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Discrepancies in Mother and Child Perceptions of Spina Bifida Medical Responsibilities during the Transition to Adolescence: Associations with Family Conflict and Medical Adherence

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Objective This study investigated mother–child discrepancies over perceptions of who is responsible for spina bifida (SB) medical tasks in relation to family conflict and medical adherence. **Method** 140 youth with SB and their mothers completed questionnaires regarding who is responsible for specific SB medical tasks, family conflict, and medical adherence. An observational measure was also used to assess family conflict. **Results** Although children viewed themselves as more responsible for medical management than mothers did, mother–child discrepancies were not associated with family conflict or medical adherence. Interaction effects revealed that adherence was better when family conflict was low and when parents were responsible for medical tasks. **Conclusions** Parental involvement in SB medical care is essential for optimal medical adherence during adolescence. The presence of family conflict also plays an influential role on SB medical adherence. Future research should evaluate the relations between discrepancies, family conflict, and medical adherence across time.

Key words adherence; adolescents; assessment; family functioning; spina bifida.

Introduction

Adolescence is characterized by rapid biological, cognitive, and social maturation in which the adolescent begins to assume new roles within the family (Hill, Bromell, Tyson & Flint, 2007). For pediatric populations, including youth with spina bifida (SB), this developmental period also represents a time when caregivers gradually relinquish control over medical tasks to their child and the child begins to act more autonomously with his or her care. However, the changes that characterize adolescence may also cause parent and child perceptions of the child's autonomy-related development to diverge (Holmbeck, 1996). These discrepancies may occur because rapid 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. Typically, adolescents view themselves as more independent, competent, and capable of achieving developmental milestones than parents do (Dekovic, Noom, & Meeus, 1997). For youth with chronic health conditions (such as SB), parent–child discrepancies in perceptions of who is responsible for medical tasks may indicate that communication in families about medical management has not kept pace with the shifting of responsibilities from parent to child (Anderson, Auslander, Jung, Miller, & Santiago, 1990).

SB is one of the most common and disabling birth defects, occurring in roughly 3 out of every 10,000 live births (Centers for Disease Control and Prevention, 2011). SB is caused by the incomplete closure of the neural tube during the early stages of pregnancy, resulting in malformations of the spinal cord and cerebral cortex. Children with SB require intense medical care throughout their lifetime, such as intermittent catheterization, medications, bowel programs, physical therapy, dietary

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restrictions, and routine skin checks to prevent pressure sores. Similar to other pediatric populations, adolescents with SB are granted increasing responsibility for medical regimens over time (Stepansky, Roache, Holmbeck, & Schultz., 2010). Despite these gains, it has also been observed that children with SB tend to achieve lower overall levels of decision-making autonomy during adolescence compared with typically developing children (Davis, Shurtleff, Walker & Seidel, 2006; Devine, Wasserman, Gershenson, Holmbeck, & Essner, 2011; Friedman, Holmbeck, DeLucia, Jandasek, & Zebracki, 2009).

The transfer of disease responsibilities from parent to child may be particularly challenging in families of youth with SB for a number of reasons. First, the neuropsychological impairments associated with SB (e.g., executive dysfunction and inattention) may impact children's abilities to follow through on treatments, as well as parents' confidence in their child's ability to complete these tasks independently. Second, it has been found that parents of youth with SB are more likely to be overprotective because they perceive their child as vulnerable (Holmbeck, Johnson, et al., 2002), and may be less likely to encourage the practice and skills necessary for autonomous medical care. Third, the social deficits that are associated with SB (e.g., passivity in family interactions) may make communication about medical tasks difficult. Finally, mothers and adolescents with SB have demonstrated differences in their perceptions of general adolescent autonomy development (Sawin et al., 2006), with allocation of decision-making responsibilities to the child tending to occur at a later age than occurs in typically developing adolescents (Devine et al., 2011).

While informant discrepancies have been observed across different informants, behaviors, and assessment tools, more research is needed to understand why discrepancies exist and how they relate to outcomes of interest (De Los Reyes & Kazdin, 2005). Parent–child discrepancies regarding the child's level of autonomy may be important indicators of how families are negotiating the child's transition to adolescence and the degree to which the child has an increased need for independence. For instance, parent–child discrepancies may be caused by child autonomy-seeking, which may produce conflict within the family (Collins, Laursen, Mortenson, Luebker, & Ferreira, 1997; Holmbeck & O'Donnell, 1991). Indeed, the relation between parent–child discrepancies 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), although fewer of these studies have focused on the relation between conflict and discrepancies over responsibilities in the family (e.g., Holmbeck & O'Donnell, 1991; Miller & Drotar, 2003), as compared with research on discrepancies in perceptions of problematic childhood behaviors (e.g., externalizing behaviors; De Los Reyes & Kazdin, 2006; Grills & Ollendick, 2002). Though parent–child discrepancies over child autonomy have been associated with increased family conflict, they have also been considered to be a part of the normative process of development that promotes realignments in decision-making responsibilities within the family system (Butner et al., 2009; Holmbeck, 1996). However, chronically high levels of unresolved discrepancies may be associated with less adaptive outcomes (Anderson et al., 1990, 2009).

Parent–child discrepancies over the child's level of responsibility within the medical domain may not only be related to higher levels of family conflict, but such discrepancies may also be associated with poor health outcomes, such as medical adherence (Anderson et al., 2009; Butner et al., 2009). Indeed, if neither parent nor child assumes responsibility for a medical task, then the medical task may not be completed. At the most complex level of analysis, it may be that the relationship between parent–child discrepancies and medical adherence is mediated by family conflict, such that discrepancies over perceptions of who is responsible for medical treatments may be associated with higher levels of family conflict which, in turn, may relate to lower levels of adherence. It is also possible that the relationship between parent–child discrepancies over the sharing of SB medical responsibilities and medical adherence may be moderated by family conflict. For families who are high in conflict and high in parent–child discrepancies, discrepancies may be less likely to be resolved through more adaptive communication strategies. In other words, the interactive effect of chronic disagreement and high levels of family conflict may also be associated with medical adherence.

The purpose of this study was to evaluate mother–child discrepancies over who is perceived to be responsible for SB medical tasks in relation to family conflict and medical adherence. Although a few studies have evaluated discrepant beliefs in pediatric populations (e.g., Butner et al., 2009; Devine et al, 2011; Miller & Drotar, 2003; Anderson et al., 2009), no studies have investigated mother–child differences in perceived control over SB-related medical tasks. Furthermore, much of the existing body of literature on informant discrepancies has focused on informant discrepancies by calculating difference scores, rather than conducting a more fine-grained assessment of different types of parent–child agreement and

Table I. *Discrepancies Based on Child and Mother Reports of Who is Responsible for Spina Bifida Medical Tasks*

		Parent report		
		Child responsibility	Equal responsibility	Parent responsibility
Child report	Child responsibility	1 Full concordance: child responsible *16.74% of responses*	2	3 Full discrepancy, "both report being responsible" *2.28% of responses*
	Equal responsibility	4	5 Full concordance: shared responsibility *12.01% of responses*	6
	Parent responsibility	7 Full discrepancy, "both report that the other is in charge" *7.28% of responses*	8	9 Full concordance: parent responsible *28.15% of responses*

Note. Only categories of full discrepancy or full concordance were used (i.e., cells 1, 3, 5, 7, and 9). The remaining four categories (i.e., cells 2, 4, 6, and 8) were not analyzed, as these categories represent only partial discrepancies.

disagreement (Devine et al., 2011; see Table I). We chose to evaluate cases when informant discrepancies were small (i.e., concordance) in addition to large discrepancies, as concordance about the child's medical autonomy represents a reliable proxy assessment of who is performing particular SB tasks (similar to interrater reliability). In other words, if the child and the mother agree that the mother is in charge of a particular task, for example, it is likely that she is, in fact, in charge of this responsibility. For this study, it was expected that mothers and children with SB may not consistently agree about who is responsible for disease management. Because it has been suggested that mothers are more likely to provide accurate reports of their child's daily behavior compared with other informants (e.g., fathers, teachers, and peers: De Los Reyes & Kazdin, 2005), father reports were not used for this study.

It was hypothesized that mother–child discrepancies over perceptions of who is responsible for SB medical treatments would relate to higher levels of family conflict, whereas mother–child concordance would relate to lower levels of family conflict. Second, it was expected that mother–child discrepancies in reports of who is responsible for SB medical tasks would relate to poorer medical adherence and concordance would relate to higher levels of medical adherence. Third, it was hypothesized that family conflict would mediate the relationship between parent–child discrepancies in perceptions of the child's medical autonomy and medical adherence (see Figure 1). Finally, it was hypothesized that family conflict would moderate the relationship between mother–child discrepancies and medical adherence (Figure 1).

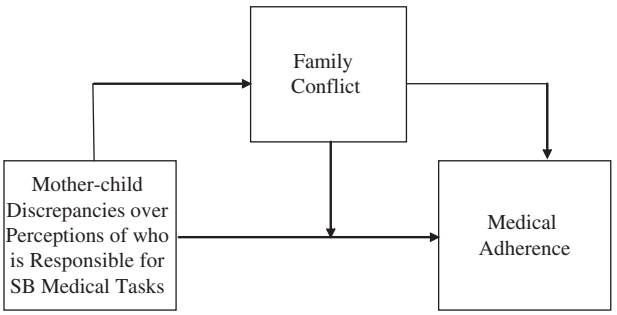

Figure 1. Mediation and moderation model for mother–child discrepancies predicting family conflict and medical adherence.

Materials and Methods

Participants

Participants were part of a larger longitudinal study at Loyola University Chicago examining family, psychosocial, and neurocognitive functioning among children with SB (Devine et al., 2011). This study focused on children with SB at Time 1, when youth were between the ages of 8 and 15 years. Families of children with SB were recruited from four hospitals and a statewide SB association in the Midwest. Inclusion criteria consisted of (1) diagnosis of SB (types included myelomeningocele, lipomeningocele, myelocystocele); (2) age 8–15 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

Table II. *Child Demographic and Medical Information for the Original Sample at Time 1*

Characteristic	Child with spina bifida $n = 140$
Age M (SD)	11.40 (2.48)
IQ M (SD)	85.85 (19.70)
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)
Spina bifida type	
% Myelomeningocele	87.9
% Lipomeningocele	8.3
% Other	3.8
Lesion Level	
% Lumbar	62.9
% Sacral	19
% Thoracic	18.1
% Shunt	80.3
Ambulation	
% Braces	81.1
% Wheelchair	61.4

Note. SD = standard deviation.
The percentages of children who use braces or wheelchairs do not add up to 100% because many children use both methods of ambulation.

were not able to be contacted or later declined, and two of these families did not actually meet inclusion criteria. The final participants included 140 families of children with SB (53.6% female; M age = 11.40). Of these 140 children, 53.6% were Caucasian, 27.9% were Hispanic, 12.9% were African American, and 5.7% were of another ethnicity. The majority of the sample had the most severe form of SB, myelomeningocele (87.9%), and the average child IQ was in the low average range (M = 85.85, standard deviation = 19.70). Further child demographic and medical information is provided in Table II. Children of families who declined participation did not differ from those who agreed to participate with respect to type of SB (e.g., myelomeningocele or other), χ^2 (1) = .000, $p > .05$, shunt status, χ^2 (1) = .003, $p > .05$, or occurrence/nonoccurrence of shunt infections, χ^2 (1) = 1.08, $p > .05$.

Procedure

At Time 1, data were collected by trained undergraduate and graduate student research assistants during two home visits, lasting approximately 3 hr. Families who completed all parts of the study received monetary compensation ($150 for families) and gifts (e.g., t-shirts and pens). Informed consent from parents and assent from children were obtained before the start of the first home visit at the participant's home. During the home visits, children with SB and their parents independently completed questionnaires and participated in audio- and video-taped structured interaction tasks. Children also participated in neuropsychological testing. The videotaped family interactions (with the target child and one or both parents) consisted of four structured family 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 salient family conflict issues that were endorsed on questionnaires by the family members (Smetana, Yau, Restrepo, & Braeges, 1991).

Measures

Mother–Child Discrepancies and Concordance Regarding SB Responsibilities

The Sharing of Spina Bifida Management Responsibilities (SOSBMR), an adaptation of the Diabetes Family Responsibility Questionnaire (Anderson et al., 1990), was used to examine mother–child discrepancies over who takes responsibility for SB medical tasks. For this measure, parents and children independently rated who was primarily responsible for each task (e.g., Parent, Child, Equal, or Not Applicable). The SOSBMR consists of 34 items that describe SB or general health-related tasks that are relevant to children with SB (e.g., ''Remembering to catheterize regularly, every 2–4 hr''). These items are grouped into several subscales: Health appointments, communication about SB, medications, general needs and self-care, ambulation, skin care, catheterization, bowel management, and exercise and diet. This measure was found to have acceptable alphas in the current study ($\alpha = .89$ for mothers and $\alpha = .90$ for children). Among the subscales, acceptable alphas were found for communication ($\alpha = .68$ for mothers and $\alpha = .60$ for children), medications ($\alpha = .52$ for mothers and $\alpha = .67$ for children), ambulation ($\alpha = .73$ for mothers and $\alpha = .62$ for children), skin care ($\alpha = .63$ for mothers and $\alpha = .69$ for children), catheterization ($\alpha = .94$ for mothers and $\alpha = .92$ for children), and bowel management ($\alpha = .88$ for mothers and $\alpha = .87$ for children). Due to little variability among the responses, an unacceptable alpha was found for mother-reported appointment keeping. Thus, appointment keeping was not analyzed at the subscale level. Alpha coefficients could not be computed for general needs/self-care and exercise because each of these subscales consists of only one item.

Discrepancies were calculated by using procedures outlined by Devine et al. (2011). Mother and child responses were compared at the item level and responses from each dyad for each item were placed in one of nine categories (see Table I). For example, if a mother and a child both stated that the child was responsible for a given task, they received a ''1'' for this task in cell 1 of Table I. After mother and child responses on each of the 34 items were analyzed in this way, the response pairs that fell into each of the nine matrix boxes were summed. The proportion of responses in each category was calculated to control for the number of items answered (because respondents could endorse ''not applicable'') by dividing the total number of items that fell in one category by the total number of joint responses in all nine categories (maximum number of joint responses = 34). For this study, the categories of full mother–child discrepancy and concordance were used (i.e., cells 1, 3, 5, 7, and 9 in Table I). The remaining four categories (i.e., cells 2, 4, 6, and 8 in Table I) were not analyzed, as these categories represent only partial discrepancies/concordance.

Family Conflict (Questionnaire Data)

The Parent–Adolescent Conflict scale (PAC), a brief version of the Issues Checklist (Robin & Foster, 1989), was adapted for this study to assess nonmedical (i.e., conflicts over chores) and medical conflicts in the family (i.e., conflicts over particular SB medical tasks). The PAC measures conflict by asking informants to respond to 15 potential general, nonmedical 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 medical conflict issues that are typically discussed in families of children with SB (e.g., how he/she does his/her catheterization), yielding medical and nonmedical subscales. Alpha coefficients were not available for this measure, as each family member only answers items they have personally discussed and each respondent rarely answers *every* item (i.e., the SPSS algorithm for reliability uses listwise deletion and only includes participants that responded to *all* items).

Family Conflict (Observational Data)

This study also investigated family conflict via coding of observed family interaction tasks from Time 1. Each interaction task was coded by two trained undergraduate or graduate research assistants using the Family Interaction Macro-coding System (FIMS; Holmbeck, Zebracki, Johnson, Belvedere, & Schneider, 2007; Kaugars et al., 2011), an adaptation of a coding system developed by Smetana et al. (1991). Research assistants received approximately 10 hr of training before coding the video tapes. Coders were instructed to view one interaction task 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. For this project, the family conflict item (which was assessed by finding the mean conflict score across all four tasks) was used. This measure was found to have acceptable interrater reliability (intra-class correlation; ICC = .73).

Medical Adherence

The Spina Bifida Self-Management Profile (Wysocki & Gavin, 2006) is a 14-item structure interview that was used to measure adherence to SB medical treatments based on mother self-report. Total scores were transformed into z-scores because the scale range varied across items (i.e., 4-, 5-, and 6-point scales). In past research, internal consistency was acceptable, with an alpha of .66 for mothers of children with SB (Wysocki & Gavin, 2006). Owing to a low number of participants who completed each item (i.e., parents can endorse ''not applicable'' for certain items), scale reliability could not be computed for this sample.

Covariates

The Wechsler Abbreviated Scale of Intelligence (Wechsler, 1999) Matrix Reasoning and Vocabulary subtests were used to create a composite of child intellectual ability at Time 1. In this investigation, child cognitive ability was controlled, as cognitive ability may influence the child's ability to understand and respond to questionnaire measures accurately. In SB, lesion level (i.e., sacral, lumbar, thoracic) is one proxy indicator of SB severity (Hommeyer, Holmbeck, Wills, & Coers, 1999). As lesion level has been associated with independence outcomes in young adults with SB (Verhoef et al., 2006), this severity variable (assessed with medical chart data) was also controlled in this study. Finally, due to the relatively large age range for the children in this study (i.e., children between the ages of 8–15 years), child age was controlled in all analyses.

Results

Preliminary Analyses

A power analysis was used to assess whether the sample size was appropriate for the statistical analyses (Aiken & West, 1991; Cohen, 1992). 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 (six predictors and a single outcome; Cohen,

1992). Therefore, the current study had adequate power to detect a medium effect size.

Medical and Nonmedical Conflict

Before examining the main hypotheses of the study, the relationships between medical and nonmedical conflict were examined separately for mother and child self-reports (measured by the PAC). Because child reports of medical and nonmedical conflict ($r = .46$, $p = .00$) and mother reports of medical and nonmedical conflict ($r = .50$, $p = .00$) were significantly correlated, medical and nonmedical conflict scores were combined to form general measures of mother- and child-reported conflict. Mother and child reports of general family conflict were not highly correlated ($r = .15$, $p > .05$), and thus were examined separately.

Evaluating Mother–Child Discrepancies/Concordance

The five different types of mother–child discrepancies/concordance were investigated to further understand how prevalent certain types of discrepancies were, and whether perceptions of who was responsible for medical tasks were significantly different at the scale level. Descriptive statistics were used to evaluate the average proportion of responses in each of the five categories of discrepancies (see Table I), with cell 9 (i.e., concordance that the responsibility belonged to the mother) having the highest proportion of responses (28.15%). Although the primary focus of this study was to evaluate mother–child discrepancies at the item level, another approach for assessing different informant perceptions 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., communication about SB, medications, general needs and self-care, ambulation, skin care, catheterization, bowel management, and exercise and diet). *T*-tests revealed that mother and child total scores on the SOSBMR were found to be significantly different, $t(111) = -5.42$, $p < .01$. Mother and child reports on the following subscales of the SOSBMR were also found to be statistically different: responsibilities for communication about SB ($t[108] = -7.43$, $p < .01$), medications ($t[105] = -4.93$, $p < .01$), ambulation ($t[98] = -3.69$, $p < .01$), and bowel management ($t[109] = -5.50$, $p < .01$). Across all of these domains, children rated themselves as more responsible for completing medical tasks than mothers rated the children. Mother and child subscale scores were not significantly different for general needs and self-care, skin care, catheterization, and exercise and diet.

The relationships between mother–child discrepancies/concordance and the continuous covariates (i.e., age and IQ) were also evaluated. Responses in cell 1 or f that the child was responsible for medical tasks was positively correlated with age ($r = .48$, $p < .01$) and IQ ($r = .20$, $p < .05$), whereas responses in cell 9 or concordance that the responsibility belonged to the mother was negatively associated with age ($r = -.48$, $p < .01$) and IQ ($r = -.21$, $p < .05$). Concordance that the responsibility was shared (cell 5) and discrepancies in cell 3 (''Both report being responsible'') were not associated with age and IQ. Mother–child discrepancies in cell 7 (''Both reported that the other person is in charge'') were negatively related to IQ ($r = -.26$, $p < .05$), but were unrelated to age.

Data Analyses to Test Hypotheses

Linear regression analyses were used to examine associations between mother–child discrepancy/concordance over the sharing of SB medical responsibilities, family conflict, and medical adherence. For all analyses, child age, IQ, and lesion level were entered at the first step of the model as covariates. Discrepancy/concordance predictors were evaluated in separate regression analyses and entered at the second step of the model.

Hypothesis I: It was expected that both types of mother–child discrepancies over the perceived responsibility for SB medical tasks (i.e., cells 3 and 7 in Table I) would be positively related to family conflict, and that all three types of concordance (i.e., cells 1, 5 and 9 in Table I) would be negatively related to family conflict. A total of 15 regression analyses were conducted to test this hypothesis (i.e., five levels of discrepancies and three measures of conflict). Contrary to Hypothesis I, all five categories of mother–child discrepancies/concordance were not related to conflict of any type. Thus, the first hypothesis was not supported.

Hypothesis II: It was hypothesized that mother–child discrepancies over perceived medical responsibility would be associated with lower levels of medical adherence. It was also hypothesized that mother–child concordance would be associated with higher levels of medical adherence. Contrary to the hypothesis, it was found that mother–child concordance that the child was responsible for SB medical tasks was negatively associated with medical adherence ($B = -.69$, $\beta = -.24$, $t[108] = -2.04$, $p < .05$), suggesting that mother–child concordance that the child was responsible was associated with poorer medical adherence. The remaining two categories of concordance and two discrepancy categories were not associated with adherence. Thus, the second hypothesis was not supported. On the other hand, the significant effect that did emerge suggests that adherence levels are lower when children are in charge of their medical regimen.

Hypothesis III: It was expected that family conflict would mediate associations between mother–child discrepancies and medical adherence. Although mother–child discrepancies were expected to be associated with poorer medical adherence, it was expected that the relation between mother–child discrepancies and medical adherence would be significantly reduced when controlling for family conflict.

The proposed mediation models were not supported because mother–child discrepancies were not significantly related to medical adherence, with the exception of mother–child concordance that the child was responsible (Hypothesis II). Moreover, the pathways between mother–child discrepancies and family conflict were not supported (Hypothesis I). However, it was found that mother self-report of family conflict was negatively related to medical adherence ($B = -.19$, $\beta = -.20$, $t\,[113] = -2.22$, $p < .05$). Despite these two significant paths, the overall mediational models were not supported.

Hypothesis IV: It was hypothesized that family conflict would moderate associations between mother–child discrepancies and medical adherence. That is, the relationship between mother–child discrepancies and medical adherence were expected to 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. If a significant moderation effect was found, post hoc simple slope analyses were conducted to examine the nature of the interaction (Holmbeck, 2002).

When evaluating family conflict as a moderator of the relationship between mother–child concordance that the child was responsible (i.e., cell 1 in Table I) and medical adherence, it was found that the main effect of concordance was significantly related to medical adherence for all three moderation analyses (see Table III). The main effect of mother-reported family conflict was also significant, though the main effects of child-report of conflict and the observational measure of conflict predicting medical adherence were not significant. The Concordance (Child) × Conflict (Mother Report) interaction was nonsignificant, as was the Concordance (Child) × Conflict (Child Report) interaction. A significant Concordance (Child) × Observed Conflict interaction was found ($B = 1.61$, $\beta = .24$, $t\,[107] = 2.56$, $p = .01$), suggesting that the relationship between concordance that the child was responsible and medical adherence depends on the presence of high or low observed family conflict.

For analyses evaluating family conflict as the moderator of the relationship between concordance that the parent was responsible (i.e., cell 9 in Table I) and adherence, the main effect of concordance was not related to medical adherence for any of the three moderation analyses (see Table IV). The main effect of mother-reported conflict was significant, though child-report and the observational measure were not significant. The Concordance (Parent) × Conflict (Child Report) interaction was also nonsignificant, as was the Concordance (Parent) × Observational Conflict interaction. A significant Concordance (Parent) × Conflict (Mother Report) interaction was found, suggesting that the relationship between concordance that the child was responsible and medical adherence depends on the presence of high or low mother-reported family conflict.

To probe the two significant interactions, post hoc analyses were conducted in line with recommendations by Aiken and West (1991) and Holmbeck (2002). For the Concordance (Child) × Observational Conflict interaction, simple slope tests revealed that concordance that the child was responsible was only related to medical adherence for families with low conflict (see Figure 3). For families with high conflict, there was no relation between concordance that the child was responsible and medical adherence. Put another way, youth with the highest level of

Table III. *Regression Analyses for Hypothesis IV: Concordance (Child Responsible) × Conflict Predicting Spina Bifida Medical Adherence*

Predictor	*b*	*β*	*t*	*p*
IV = Mother self-report conflict				
Covariate: thoracic vs. lumbar	−0.05	0.22	2.25	.03*
Covariate: sacral vs. lumber	−0.2	−0.15	−1.56	0.12
Covariate: IQ	0	−0.09	−0.97	0.34
Covariate: age	0	−0.01	−0.09	0.93
Concordance (child responsible)	−0.71	−0.25	−2.1	.04*
Conflict	−0.18	−0.19	−2.02	.05*
Concordance (child responsible) × conflict	0.88	0.15	1.53	0.13
IV = Child self-report conflict				
Covariate: thoracic vs. lumbar	0.34	0.22	2.29	.02*
Covariate: sacral vs. lumber	−0.19	−0.14	−1.48	0.14
Covariate: IQ	0	0.09	−0.87	0.39
Covariate: age	0	−0.02	−0.15	0.88
Concordance (child responsible)	−0.69	−0.23	−2.01	.05*
Conflict	−0.03	−0.04	−0.39	0.7
Concordance (child responsible) × conflict	0.09	0.02	0.18	0.86
IV = Observational measure of conflict				
Covariate: thoracic vs. lumbar	0.35	0.23	2.43	.02*
Covariate: sacral vs. lumber	−0.21	−0.15	−1.59	0.12
Covariate: IQ	0	−0.09	−0.88	0.38
Covariate: age	0	−0.01	−0.13	0.9
Concordance (child responsible)	0.68	−0.23	−1.98	.05*
Conflict	−0.1	−0.09	−0.93	0.35
Concordance (child responsible) × conflict	1.61	0.24	2.56	.01*

*$p < .05$.

Table IV. *Regression Analyses for Hypothesis IV: Concordance (Mother Responsible) × Conflict Predicting Spina Bifida Medical Adherence*

Predictor	*b*	*β*	*t*	*p*
IV = Mother self-report conflict				
Covariate: thoracic vs. lumbar	0.33	0.22	2.25	.03*
Covariate: sacral vs. lumber	−0.2	−0.15	−1.56	0.12
Covariate: IQ	0	−0.09	−0.97	0.34
Covariate: age	0	−0.01	−0.09	0.93
Concordance (parent responsible)	0.28	−0.11	−2.1	0.37
Conflict	−0.19	−0.19	−2.02	.04*
Concordance × conflict	−1	−0.21	1.53	.04*
IV = Child self-report conflict				
Covariate: thoracic vs. lumbar	0.34	0.22	2.29	.02*
Covariate: sacral vs. lumber	−0.19	−0.14	−1.48	0.14
Covariate: IQ	0	0.09	−0.87	0.39
Covariate: age	0	−0.02	−0.15	0.88
Concordance (parent responsible)	0.29	0.11	0.9	0.37
Conflict	−0.03	−0.03	−0.31	0.76
Concordance × conflict	0.07	0.02	0.16	0.87
IV = Observational measure of conflict				
Covariate: thoracic vs. lumbar	0.35	0.23	2.43	.02*
Covariate: sacral vs. lumber	−0.21	−0.15	−1.59	0.12
Covariate: IQ	0	−0.09	−0.88	0.38
Covariate: age	0	−0.01	−0.13	0.9
Concordance (parent responsible)	0.29	0.11	0.93	0.36
Conflict	−0.1	−0.09	−0.88	0.38
Concordance × conflict	−0.56	−0.1	−1.08	0.28

*$p < .05$.

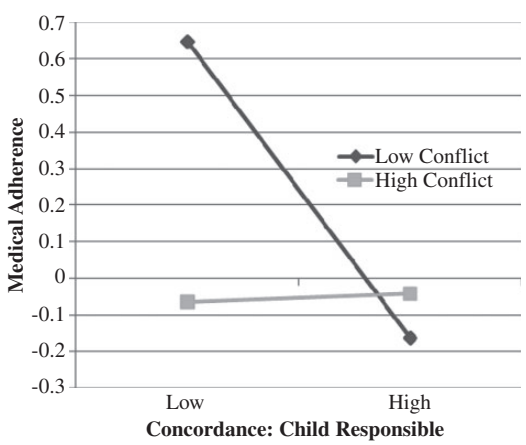

Figure 2. Predicting medical adherence from concordance that child is responsible for spina bifida medical tasks and observations of family conflict. Low in conflict, $\beta = -.468$, $p < .05$. *Note.* Negative values were observed because z-scores for medical adherence were used.

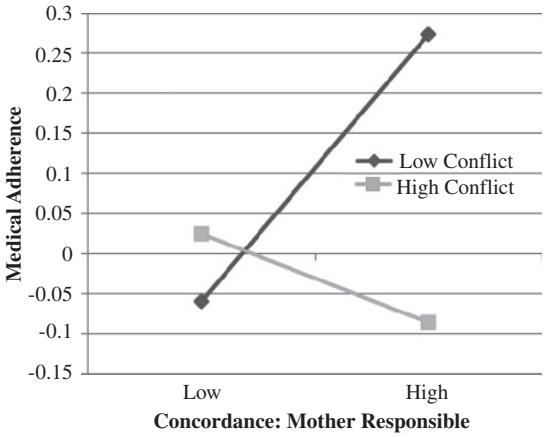

Figure 3. Predicting medical adherence from concordance that mother is responsible for spina bifida medical tasks and mother reported family conflict. Low in conflict, $\beta = .325$, $p < .05$. *Note.* Negative values were observed because z-scores for medical adherence were used.

medical adherence were less likely to be responsible for their medical regimen and their families tended to exhibit lower levels of conflict (see Figure 2).

For the Concordance (Parent) × Conflict (Mother Report) interaction, simple slope tests revealed that concordance that the mother was responsible was only related to medical adherence for families with low conflict (see Figure 3). For families with high conflict, there was no relation between concordance that the mother was responsible and medical adherence. In other words, families where mothers and children agreed that parents were in charge and where families exhibited lower levels of conflict evidenced the highest levels of medical adherence. Combining across both interaction effects, it appears that adherence is better when conflict is low and parents, rather than children, are responsible for managing the medical care of the target child.

Discussion

Although informant discrepancies have been observed across different informants, behaviors, and assessment tools, little is known about the implications of differing perspectives of child behavior on illness-related outcomes (De Los Reyes & Kazdin, 2005). This study attempted to address this limitation by examining mother–child discrepancies over the sharing of SB responsibilities in relation to family conflict and SB medical adherence. Mother–child discrepancies over who was responsible of SB medical responsibilities were examined during late childhood and early adolescence, as discrepancies 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 discrepancies for outcomes of interest, using a more fine-grained methodology for calculating mother–child discrepancies at the item level (Devine et al., 2011) and using a multi-method and multi-informant approach for evaluating the moderating and mediating role of family conflict on the relationship between mother–child discrepancies and medical adherence. The current study was the first investigation to replicate Devine et al (2011) methodology for calculating discrepancies at the item level. Consistent with past research (e.g., Anderson et al., 1991), this study found that different types of agreements were linked to different outcomes, suggesting that the direction of concordance/disagreement is important.

During this developmental period, 57.25% of responses fell into the categories of full concordance (i.e., mother–child concordance that the mother was responsible, concordance that the child is responsible, or concordance that the responsibilities are shared) and <10% of responses fell in the two categories of full discrepancy. Exploratory analyses revealed that mother and child total scores and subscale scores on the SOSMBR were significantly different. Similar to research with nonpediatric samples (Dekovic, Noom, & Meeus, 1997), youth perceived themselves as generally more responsible than mothers did, as well as more responsible in specific domains (i.e., communication about SB, medications, ambulation, and bowel management responsibilities).

Discrepancies in perceptions over who is responsible for completing SB medical tasks 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 negotiations that take place during family conflicts (Holmbeck & O'Donnell, 1991). For families of children with SB, discrepant perceptions over who was responsible for SB medical did not appear to be resolved in this way. It is possible that the lack of association between mother–child discrepancies over who is responsible for SB medical tasks and family conflict could be attributed to the unique dynamics between the child with SB and his or her parents. For instance, characteristics of the child with SB (i.e., passive, and less self-reliant and independent; Holmbeck et al., 2003) and mothers of children with SB (i.e., they are more likely to be overprotective; Holmbeck, Johnson, et al., 2002) may prevent discrepant perceptions over who is responsible for medical tasks from escalating to conflict and negatively affecting medical adherence. A second possible explanation for the lack of association is that the conflict measures that were used 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. However, given the cross-sectional nature of this study, it remains to be determined whether the lack of conflict over differing perceptions of child responsibilities with his or her medical care is adaptive over time. For families of youth with SB, discrepancies over the sharing of SB medical tasks may remain unresolved due to the lack of conflict over these issues, and such discrepancies may have long-term negative effects on adolescent development.

Similar to Miller and Drotar's (2003) findings for a population of adolescents with diabetes and their mothers, mother–child discrepant perceptions over who is responsible for medical tasks were not related to medical adherence. They reasoned that adherence may relate to the actual performance of medical management tasks, whereas perceptions of who completes these tasks may not be directly linked to such performance. For instance, a mother may decide when it is time for a child to catheterize, or she may consistently remind the child to do so, but the child may actually perform the task. Thus, although mothers and children may have differing perceptions over who is responsible for particular elements of the task, the actual performance of the medical task may not be negatively affected by divergent mother–child perceptions.

Despite the lack of findings for mother–child discrepancies, significant findings emerged for mother–child *concordance* over the management of SB medical tasks (i.e., cases when there were convergent mother–child perceptions over medical responsibilities). Specifically, it was found that high concordance that the responsibility belonged to the child was directly associated with poor medical adherence. Most importantly, significant interactions were also found (Figures 2 and 3), which suggested that adherence is maximized when parents are primarily responsible for SB medical tasks and when levels of family conflict are low. Interestingly, such interactions emerged for both observational and questionnaire data. 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., 1991; Ellis, Podolski, Naar-King, Frey, Wang, & Moltz, 2007; Helgeson, Reynolds, Siminerio, Escobar, & Becker, 2008; Wiebe et al., 2005; Wysocki & Gavin, 2006). Considering the neuropsychological deficits (e.g., poor executive functions) that

characterize SB, parental involvement during early adolescence may be especially important for children with SB.

Although it is clear that parental involvement is an important facet of SB medical adherence during early adolescence, more research is needed to evaluate whether this involvement is adaptive over time. Given that youth with SB tend to lag behind typically developing youth in general independence development by approximately 2 years (Devine et al., 2011), and parents of youth with SB are more likely to overprotect their child because they perceive their child as vulnerable (Holmbeck, Johnson, et al., 2002), children may not receive the practice and encouragement that is necessary to become autonomous with their care. While parental involvement was associated with better 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).

There are several limitations of the current study that should be addressed in future work. As is typical in studies of pediatric populations, the sample size in this study was relatively small. A second limitation of this study was that the majority of the population was Caucasian. Future research should continue to strive for a more representative sample of Spanish-speaking families, as well as other ethnic groups. Third, this work did not include fathers; thus, we did not examine father–child or father–mother discrepancies. As fathers may offer unique perceptions of how the transfer of medical responsibilities is unfolding in the family, it is recommended that future research include father data. Fourth, 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 discrepancies regarding the sharing of SB responsibilities on family conflict and medical adherence across time cannot be determined with these data (e.g., family conflict may cause poor medical adherence or poor medical adherence may produce increases in family conflict). Moreover, the use of cross-sectional data to test for mediation is less than ideal. Finally, this study only evaluated the categories that indicated full discrepancy or concordance (thus leaving out those who represented categories of partial discrepancy). Although this strategy provided more clarity when interpreting research findings, this methodology also sacrificed approximately one-third of the data available from the SOSBMR.

There were also several limitations regarding the measurement of medical adherence in this study. The reliance on self-report questionnaires to assess adherence, which has 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 SB populations. Additionally, the adherence measure used in this study did not account for the child's prescribed medical regimen. Other methodologies, such as the daily diary method, have been shown to be more precise for evaluating medical adherence (Quittner et al., 2008). Although this methodology has yet to be used for youth with SB and their families, this strategy may yield a more accurate depiction of medical adherence in this population.

The results of this study have important clinical implications. Parental involvement in SB medical care appears to be essential for optimal adherence during preadolescence and early adolescence. The findings of this study demonstrated that parental involvement resulted in higher levels of adherence, even after controlling for relevant developmental factors, such as child age, IQ, and lesion level. Studies of other illness populations have found that a rapid transfer of responsibility from parent to child may prevent the development of appropriate medical self-care, especially when the child is not yet ready to become responsible for these tasks (Wysocki et al., 1996). 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 have an impact on the child's readiness to become independent with his or her medical care, the findings of this study indicate that some parents of youth with SB may be prematurely granting medical autonomy to their children. Healthcare providers should caution parents not to transfer responsibility for SB medical management to their adolescent before their child is developmentally ready to manage these responsibilities. Furthermore, future research should work toward understanding the unfolding of medical autonomy and adherence in youth with SB across the span of adolescence, as well as toward developing intervention programs that address meaningful risk factors of nonadherence in this population (such as family conflict).

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