this research was that the cross-sectional nature of this study did not allow for an examination of the temporal ordering of the variables studied. Thus, the directionality and influence of mother-child agreement and disagreement over the sharing of spina bifida responsibilities on family conflict and medical adherence across time cannot be determined. For instance, when mothers and children had high agreement that the child was responsible for spina bifida medical tasks, family conflict may have caused poor medical adherence or poor medical adherence may cause family conflict. Due to this limitation, the mediational model proposed in this study should not be considered a true test of mediation (which would benefit from longitudinal data). Rather, the mediational model served as a theoretical model to further understand the relationships between mother-child agreement/disagreement, conflict, and medical adherence. Although the proposed mediation was not supported in this study, it is possible that this model would be supported with longitudinal data. Thus, future research

is needed to examine the consequences of divergent parent and child perceptions of child medical autonomy across time.

There were also several limitations regarding the measurement of medical adherence in this study. Studying adherence in pediatric populations is a complex issue, as both children and families must be viewed as active players in medical decision-making (La Greca & Mackey, 2009). The reliance on self-report questionnaires to assess adherence, which have consistently yielded inflated rates of adherence across a variety of pediatric populations and respondents (e.g., Bender et al., 2000), may not be sufficient to fully understand the complexity of adherence behaviors in spina bifida populations. An additional limitation of the adherence measure utilized in this study is that it does not account for the child's prescribed medical regimen. Although a "not applicable" option was included in the questionnaire to account for tasks not included in the child's regimen, this study cannot fully account for whether the child's medical behaviors correspond with medical providers' prescribed medical regimen. Other methodologies, such as the daily diary method, have been shown to be more precise methods for evaluating medical adherence in families (Quittner et al., 2008). Though this methodology has yet to be adopted for youth with spina bifida and their families, this work may yield a more accurate depiction of spina bifida medical adherence. Considering that adherence to pediatric medical tasks involves the whole family, and certain members of the family may be more in tune to whether the completion of certain medical tasks has occurred, future work should include a multi-informant measure of adherence to spina bifida medical recommendations.

Finally, although a multi-informant and multi-method approach was utilized to measure family conflict, family conflict may have not been measured in the best way. Since the focus of this study was on mother-child perceptions of the child's medical autonomy, the conflict measures in this study may have been too broad. For instance, the conflict measures were not specific to mother-child conflict and were not restricted to conflicts over how medical tasks are completed in the family.

<div align="center">Conclusions and Clinical Implications</div>

Despite the potential limitations of this study, there were also several strengths. This study utilized a multisource and multimethod design to provide evidence for the moderating role of family conflict on the relationship between mother-child agreement over the sharing of spina bifida medical responsibilities and medical adherence. For example, family conflict was assessed through child-report, mother-report, and through the use of an observational measure. Secondly, this study focused specifically on the preadolescent and adolescent years. This developmental period is particularly important to study in regards to healthcare behaviors because healthcare roles are often established and negotiated between parents and children during the early adolescent years. Furthermore, responsibilities for medical tasks begin to transfer from parent to child during this developmental period. In addition, as previously discussed, there was an increased effort to recruit Hispanic, Spanish-speaking youth with spina bifida, given the higher rates of spina bifida within the Hispanic population (Lary & Edmonds, 1996). As such, this strategy increased the generalizability of the findings of this study, as compared to other studies of youth with spina bifida.

The current study was the first investigation to replicate Devine and colleagues (2011) methodology for calculating agreement/disagreement levels at the item level. In Devine and colleagues paper, it was found that adolescents with spina bifida and their mothers agreed upon the adolescents' decision-making autonomy at a later age than typically developing adolescents and their mothers. Compared to past research which has investigated informant disagreements using alternative methods (such as calculating difference scores), this study conducted a more fine-grained assessment of how medical responsibilities are distributed in the family. The study of agreement and disagreement over the sharing of spina bifida responsibilities allowed for a more valid investigation of how the transfer of medical responsibilities from parent to child is going in the family (similar to inter-rater reliability). Consistent with past research (e.g., Anderson et al., 199; Butner et al., 2009; Miller & Drotar, 2003), the current study found that different types of agreements are linked to different outcomes, suggesting that the direction of agreement/disagreement is important. Thus, it is recommended that future research adopt the procedure created by Devine and colleagues to evaluate how different types of parent-child agreement and disagreement over the child's autonomy development relate to outcomes of interest.

The results of this study have important clinical implications. First, parental involvement in spina bifida medical care appears to be essential for optimal adherence during preadolescence and early adolescence. The significant findings of this study consistently demonstrated that parental involvement resulted in higher levels of adherence, even after controlling for relevant developmental factors, such as child age and IQ. Thus, regardless of the child's developmental level, preadolescence and early

adolescence may represent a time period when it is premature to grant youth full responsibility for their disease. Studies of other illness populations have found that the transfer of responsibility from parent to child when the child is not yet ready to become responsible for these tasks may prevent the development of appropriate medical self-care (Wysocki et al., 1996). For youth with chronic health conditions, including those with spina bifida, the development of autonomous medical care is an important prerequisite for transitioning to adulthood successfully (i.e., living independently). Although more research is needed to identify particular characteristics of the child (e.g., executive functions and attention) and parents (e.g., intrusiveness) that may determine child readiness to become independent with his or her medical care, the findings of this study indicate that some families of youth with spina bifida are prematurely granting medical autonomy to their children. Thus, a longitudinal examination of variables that promote or prevent an adolescent's ability to independently adhere to his or her medical regimen is essential.

High conflict resulted in low levels of adherence, regardless of who was primarily responsible for disease tasks. Thus, the presence of family conflict disrupts both the child and parent's abilities to complete medical tasks successfully. This finding supports Stepansky and colleagues finding, in a separate sample of youth with spina bifida (2010), that conflict surrounding medical care led to a decrease in medical adherence over time. The results of these studies suggest that it is important that family-based interventions be developed and implemented to target medical adherence issues. Perhaps, a family systems approach would be the most beneficial for resolving conflicts and maximizing adherence behaviors. Other studies have found that socioeconomic status is a salient

predictor of high conflict and low cohesion in families of youth with spina bifida (Holmbeck et al., 2002a), suggesting that families who are burdened by financial difficulties may be at particular risk for high levels of family conflict and poor adherence. Thus, families with a child with spina bifida and of low socioeconomic status may represent a high risk group to target in adherence interventions. Future research should evaluate this hypothesis, as well as investigating other salient issues such as access to healthcare and cultural differences in healthcare utilization.

APPENDIX A

QUESTIONNAIRE ITEMS

PAC-P

Below is a list of things that sometimes get talked about at home. We would like you to look carefully at each topic on the left-hand side of the page in the first column. Circle **YES** for the topics that you and your child have talked about **at all** during the last two weeks. Circle **NO** for those that have not come up. Now go back over the list. For those circled **YES**, answer these two questions:

　　　　1. Circle the number that shows **HOW OFTEN** during the last two weeks you
　　　　　　discussed each topic with your child.
　　　　2. Next, circle the number that shows how **HOT** the discussions were.

Did you and your child discuss this topic in the last two weeks?		If yes, **HOW OFTEN** was the topic discussed during the last two weeks? Not Very Often Often	If yes, how **HOT** did the discussions get? A Little Very Calm Angry Angry
1. Whether s/he does chores around the house	YES NO	1 2 3 4	1 2 3 4 5
2. When s/he has to do his/her homework	YES NO	1 2 3 4	1 2 3 4 5
3. How much time s/he has to spend on homework each day	YES NO	1 2 3 4	1 2 3 4 5
4. What time s/he has to be home	YES NO	1 2 3 4	1 2 3 4 5
5. How s/he spends his/her own money	YES NO	1 2 3 4	1 2 3 4 5
6. What clothes s/he wears to school	YES NO	1 2 3 4	1 2 3 4 5
7. Which friends s/he spends time with	YES NO	1 2 3 4	1 2 3 4 5
8. What time s/he has to go to sleep on school nights	YES NO	1 2 3 4	1 2 3 4 5
9. How s/he spends his/her time after school	YES NO	1 2 3 4	1 2 3 4 5
10. Whether s/he has to let me know where s/he is when s/he goes out	YES NO	1 2 3 4	1 2 3 4 5
11. Whether s/he can have friends over when I'm not home	YES NO	1 2 3 4	1 2 3 4 5
12. Whether s/he has to go on family visits or outings	YES NO	1 2 3 4	1 2 3 4 5
13. What s/he can	YES NO	1 2 3 4	1 2 3 4 5

watch on television

Did you and your child discuss this topic in the last two weeks?	If yes, **HOW OFTEN** was the topic discussed during the last two weeks? Not Very Often Often	If yes, how **HOT** did the discussions get? A Little Very Calm Angry Angry
14. How much time s/he spends with friends	YES NO	1 2 3 4	1 2 3 4 5
15. What clubs or hobbies s/he is involved with	YES NO	1 2 3 4	1 2 3 4 5
16. How s/he does his/her catheterization	YES NO	1 2 3 4	1 2 3 4 5
17. Whether s/he takes his/her pills	YES NO	1 2 3 4	1 2 3 4 5
18. How s/he does his/her bowel program	YES NO	1 2 3 4	1 2 3 4 5
19. What sorts of food s/he eats	YES NO	1 2 3 4	1 2 3 4 5
20. How s/he puts on his/her braces or uses his/her wheelchair	YES NO	1 2 3 4	1 2 3 4 5
21. How s/he does his/her skin checks	YES NO	1 2 3 4	1 2 3 4 5
22. How s/he exercises	YES NO	1 2 3 4	1 2 3 4 5
23. How s/he talks about spina bifida with others (friends, nurses, doctors, teachers)	YES NO	1 2 3 4	1 2 3 4 5
24. How independent s/he is with self-care and keeping clean	YES NO	1 2 3 4	1 2 3 4 5
25. Cleaning up after his/herself if s/he has a bowel or urinary accident	YES NO	1 2 3 4	1 2 3 4 5

PAC-C

Below is a list of things that sometimes get talked about at home. We would like you to look carefully at each topic on the left-hand side of the page in the first column. Circle **YES** for the topics that you and your parent(s) have talked about **at all** during the last two weeks. Circle **NO** for those that have not come up. Now go back over the list. For those circled **YES**, answer these two questions:

1. Circle the number that shows **HOW OFTEN** during the last two weeks you discussed each topic with your child.
2. Next, circle the number that shows how **HOT** the discussions were.

Did you and your parent(s) discuss this topic in the last two weeks?	If yes, **HOW OFTEN** was the topic discussed during the last two weeks? Not Very Often Often	If yes, how **HOT** did the discussions get? A Little Very Calm Angry Angry
1. Whether I do chores around the house	YES NO	1 2 3 4	1 2 3 4 5
2. When I have to do my homework	YES NO	1 2 3 4	1 2 3 4 5
3. How much time I have to spend on homework each day	YES NO	1 2 3 4	1 2 3 4 5
4. What time I have to be home	YES NO	1 2 3 4	1 2 3 4 5
5. How I spends my own money	YES NO	1 2 3 4	1 2 3 4 5
6. What clothes I wear to school	YES NO	1 2 3 4	1 2 3 4 5
7. Which friends I spend time with	YES NO	1 2 3 4	1 2 3 4 5
8. What time I have to go to sleep on school nights	YES NO	1 2 3 4	1 2 3 4 5
9. How I spends my time after school	YES NO	1 2 3 4	1 2 3 4 5
10. Whether I have to let my parent(s) know where I am when I go out	YES NO	1 2 3 4	1 2 3 4 5
11. Whether I can have friends over when my parent(s) are not home	YES NO	1 2 3 4	1 2 3 4 5
12. Whether I have to go on family visits or outings	YES NO	1 2 3 4	1 2 3 4 5
13. What I can watch on television	YES NO	1 2 3 4	1 2 3 4 5

	Did you and your parent(s) discuss this topic in the last two weeks?	If yes, **HOW OFTEN** was the topic discussed during the last two weeks? Not Very Often Often	If yes, how **HOT** did the discussions get? A Little Very Calm Angry Angry
14. How much time I spend with friends	YES NO	1 2 3 4	1 2 3 4 5
15. What clubs or hobbies I am involved with	YES NO	1 2 3 4	1 2 3 4 5
16. How I do my catheterization	YES NO	1 2 3 4	1 2 3 4 5
17. Whether I take my pills	YES NO	1 2 3 4	1 2 3 4 5
18. How I do my bowel program	YES NO	1 2 3 4	1 2 3 4 5
19. What sorts of food I eat	YES NO	1 2 3 4	1 2 3 4 5
20. How I put on my braces or use my wheelchair	YES NO	1 2 3 4	1 2 3 4 5
21. How I do my skin checks	YES NO	1 2 3 4	1 2 3 4 5
22. How I exercise	YES NO	1 2 3 4	1 2 3 4 5
23. How I talk about spina bifida with others (friends, nurses, doctors, teachers)	YES NO	1 2 3 4	1 2 3 4 5
24. How independent I am with self-care and keeping clean	YES NO	1 2 3 4	1 2 3 4 5
25. Cleaning up after myself if I have a bowel or urinary accident	YES NO	1 2 3 4	1 2 3 4 5

SPINA BIFIDA SELF-MANAGEMENT PROFILE

Taking care of spina bifida means doing a lot of different things like doing clean intermittent catheterization, taking medications, handling infections, being on a bowel control program and cooperating with tests like x-rays and urologic (bladder) studies, It's not easy doing all of these things exactly the way doctors and nurses might want. Very few kids with spina bifida and their families do everything exactly according to plan. Sometimes there are other things that grab your attention or you might just forget to take care of these things, even though you may have wanted to. Most kids with spina bifida, and their families, develop their own habits for taking care of it that are comfortable for them. What we're trying to learn in this questionnaire is what you and your child usually do to take care of your child's spina bifida. Your answers won't be shared with anyone else, so you can feel comfortable writing exactly what you do not just what you think you're supposed to do or what you think you should say. So, try to be completely honest about what you and your child have usually done in taking care of your child's spina bifida in the past 6 months.

APPOINTMENT KEEPING

Taking care of spina bifida requires lots of clinic visits. Sometimes it's hard to keep all of those appointments because you may be busy with lots of other important things. This part of the questionnaire is about what you and your child usually do about keeping medical appointments.

1. **When your child has had medical appointments within the past 6 months, how often have you and your child come to that appointment? (please check one)**
___ Arrived on time for every scheduled appointment
___ Came to every appointment but was a little late sometimes
___ Cancelled appointment more than 24 hours before the appointment and
       rescheduled another appointment
___ Arrived so late for an appointment that it had to be rescheduled
___ Forgot or otherwise did not come to an appointment

BOWEL CONTROL PROGRAM

Spina bifida makes it harder to have regular bowel movements and so your doctor may have given you a program to help you to develop consistent habits. This may include eating foods that contain plenty of fiber, staying away from some other foods, recording your bowel movements, and taking an enema or suppository if your bowel movements aren't frequent enough. This part of the questionnaire is about how carefully your child has done these things in the past 6 months.

2. **In the past 6 months, how often has your child stayed within the diet recommendations that the doctor has given you? (please check one)**
___ Always eats according to the recommendations (100%)
___ Usually eats according to the recommendations (80-100%)
___ Often eats according to the recommendations (50-80%)
___ Sometimes eats according to the recommendations (10-50%)
___ Rarely or never eats according to the recommendations (0-10%)

3. When your child has gotten constipated in the last 6 months, how often has your child taken a suppository, enema or stool-softening medication as prescribed by the doctor? (please check one)
___ No constipation in past 6 months
___ Always takes the prescribed enema, suppository or stool-softening medication as instructed (100% of the time)
___ Usually takes the prescribed enema, suppository or stool-softening medication as instructed (80-99% of the time)
___ Often takes the prescribed enema, suppository or stool softening medication as instructed (50-79% of the time)
___ Sometimes takes the prescribed enema, suppository or stool-softening medication as instructed (10-49% of the time)
___ Rarely or never takes the prescribed enema or suppository as instructed (Less than 10% of the time)

SKIN AND WOUND CARE

Most kids with spina bifida need to be careful about skin and wound care. Your care team may ask you and your child to check the skin on a daily basis for any sores or places where the skin is breaking down. It is important to recognize the signs of these kinds of wounds quickly, as they might develop into pressure sores that are difficult to heal. This question is about your usual habits in checking skin.

4. In the past 6 months, how often did you and your child check your child's skin? (please check one)
___ Checks all over the body every day
___ Checks certain parts of body every day
___ Checks all over the body 2-3 times per week

EXERCISE

Your child's care team has probably explained the importance of getting some kind of exercise every day. Depending on how mobile your child is, this might include anything from walking, to moving around in a wheelchair, to doing arm pushups in a chair. Sometimes kids don't like to do this, or are busy with other things and would rather do other stuff. This question is about exercise.

5. In the past 6 months, how often does your child do the exercise that is asked of him or her? (please check one)
___ Does exercise every day on average
___ Does exercise every other day, on average
___ Does exercise one time, per week
___ Rarely exercises

MEDICATIONS

Treatment of spina bifida also often includes taking medicines for several different purposes. Most kids and their families have at least some trouble taking all of these medicines in exactly the right amounts and at the scheduled times. This part of the questionnaire is about how regular your family is about giving medicines as the doctor has asked you and your child to do.

6. Many kids with spina bifida are expected to take antibiotics every day to prevent urinary tract infections, whether they are sick or not. How regular has your child been in taking this antibiotic in the past 6 months? (please check one)
___ Almost always takes the prescribed amount of antibiotic on time (Misses no more than two doses per month)
___ Usually takes the prescribed amount of antibiotic on time (Misses no more than 5 doses per month)
___ Often takes the prescribed amount of antibiotic on time (Misses no more than 10 doses per month)
___ Sometimes takes the prescribed amount of antibiotic on time (Misses no more than 20 doses per month)
___ Rarely or never takes the prescribed amount of antibiotic on time (Misses at least 20 doses per month)
___ Not prescribed antibiotics

7. Your child may also be asked to take Ditropan or a similar medicine to keep your bladder functioning well. In the past 6 months, how often has your child taken the correct dose of this medicine at the right time? (please check one)
___ Always takes the prescribed amount on time.
___ Usually (Over 80%) takes the prescribed amount on time
___ Often (50-80%) takes the prescribed amount on time
___ Sometimes (10-50%) takes the prescribed amount on time
___ Rarely or never (0-10%) takes the prescribed amount on time
___ Not prescribed this type of medicine

CLEAN INTERMITTENT CATHETERIZATION

Many kids with spina bifida must be catheterized several times daily, either by themselves or their parents and these procedures must be followed very carefully. Lots of things can get in the way of doing this and, even when they try their best, many kids and parents still struggle with doing this exactly according to the plan. For example, it might be hard to follow every step of the procedure exactly as you were taught or to do it exactly on time. This part of the questionnaire will be asking about your family's habits about clean intermittent catheterization at home and away from home. Try to be as honest and accurate as you can about your catheterization habits in the past 6 months.

8. Many kids with spina bifida are asked to catheterize themselves, or to have their parents do this for them, several times daily. In the past 6 months, how often has this been done exactly according to schedule? (please check one)
___ Never or rarely misses doing catheterization as often as prescribed (Once a week or less)
___ Occasionally misses doing catheterization as often as prescribed (2-3 times a week)
___ Sometimes misses doing catheterization as often as prescribed (4-5 times a week)
___ Frequently misses doing catheterization as often as prescribed (Once a day)
___ Usually misses doing catheterization as often as prescribed (More than once a day)
___ Not asked to do clean intermittent catheterization

9. You and your child are asked to follow some careful steps whenever you complete catheterization. This includes five steps: 1.) Having all the supplies together, 2.) Washing your hands first, 3.) Correct positioning of the child, 4.) Inserting the catheter with slow steady pressure until urine begins to flow, and 5.) Washing the catheter in warm soapy water. In the past 6 months during catheterization, how many of these five steps do you or your child always do? (please check one)
___ Completes all five steps.
___ Completes four steps.
___ Completes three steps.
___ Completes two steps.
___ Completes 0-1 steps.

10. If you re-use catheters, how often do sterilize the catheter by either washing it in antibacterial soap or boiling it in clean water for 10 minutes or more before you use it again? (please check one)
___ Does not re-use catheters.
___ Almost always sterilizes catheter between uses. (Misses no more than once per month)
___ Usually sterilizes catheter between uses. (Misses 2-5 times per month)
___ Often sterilizes catheter between uses. (Misses 6-10 times per month)
___ Sometimes sterilizes catheter between uses. (Misses 10-20 times per month)
___Infrequently or never sterilizes catheter between uses. (Misses more than 20 times per month)

DEALING WITH URINARY TRACT INFECTIONS

Most kids with spina bifida get urinary tract infections now and then. It is important to recognize the signs of these infections quickly, call in for treatment and take any medicines that are prescribed for this, but it isn't always easy to do these things. This part of the questionnaire is about your usual habits in recognizing urinary tract infections and the actions you take once you discover an infection.

11. ln the past 6 months, what did you and your child usually do when you first thought that your child might have a urinary tract infection? (please check one)
___ No symptoms of urinary tract infection in the past 3 months
___ Call the clinic immediately to report the symptoms and get advice
___ Wait a few hours before calling to see if the symptoms went away
___ Wait until the next day before calling to see if the symptoms went away
___ Wait a few days before calling to see if the symptoms went away
___ Don't call at all

12.The last time your child had a urinary tract infection, how did your child do with taking the prescribed antibiotic medication on time? (please check one)
___ Always takes the prescribed amount of antibiotic on time (100%)
___ Usually takes the prescribed amount of antibiotic on time (80-100%)
___ Often takes the prescribed amount of antibiotic on time (50-80%)
___ Sometimes takes the prescribed amount of antibiotic on time (10-50%)
___ Rarely or never takes the prescribed amount of antibiotic on time (0-10%)

13. The last time your child had a urinary tract infection, how quickly did you fill the prescription for the antibiotic medication that the doctor prescribed for treating it? (please check one)
___ Within 6 hours after receiving the prescription
___ Between 6 and 12 hours after receiving the prescription
___ Between 12 and 24 hours after receiving the prescription
___ More than 24 hours after receiving the prescription
___ Did not fill the prescription

14.The last time your child had a urinary tract infection, how much of the prescribed antibiotic medication did your child actually take? (please check one)
___ Took every scheduled dose until the medicine was gone
___ Took at least 80% of scheduled doses of the medicine
___ Took 50-80% of the scheduled doses of the medicine
___ Took 10-5% of the scheduled doses of the medicine
___ Took less than 10% of the scheduled doses of the medicine
___ Did not fill the prescription

SOSBMR-C

For each of the following parts of spina bifida care, choose the number of the answer that best describes the way you handled things at home **during the last month**.

CHILD-I took responsibility for this almost all of the time, by myself.

EQUAL-My parent(s) and I shared responsibility for this about equally.

PARENT-My parent(s) took responsibility for this almost all of the time.

N/A- Not Applicable. This does not describe a part of my spina bifida care.

	Who Has Responsibility?			
	CHILD	**EQUAL**	**PARENT**	**N/A**
1. Remembering day of clinic appointment.	□□	□□	□□	□□
2. Making appointments with doctors.	□□	□□	□□	□□
3. Talking with doctors about medical questions and requests (for example, medication refill).	□□	□□	□□	□□
4. Explaining absences from school to teachers or other school personnel.	□□	□□	□□	□□
5. Telling my teachers about spina bifida.	□□	□□	□□	□□
6. Telling my relatives about spina bifida.	□□	□□	□□	□□
7. Telling my friends about spina bifida.	□□	□□	□□	□□
8. Remembering to take medication, as prescribed.	□□	□□	□□	□□

	CHILD	EQUAL	PARENT	N/A
9. Checking expiration dates on medical supplies.	□□	□□	□□	□□
10. Taking proper care of my wheelchair and braces.	□□	□□	□□	□□
11. Wearing orthotics (braces) as prescribed by doctor/physical therapist.	□□	□□	□□	□□
12. Getting around in my wheelchair from place to place inside of the home.	□□	□□	□□	□□
13. Getting around in my wheelchair from place to place outside of the home.	□□	□□	□□	□□
14. Getting in and out of my wheelchair.	□□	□□	□□	□□
15. Taking care of my basic needs (for example, bathing, dressing).	□□	□□	□□	□□
16. Avoiding products that may contain latex, if allergic to latex.	□□	□□	□□	□□
17. Protecting my skin from temperature, textures, and injury.	□□	□□	□□	□□
18. Conducting daily skin checks.	□□	□□	□□	□□
19. Taking medications for urinary tract infection.	□□	□□	□□	□□
20. Noticing differences in urine that could indicate a urinary tract infection.	□□	□□	□□	□□

	CHILD	**EQUAL**	**PARENT**	**N/A**
21. Remembering to catheterize regularly, every 2-4 hours.	□ □	□ □	□ □	□ □
22. Washing hands and genital area before catheterizing.	□ □	□ □	□ □	□ □
23. Gathering appropriate catheterization equipment (for example, catheter, lubricant)	□ □	□ □	□ □	□ □
24. Lubricating catheter.	□ □	□ □	□ □	□ □
25. Properly inserting catheter.	□ □	□ □	□ □	□ □
26. Draining bladder completely and removing catheter.	□ □	□ □	□ □	□ □
27. Cleaning, storing, and discarding catheterization equipment properly.	□ □	□ □	□ □	□ □
28. Following a regular physical exercise routine.	□ □	□ □	□ □	□ □
29. Remembering to eat foods with lots of fiber and avoiding other foods (for example, chocolate, cheese).	□ □	□ □	□ □	□ □
30. Remembering to drink lots of fluid.	□ □	□ □	□ □	□ □
31. Taking suppositories, enemas, stool softeners, or laxatives as needed.	□ □	□ □	□ □	□ □
32. Maintaining a regular bowel toileting time.	□ □	□ □	□ □	□ □
33. Cleaning up after myself, if an accident occurred.	□ □	□ □	□ □	□ □
34. Monitoring bowel functioning by keeping a log.	□ □	□ □	□ □	□ □

SOSBMR-P

For each of the following parts of spina bifida care, choose the number of the answer that best describes the way you handled things at home **during the last month**.

CHILD-Child took responsibility for this almost all of the time, by him/herself.

EQUAL-Parent(s) and child shared responsibility for this about equally.

PARENT-Parent(s) took responsibility for this almost all of the time.

N/A- Not Applicable. This does not describe a part of your child's spina bifida care.

Who Has Responsibility?

	<u>CHILD</u>	<u>EQUAL</u>	<u>PARENT</u>	<u>N/A</u>
1. Remembering day of clinic appointment.	□□	□□	□□	□□
2. Making appointments with doctors.	□□	□□	□□	□□
3. Talking with doctors about medical questions and requests (for example, medication refill).	□□	□□	□□	□□
4. Explaining absences from school to teachers or other school personnel.	□□	□□	□□	□□
5. Telling my teachers about spina bifida.	□□	□□	□□	□□
6. Telling my relatives about spina bifida.	□□	□□	□□	□□
7. Telling my friends about spina bifida.	□□	□□	□□	□□
8. Remembering to take medication, as prescribed.	□□	□□	□□	□□

	CHILD	**EQUAL**	**PARENT**	**N/A**
9. Checking expiration dates on medical supplies.	□□	□□	□□	□□
10. Taking proper care of my wheelchair and braces.	□□	□□	□□	□□
11. Wearing orthotics (braces) as prescribed by doctor/physical therapist.	□□	□□	□□	□□
12. Getting around in my wheelchair from place to place inside of the home.	□□	□□	□□	□□
13. Getting around in my wheelchair from place to place outside of the home.	□□	□□	□□	□□
14. Getting in and out of my wheelchair.	□□	□□	□□	□□
15. Taking care of my basic needs (for example, bathing, dressing).	□□	□□	□□	□□
16. Avoiding products that may contain latex, if allergic to latex.	□□	□□	□□	□□
17. Protecting my skin from temperature, textures, and injury.	□□	□□	□□	□□
18. Conducting daily skin checks.	□□	□□	□□	□□
19. Taking medications for urinary tract infection.	□□	□□	□□	□□
20. Noticing differences in urine that could indicate a urinary tract infection.	□□	□□	□□	□□

	CHILD	EQUAL	PARENT	N/A
21. Remembering to catheterize regularly, every 2-4 hours.	□□	□□	□□	□□
22. Washing hands and genital area before catheterizing.	□□	□□	□□	□□
23. Gathering appropriate catheterization equipment (for example, catheter, lubricant)	□□	□□	□□	□□
24. Lubricating catheter.	□□	□□	□□	□□
25. Properly inserting catheter.	□□	□□	□□	□□
26. Draining bladder completely and removing catheter.	□□	□□	□□	□□
27. Cleaning, storing, and discarding catheterization equipment properly.	□□	□□	□□	□□
28. Following a regular physical exercise routine.	□□	□□	□□	□□
29. Remembering to eat foods with lots of fiber and avoiding other foods (for example, chocolate, cheese).	□□	□□	□□	□□
30. Remembering to drink lots of fluid.	□□	□□	□□	□□
31. Taking suppositories, enemas, stool softeners, or laxatives as needed.	□□	□□	□□	□□
32. Maintaining a regular bowel toileting time.				□□
33. Cleaning up after an accident	□□	□□	□□	
34. Monitoring bowel functioning by keeping a log				

APPENDIX B

OBSERVATIONAL CONFLICT CODE

85

II. CONFLICT

P. <u>Level of conflict within dyads</u> (51-53). Conflict between two members may be manifested verbally and/or nonverbally during interaction. VERBAL: statements that indicate that one person overreacts towards other person; being verbally defensive in relation to issue discussed and not taking responsibility for own actions or thoughts; interrupting abruptly another member's speech to impose own ideas; speaking loudly to another member of triad. NONVERBAL: looking bothered, body gesture expressions of excitement or hesitation, tension between family members. **Note:** An amicable conflict (e.g., dyad is supportive of each individual despite the conflict, mood continues to be relatively light even with the conflict) would be scored lower than a disagreeable conflict. If there is no conflict during the interaction, code a "1".

    5. <u>Very Often</u> = Members of dyad are against each other (at least one of the members is attacking the other), the mood is very tense and they express several verbal and nonverbal indications of this tension.

    4. <u>Frequently</u> = Members of dyad seem to be polarized in relation to issues, some verbal and nonverbal indications of conflict are expressed, interaction is rather tense and communication is difficult.

    3. <u>Sometimes</u> = One of the members of dyad manifests some verbal or nonverbal indications to other members of having some trouble in relation to issue. This causes some tension in the interaction and/or the relationship.

    2. <u>Rarely</u> = The dyad seems to have some difference that they take seriously and one of the members gives a verbal or nonverbal indication of it. However, there is a rather good mood between the family members and issues are discussed well.

    1. <u>Not at All</u> = The dyad discusses issues appropriately, differences seem easy to solve and there is a good mood between the family members.

BIBLIOGRAPHY

Achenbach, T. M. (2006). As others see us clinical and research implications of cross-informant correlations for psychopathology. *Current Directions in Psychological Science, 15*(2), 94-98.

Achenbach, T. M., McConaughy, S. H., & Howell, C. T. (1987). Child/Adolescent behavioral and emotional problems: Implications of cross-informant correlations for situational specificity. *Psychological Bulletin, 101*(2), 213-232.

Aiken, L. S., & West, S. G. (1991). Multiple regression: Testing and interpreting regressions. London: Sage Publications.

Anderson, B. J., & Coyne, J. C. (1991). "Miscarried helping" in the families of children and adolescents with chronic diseases. In J. H. Johnson, & S. B. Johnson (Eds.), *Advances in child health psychology* (pp. 167-177). Gainsville: University of Florida Press.

Anderson, B., Ho, J., Brackett, J., Finkelstein, D., & Laffel, L. (1997). Parental involvement in diabetes management tasks: Relationships to blood glucose monitoring adherence and metabolic control in young adolescents with insulin-dependent diabetes mellitus. *Journal of Pediatrics, 130*(2), 257-265.

Anderson, B. J., Auslander, W. F., Jung, K. C., Miller, J. P., & Santiago, J. V. (1990). Assessing family sharing of diabetes responsibilities. *Journal of Pediatric Psychology, 15*(4), 477-492.

Anderson, B. J., Holmbeck, G., Iannotti, R. J., McKay, S. V., Lochrie, A., Volkening, L. K., & Laffel, L. (2009). Dyadic measures of the parent-child relationship during the transition to adolescence and glycemic control in children with type I diabetes. *Families, Systems & Health, 27*(2), 141-152.

Baron, R. M. & Kenny, D. A. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology, 51*(6), 1173-1182.

Bender, B., Wamboldt, F. S., O'Connor, S. L., Rand, C., Szefler, S., Milgrom, H., & Wamboldt, M. Z. (2000). Measurement of children's asthma medication adherence by self-report, mother report, canister weight, and Doser

CT. *Annals of Allergy, Asthma & Immunology : Official Publication of the American College of Allergy, Asthma, & Immunology, 85,* 416-21Blum, 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*(2), 280-285.

Butner, J., Berg, C. A., Osborn, P., Butler, J. M., Godri, C., Fortenberry, K. T., . . . Le, H. (2009). Parent-adolescent discrepancies in adolescents' competence and the balance of adolescent autonomy and adolescent and parent well-being in the context of type I diabetes. *Developmental Psychology, 45*(3), 835-849.

Centers for Disease Control and Prevention (2011). *Neural tube defect ascertainment project.* Retrieved June 26, 2011, from http://www.nbdpn.org

Chi, T. C., & Hinshaw, S. P. (2002). Mother-child relationships of children with ADHD: The role of maternal depressive symptoms and depression-related distortions. *Journal of Abnormal Child Psychology, 30*(4), 387-400.

Coakley, R. M., Holmbeck, G. N., Friedman, D., Greenley, R. N., & Thill, A. W. (2002). A longitudinal study of pubertal timing, parent-child conflict, and cohesion in families of young adolescents with spina bifida. *Journal of Pediatric Psychology, 27*(5), 461-473.

Cohen, J. (1992). A power primer. *Psychological Bulletin, 112*(1), 155-159.

Collins, W. A., Laursen, B., Mortenson, N., Luebker, C., & Ferreira, M. (1997). Conflict processes and transitions in parent and peer relationships: Implications for autonomy and regulation. *Journal of Adolescent Research, 12*(2), 178-198.

Davis, B. E., Shurtleff, D. B., Walker, W. O., & Seidel, K. D. (2006). Acquisition of autonomy skills in adolescents with myelomeningocele. *Developmental Medicine & Child Neurology, 48*, 253-258.

De Los Reyes, A. (2011). Introduction to the special section: More than measurement error: Discovering meaning behind informant discrepancies in clinical assessments of children and adolescents. *Journal of Clinical Child & Adolescent Psychology, 40*(1), 1-9.

De Los Reyes, A., Goodman, K. L., Kliewer, W., & Reid-Quinones, K. (2008). Whose depression relates to discrepancies? Testing relations between informant characteristics and informant discrepancies from both informants perspectives. *Psychological Assessment, 20*(2), 139-149.

De Los Reyes, A., & Kazak, A. E. (2006). Informant discrepancies in assessing child dysfunction relate to dysfunction within mother-child interactions. *Journal of Child and Family Studies, 15*(5), 643-661.

De Los Reyes, A., & Kazdin, A. E. (2005). Informant discrepancies in the assessment of child psychopathology: A critical review, theoretical framework, and recommendations for further study. *Psychological Bulletin, 131*(5), 483-509.

Dekovic, M., Noom, M. J., & Meeus, W. (1997). Expectations regarding development during adolescence: Parental and adolescent perceptions. *Journal of Youth and Adolescence, 26*(3), 253-272.

Devine, K. A., Wasserman, R. M., Gershenson, L. S., Holmbeck, G. N., & Essner, B. S. (2011). Mother-adolescent agreement regarding decision-making autonomy: A longitudinal comparison of families of adolescents with and without spina bifida. *Journal of Pediatric Psychology, 36*(3), 277-288.

Ellis, D. A., Podolski, C., Naar-King, S., Frey, M., Wang, B., & Moltz, K. (2007). The role of parental monitoring in adolescent health outcomes: Impact on regimen adherence in youth with type 1 diabetes. *Journal of Pediatric Psychology, 32,* 907-917.

Friedman, D., Holmbeck, G. N., DeLucia, C., Jandasek, B., & Zebracki, K. (2009). Trajectories of autonomy development across the adolescent transition in children with spina bifida. *Rehabilitation Psychology, 54*(1), 16-27.

Greenley, R. N., Holmbeck, G. N., & Rose, B. M. (2006). Predictors of parenting behavior trajectories among families of young adolescents with and without spina bifida. *Journal of Pediatric Psychology, 31*(10), 1057-1071.

Grills, A. E., & Ollendick, T. H. (2002). Issues in parent-child agreement: The case of structured diagnostic interviews. *Clinical Child and Family Psychology Review, 5*(1), 57-83.

Guion, K., Mrug, S., & Windle, M. (2009). Predictive value of informant discrepancies in reports of parenting: Relations to early adolescents' adjustment. *Journal of Abnormal Child Psychology, 37*(1), 17-30.

Helgeson, V. S., Siminerio, L., Escobar, O., & Becker, D. (2008). Predictors of metabolic control among adolescents with diabetes: A 4-year longitudinal study. *Journal of Pediatric Psychology, 34*(3), 254-270.

Helgeson, V. S., Reynolds, K. A., Siminerio, L., Escobar, O., & Becker, D. (2008). Parent and Adolescent Distribution of Responsibility for Diabetes Self-care: Links to Health Outcomes. *Journal of Pediatric Psychology, 33,* 497-508.

Hollingshead, A. B. (1975). *Four factor index of social status*. New Haven, CT: Yale University Press.

Hill, N. E., Bromell, L., Tyson, D. F., & Flint, R. (2007). Developmental commentary: Ecological perspective on parental influences during adolescence. *Journal of Clinical Child and Adolescent Psychology, 36*(3), 367-377.

Holmbeck, G. (2002). A developmental perspective on adolescent health and illness: An introduction to the special issues. *Journal of Pediatric Psychology, 27*(5), 409-415.

Holmbeck, G. N. (1996). A model of family relational transformations during the transition to adolescence: Parent-adolescent conflict and adaptation. In J. Graber, J. Brooks-Funn & A. Petersen (Eds.), *Transitions through adolescence: Interpersonal domains and context* (pp. 167-200). New Jersey: Lawrence Erlbaum Associates, Inc.

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*(4), 599-610.

Holmbeck, G. N., DeLucia, C., Essner, B., Kelly, L., Zebracki, K., Friedman, D., & Jandasek, B. (2010). Trajectories of psychosocial adjustment in adolescents with spina bifida: A 6-year, four-wave longitudinal follow-up. *Journal of Consulting and Clinical Psycology, 78*(4), 511-525.

Holmbeck, G. N., Johnson, S. Z., Wills, K. E., McKernon, W., Rose, B., Erklin, S., & Kemper, T. (2002a). Observed and perceive parental overprotection in relation to psychosocial adjustment in preadolescents with a physical disability: The mediational role of   behavioral autonomy. *Journal of Consulting and Clinical Psychology, 70*(1), 96-110.

Holmbeck, G. N., Li, S. T., Schurman, J. V., Friedman, D., & Coakley, R. M. (2002b). Collecting and managing multisource and multimethod data in studies of pediatric populations. *Journal of Pediatric Psychology, 27*(1), 5-18.

Holmbeck, G. N., & O'Donnell, K. (1991). Discrepancies between perceptions of decision making and behavioral autonomy. *New Directions for Child Development, 51*, 51-69.

Holmbeck, G. N., Westhoven, V. C., Phillips, W. S., Bowers, R., Gruse, C., Nikolopoulos, T., & Totura, C. M. W. (2003). A multimethod, multi-informant,

and multidimensional perspective on psychosocial adjustment in preadolescents with spina bifida. *Journal of Consulting and Clinical Psychology, 71*(4), 782-796.

Holmbeck, G. N., Zebracki, K., Johnson, S.Z., Belvedere, M., & Schneider, J. (2007). *Parent-Child Interaction Macro-Coding Manual.* Unpublished manual, Loyola University of Chicago.

Hope, T. L., Adams, C., Reynolds, L., Powers, D., Perez, R. A., & Kelley, M. L. (1999). Parent vs. self-report: Contributions toward diagnosis of adolescent psychopathology. *Journal of Psychopathology and Behavioral Assessment, 21*(4), 349-363.

Hunsley, J., & Mash, E. J. (2007). Evidence-based assessment. *Annual Review of Clinical Psychology, 3*, 29-51.

Jacobson, A. M., Hauser, S. T., Lavori, P., Willett, J. B., Cole, C. F., Wolfsdorf, J. I., et al. (1994). Family environment and glycemic control: A four-year prospective study of children and adolescents with insulin-dependent diabetes mellitus. *Psychosomatic Medicine, 56,* 401–409

Kaufman, A. S., Swan, W. W., & Wood, M. M. (1980). Do parents, teachers, and psychoeducational evaluators agree in their perceptions of the problems of black and white emotionally disturbed children? *Psychology in the Schools, 17*, 185-191.

Kaugars, A. S., Zebracki, K., Kichler, J. C., Fitzgerald, C. J., Greenley, R. N., Alemzadeh, R., & Holmbeck, G. N. (In press). Use of an observational coding system with families of adolescents:Psychometric properties among pediatric and healthy populations. *Journal of Pediatric Psychology,* 1-13.

La Greca, A. M., & Race Mackey, E. (2009). Adherence to pediatric treatment regimens. In M. C. Roberts, & R. G. Steele (Eds.), *Handbook of pediatric psychology* (4th ed., pp. 130-152). New York: The Guilford Press.

Lary, J. M., & Edmonds, L. D. (1996). Prevalence of spina bifida at birth – United States, 1983-1990: A comparison of two surveillance systems. *Centers for Disease Control: Morbidity and Mortality Weekly Report, 45,* 15-26.

Lewandowski, A., & Drotar, D. (2007). The relationship between parent-reported social support and adherence to medical treatment in families of adolescents with type 1 diabetes. *Journal of Pediatric Psychology, 32*(4), 427-436.

Martin, S., Elliott-DeSorbo, D. K., Wolters, P. L., Toledo-Tamula, M. A., Roby, G., & Zeichner, A., et al. (2007). Patient, caregiver and regimen characteristics associated with adherence to highly active antiretroviral therapy among HIV-

infected children and adolescence. *Journal of Pediatric Infectious Diseases, 26*, 61-67.

Miller, V. A., & Drotar, D. (2003). Discrepancies between mother and adolescent perceptions of diabetes-related decision-making autonomy and their relationship to diabetes-related conflict and adherence to treatment. *Journal of Pediatric Psychology, 28*(4), 265-274.

Modi, A. C., Marciel, K. K., Slater, S. K., Drotar, D., & Quittner, A. L. (2008). The influence of parental supervision on medical adherence in adolescents with cystic fibrosis: Developmental shifts from pre to late adolescence. *Children's Health Care, 37*(1), 78-92.

Olsen, B., Berg, C. A., & Wiebe, D. L. (2008). Dissimiliarity in mother and adolescent illness representations of type I diabetes and negative emotional adjustment. *Psychlogy and Health, 23*(1), 113-129.

Quittner, A. L., Modi, A. C., Lemanek, K. L., Ievers-Landis, C. E., & Rapoff, M. A. (2008). Evidence-based assessment of adherence to medical treatments in pediatric psychology. *Journal of Pediatric Psychology, 33*, 916-936.

Rapoff, M. A. (2010). *Adherence to pediatric medical regimens* (2nd ed.). New York: Springer.

Richters, J. E. (1992). Depressed mothers as informants about their children: A critical review of the evidence for distortion. *Psychological Bulletin, 112,* 485–499.

Robin, A. L., & Foster, S. L. (1989). *Negotiating parent-adolescent conflict: A behavioral-family systems approach*. New York: Guilford Press.

Rowe, D. E., & Jadhav, A. L. (2008). Care of the adolescent with spina bifida. *Pediatric Clinics of North America, 55*, 1359-1374.

Ryan, R. M., & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist, 55*(1), 68-78.

Sandler, A. D. (2010). Children with spina bifida: Key clinical issues. *Pediatric Clinics of North America, 57*, 879-892.

Sarwark, J. F. (1996). SPINA BIFIDA. *Pediatric Clinics of North America, 43*(5)

Sawin, K. J., Buran, C. F., Brei, T. J., & Fastenau, P. S. (2003). Correlates of functional status, self-management, and developmental competence outcomes in adolescents with spina bifida. *SCI Nursing, 20*(2), 72-85.

Sawin, K. J., Hayden Bellin, M., Builta, E., Vasel, L., & Buran, C. F. (2006). Cross-informant agreement between adolescents with myelomeningocele and their parents. *Developmental Medicine and Child Neurology, 48*(3), 188-194.

Smetana, J. G. (1989). Adolescents' and parents' reasoning about actual family conflict. *Child Development, 60*(5), 1052-1067.

Smetana, J. G., Campione-Barr, N. & Metzger, A. (2006). Adolescent development in interpersonal and societal contexts. *Annual Review of Psychology, 57*, 255-284.

Smetana, J. G., Yau, J., Restrepo, A., & Braeges, J. L. (1991). Adolescent-parent conflict in married and divorced families. *Developmental Psychology, 27*, 1000-1010.

Stepansky, M. A., Roache, C. R., Holmbeck, G. N., & Schultz, K. (2009). Medical adherence in young adolescents with spina bifida: Longitudinal associations with family functioning. *Journal of Pediatric Psychology, 32*(2), 167-176.

Thomasgard, M., & Metz, W. P. (1995). The vulnerable child syndrome revisited. *Journal of Developmental and Behavioral Pediatrics, 16*(1), 47.

Viikinsalo, M.K., Crawford, D.M., Kimbrel, H., Long, A.E., & Dashiff, C. (2005). Conflicts between young adolescents with type I diabetes and their parents. *Journal for Specialists in Pediatric Nursing, 10*, 69-81.

Wechsler, D. (1999). *WASI: Wechsler Abbreviated Scale of Intelligence Manual*. San Antonio, Texas: Harcourt Assessment, Inc.

Wiebe, D. L., Berg, C. A., Korbel, C., Palmer, D. L., Beveridge, R. M., Upchurch, R., . . . Donaldson, D. L. (2005). Children's appraisals of maternal involvement in coping with diabetes: Enhancing our understanding of adherence, metabolic control, and quality of life across adolescence. *Journal of Pediatric Psychology, 30*(2), 167-178.

Wysocki, T. & Gavin, L. (2006) Paternal involvement in the management of pediatric chronic diseases: Associations with adherence, quality of life, and health status. *Journal of Pediatric Psychology*, 31, 501-511.

Wysocki, T., Meinhold, P. M., Taylor, A., Hough, B. S., Barnard, M. U., Clark, W. L. et al. (1996). Psychometric properties and normative data for the parent version of the Diabetes Independence Survey. *The Diabetes Educator, 22,* 587-591.

Youngstrom, E., Loeber, R., & Stouthamer-Loeber, M. (2000). Patterns and correlates of agreement between parent, teacher, and male adolescent ratings of externalizing and internalizing problems. *Journal of Consulting and Clinical Psychology, 68*(6), 1038- 1050.

VITA

The author, Alexandra Marie Psihogios, was born on December 19, 1988 in Damascus, Maryland to Petros and Mary Psihogios. She graduated Cum Laude in Psychology from the University of Maryland, Baltimore Count in December 2009. In December 2012, she graduated with a Masters of Arts in Clinical Psychology at Loyola University Chicago.

Ms. Psihogios is currently pursuing her doctoral degree in Clinical Psychology at Loyola University Chicago. Her research interests are in the area of pediatric psychology and currently, her research addresses the impact of child neuropsychological functioning and parenting on adherence to spina bifida medical treatments. She currently resides in Chicago, Illinois.

94