

Trajectories of Family Processes Across the Adolescent Transition in Youth With Spina Bifida

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The current study investigated change in family processes, including conflict, cohesion, and stress, across the adolescent transition, comparing the developmental trajectories of youth with and without spina bifida. Individual growth curve modeling procedures were utilized to describe the developmental course of family processes across 4 waves of data collection, from ages 9 to 15 years, and to test whether illness status (spina bifida vs. matched comparison group [$N = 68$ for both groups at Time 1]) would significantly predict individual variability in family processes. Potential moderators (child gender, socioeconomic status [SES], and child verbal ability) of the association between illness status and family functioning were also examined. Differences were found between the trajectories of family processes for families of youth with and without spina bifida. For families of youth with spina bifida, changes in family conflict and cohesion may be less dramatic than or inconsistent with what is expected during typical adolescence. Families of youth with spina bifida from low SES homes appear to demonstrate resilience in terms of family stress.

Keywords: spina bifida, family processes, growth curve, adolescence

Extensive research has been conducted on associations between various chronic illness parameters and family functioning. Overall, this literature supports a disruption-resilience model, where families of children with chronic illness display both resilience, as well as areas of vulnerability, compared to families of healthy children (Costigan, Floyd, Harter, McClintock, 1997; Holmbeck, Coakley, Hommeyer, Shapera, & Westhoven, 2002; Kazak, Segal-Andrews, & Johnson, 1995; Vermaes, Gerris, & Janssens, 2007). Less is known, however, about how families of youth

with chronic illness navigate developmental transitions, and how developmental changes in these processes compare in families with and without youth with chronic illness.

Adolescence is typically associated with decreases in the amount of time youth spend with their family and increases in family conflict (Arnett, 1999; Laursen, Coy, & Collins, 1998). Changes in family processes during adolescence are believed to promote individual maturation, particularly in terms of autonomy development and peer socialization (Cox & Brooks-Gunn, 1999; Holmbeck, 1996; Laursen et al.,

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1998; Smetana, 1995). Family conflict and cohesion, two critical aspects of family process, are hypothesized to be influenced by contextual factors (e.g., socioeconomic status [SES]) and to play a vital role in individual development (Cox & Brooks-Gunn, 1999). Transitional developmental stages, such as adolescence, in conjunction with increased levels of stress, such as those imposed by a chronic illness, also may represent periods of vulnerability for the family system. The manner in which a family is able to manage transitions and stressors may both promote development and influence a child's concurrent and future psychosocial adjustment (Holmbeck, 1996; Kazak et al., 1995).

Thompson's stress and coping model illustrates the transactional nature of individual and family adjustment to chronic illness in the context of an ecological system (Wallerstein, Thompson, & Alriksson-Schmidt, 2003). Within this model, child adjustment and family functioning influence one another over time and are also influenced by factors such as individual cognitive processes and demographic parameters (e.g., SES, gender). Low SES, for example, is a contextual risk factor for maladjustment that may operate through multiple mechanisms; it is associated with multiple stressors as well as limited resources and access to care (Wadsworth & Achenbach, 2005). Given the important role family functioning plays in the adjustment to chronic illness, the dynamic nature of these processes during adolescence, and formative nature of this developmental transition, the present study compares trajectories of family processes during the adolescent transition in families of youth with and without spina bifida as well as the potential moderating role of relevant demographic and individual factors.

Spina bifida results from a defective neural tube formation during gestational development. This defect can occur at any level of the spine and is associated with compromised body function at and below the level of the lesion. The presentation of spina bifida is, therefore, heterogeneous, with lesions located higher on the spine indicative of greater deficits (Farley & Dunleavy, 1996; McLone & Ito, 1998). Generally, spina bifida results in impaired motor and sensory functioning of the lower extremities, often associated with the use of ambulatory aids (e.g., orthotics, braces, wheelchair), hydrocephalus, and reduced bowel and bladder functioning. The medical complications and phenomena associated with spina bifida are generally consistent and present throughout the lifespan (Charney, 1992), although some complications may occur on a more irregular basis (e.g., shunt malfunction, tethered spinal cord) or be associated with specific developmental periods (e.g., precocious puberty).

Optimal medical management of spina bifida necessitates treatment by multiple professionals including nurses, orthopedists, neurologists, urologists, physical and occupational therapists, and mental health professionals as well as coordination and cooperation between family members. Given the complexity of their medical regimen and limited physical mobility, youth with spina bifida are significantly more reliant on their families and spend more time at home relative to peers without chronic illness (Blum, Resnick,

Nelson, & St. Germaine, 1991). It is clear that the caregiver and financial burden imposed by management of this condition is high, and may be associated with higher levels of stress, lower levels of parental satisfaction, and financial disadvantage (Carr, 1991; Holmbeck et al., 1997).

Vermaes and colleagues (2007) examined the application of several theoretical hypotheses to the findings of 27 studies related to adjustment in families affected by spina bifida. Findings related to family dynamics, such as affection, communication, and the parent-child relationship, were consistent with the disruption-resilience hypothesis. Thus, despite the daily stressors that families of youth with spina bifida encounter, they also appear to demonstrate resilience. For example, the presence of spina bifida has been associated with strong family relations (Carr, 1991; Coakley, Holmbeck, Friedman, Greenley, & Thill, 2002). Also, families of children with spina bifida display equivalent or even lower rates of family conflict compared to families of typically developing children (Blum et al., 1991; Coakley et al., 2002).

A cross-sectional investigation published previously on this sample investigated dyadic and systemic family functioning in families of preadolescents with and without spina bifida, who were between 8- and 9-years old (Holmbeck, Coakley, et al., 2002). Findings indicated that illness status (spina bifida vs. comparison), SES, and child verbal ability were associated with several family functioning variables. Specifically, families of youth with spina bifida were found to be less cohesive compared to families of youth without chronic illness. Child verbal ability mediated the relationship between group status and family cohesion; children with spina bifida displayed lower verbal ability, and, in turn, lower verbal ability was associated with lower levels of family cohesion. Across both groups, families with low SES were at risk for higher family conflict, lower family cohesion, and higher levels of stress. No differences were found between the spina bifida and comparison groups in terms of levels of family conflict or parent-reported family stress. Although these findings provide information regarding family functioning in families of spina bifida, they do not address: (a) how these family processes unfold during developmental transitions, (b) how longitudinal patterns of change in families of youth with spina bifida compare to changes in families of youth without spina bifida, or (c) how relevant demographic and individual variables, such as SES, gender, and verbal ability, may impact these developmental trajectories.

A prior investigation of pubertal timing and its association with family functioning supports the notion that families of preadolescents with spina bifida may display differential patterns of change in family process (Coakley et al., 2002). This study was conducted with the same sample as the current study, but utilized only two pre-adolescent time points of data (when youth were 8- to 9-years old and 10- to 11-years old). Families of children without chronic illness were found to demonstrate increases in family conflict and decreases in family cohesion, particularly when children were undergoing pubertal changes earlier than their peers. In contrast, families of children with spina bifida displayed

lower levels of family conflict and decreases in conflict over time. Moreover, levels of family conflict and cohesion in these families were not as responsive to variation in pubertal timing as they were in comparison families. Coakley et al.'s findings may reflect decreased sensitivity to developmental changes and/or a greater investment in consistent family relationships in the context of spina bifida. Such patterns of functioning could be adaptive given the importance of collaboration among family members to manage medical tasks. Thus, in families of children with spina bifida, family processes may be more stable over time or develop more gradually to accommodate the needs of the family system.

The purpose of the current investigation was to extend prior research on chronic illness and family processes by studying change during the adolescent developmental transition. This study was designed as a follow-up to previous investigations of family functioning conducted on the same sample (Coakley et al., 2002; Holmbeck, Coakley, et al., 2002). Consistent with these studies, a comparative analysis of family functioning in families of youth with and without spina bifida was examined. However, inclusion of four waves of data collection (across ages 8 to 15 years) facilitated exploration of trajectories of family functioning into adolescence. In addition, unlike the previous research, the current study sought to explore the differential impact of demographic parameters on developmental changes in family adjustment. Family processes were assessed from several perspectives, using multiple methods and sources.

Potential differences between youth with and without spina bifida were examined using individual growth curve modeling procedures to compare individual trajectories of family processes in the two samples across the transition into adolescence. It was hypothesized that illness status (spina bifida vs. comparison group) would be a significant predictor of individual variability in family functioning. Specifically, it was expected that families of youth without spina bifida would display increases in family conflict and decreases in family cohesion over time. Based on past literature, changes in these family processes, for the spina bifida group, were expected to occur later in adolescence or to a lesser degree. In addition, families of youth with spina bifida were expected to report higher, but stable, levels of family-related stress than comparison families, given the demands of managing a chronic illness. Due to the stress associated with normative changes in family processes during adolescence, stress in families of typically developing adolescents was expected to increase over time.

The moderating roles of individual and contextual factors including verbal ability, SES, and gender on the relationship between illness status and trajectories of family processes were also examined. Given extensive literature supporting the deleterious impact of low SES on adjustment (e.g., Holmbeck, Coakley et al., 2002; Holmbeck et al., 2003; Wadsworth & Achenbach, 2005), it was hypothesized that the context of low SES would represent a cumulative risk for families of youth with spina bifida, and that these families, in particular, would demonstrate discrepant developmental trajectories. It was also expected that youth with both spina bifida and lower verbal ability would be at

greater risk for atypical development, given significant associations between verbal ability, illness status, and individual and family functioning (e.g., Holmbeck, Coakley, et al., 2002). Specifically, these families were expected to demonstrate even more marked delays or attenuations in terms of change in family conflict and cohesion, and higher levels of family stress. Finally, child gender has not been found to predict family or individual adjustment in the context of spina bifida (e.g., Holmbeck, Coakley, et al., 2002; Holmbeck et al., 2003). Thus, gender was not expected to moderate the effects of illness status on trajectories of family process.

Method

Participants

Participants in this study were part of a larger longitudinal investigation that was funded by the March of Dimes and examined family relationships and psychological adjustment in children with spina bifida during the transition into adolescence (e.g., Friedman, Holmbeck, Jandasek, Zukerman, & Abad, 2004; Holmbeck, Coakley, et al., 2002; Holmbeck, Johnson, et al., 2002; Holmbeck et al., 2003). Families with children who had spina bifida were recruited via mailed letters, from a children's hospital, a hospital for individuals with disabilities, a university-based medical center, and a state spina bifida association. The final sample of participants who agreed to participate included 68 families. Chi-square analyses revealed no differences between children of participating and nonparticipating ($n = 54$) families in terms of their spinal lesion level, $\chi^2(2) = .62$, $p > .05$; or type of spina bifida, $\chi^2(1) = 1.63$, $p > .05$.

In the final study sample, the majority of participating children had myelomeningocele (80%). In terms of lesion level, 32% had sacral level lesions, 50% had lumbar level lesions, and 13% had thoracic level lesions. Seventy-one percent of children had a shunt, 64% participated in a catheterization program, and 43% participated in a bowel program. The average number of shunt surgeries by Time 4 was 5.61, ranging from 0 to 41 surgeries. The majority of children used the ambulatory assistance of either braces (63%) or a wheelchair (18%). Nineteen percent of children did not use any type of assistance.

Families from the comparison sample were recruited from schools where participants with spina bifida were enrolled (see Holmbeck, Johnson, et al., 2002, for more information regarding recruitment) by targeting children who were in the same grade. Samples were then matched with 68 families in each sample on the basis of 10 demographic variables (i.e., child age, child gender, birth order, child ethnicity, mother age, father age, family structure, mother income, father income, and SES; Holmbeck, Coakley, et al., 2002). Children were 8- and 9-years old at recruitment; the mean age for the spina bifida sample was 8.34 years, and 8.49 years for the comparison sample. There were 37 boys and 31 girls in each matched sample. The ethnic composition of each sample was primarily White (91% in the comparison group and 82% in the spina bifida

group). For both samples, each child's biological mother participated. For the spina bifida sample, 81% of fathers and stepfathers participated, compared to 76% for the comparison sample.

Matching of the two samples on IQ was not attempted, as intelligence in children with spina bifida is characteristically lower than that of children without spina bifida. Consistent with past research, significant differences were found on a measure of receptive language, the Peabody Picture Vocabulary Test-Revised (PPVT-R; Dunn & Dunn, 1981), with the spina bifida sample scoring lower ($M = 92.49$, $SD = 18.49$; comparison sample, $M = 108.97$, $SD = 15.06$), but still within the average range. Thus, the PPVT score was included as a covariate and moderator in all analyses.

Procedure

Study procedures were reviewed and approved by the institutional review board. Trained graduate and undergraduate research assistants were responsible for collecting data. Data collection occurred during home visits, lasting approximately 3 to 4 hr. Families were paid at each visit: \$50 for Time 1, \$75 for Times 2 and 3, and \$100 for Times 4. At the beginning of each visit, the purpose and procedures of the study were reviewed with the family. Parental consent and child assent, in addition to medical and teacher release forms, were obtained at each visit. Family members were asked to complete questionnaires independently and in separate rooms to ensure privacy. Questionnaires were completed in an interview format with Likert scales presented on large cards for all children at Time 1, and on request or when reading assistance was required at subsequent waves of data collection. Trained research assistants were available to answer questions and provide assistance as needed.

In addition to completing questionnaires, families were also asked to participate in a set of audio- and videotaped interaction tasks. Videotaped interaction tasks consisted of an unfamiliar board game, the Structured Family Interaction Task (Ferreira, 1963), and a conflict task (Smetana, Yau, Restrepo, & Braeges, 1991) to generate family discussion and interaction regarding a variety of topics. The order of the three tasks, following a warm-up exercise, was counterbalanced (see Holmbeck, Johnson, et al., 2002, for details regarding family interaction procedures). Observational data were coded using a global-coding method developed by Holmbeck, Belvedere, Gorey-Ferguson and Schneider (1995), based on a system developed by Smetana and colleagues (1991). Trained research assistants viewed individual family interaction tasks and then coded each interaction along a variety of dimensions for that task, using a 5-point Likert scale (e.g., 1 = almost never, 5 = almost always) and accompanying behavioral descriptions. Several domains of family functioning including parenting behavior, child behavior, and parent-child relationships were evaluated.

The initial wave of data collection (Time 1) occurred when children were 8- and 9-years old. Subsequent waves of data collection occurred every 2 years; youth were 10- and 11-years old at Time 2, 12 and 13 at Time 3, and 14 and 15 at Time 4. Of the 68 families in each group, 67 families

with spina bifida (99%) and 66 comparison families (97%) participated in Time 2 data collection. At Time 3, 3 more families from the spina bifida group declined participation ($n = 64$; 94%), whereas the number of participating comparison families remained stable ($n = 66$, 97%). Finally, at Time 4, retention rates were 88% ($n = 60$) and 96% ($n = 65$), respectively, for the spina bifida and comparison groups.

Measures

Demographic information. At each session, parents were asked to complete a brief questionnaire assessing demographic information. Specifically, this questionnaire obtained information such as child gender, date of birth, ethnic background, family SES, and family structure. Family SES was computed at Time 1 using a Hollingshead Scale (Hollingshead, 1975) based on parents' occupations and educational attainment. Child illness status, gender, and SES were examined as predictors in subsequent growth curve analyses. Child age was calculated for each wave of data collection based on the child's date of birth and the completion date of that home visit. Child's age, centered at age 9, the average age of entry into the study, was used to represent time in the growth curve modeling.

Child verbal ability. The PPVT-R (Dunn & Dunn, 1981) is a measure of receptive language ability. Administration of this measure was conducted according to standardized instructions provided in the test manual by a trained research assistant, at Time 1 only. This measure has demonstrated test-retest reliability and convergent validity with other tests measuring intelligence and verbal ability (Sattler, 2002).

Family conflict. Three indexes of family conflict were utilized in this study: (a) self-reported family conflict intensity, (b) observed dyadic conflict, and (c) self-reported overall family conflict. Intensity of family conflict was measured using a 15-item Parent-Adolescent Conflict Scale (PAC), a brief version of the Issues Checklist (Robin & Foster, 1989). The PAC is composed of a list of common conflicts often discussed in families with preadolescents. A range of issues was included that apply to youth across both the preadolescent and adolescent developmental spectrum (e.g., completion of chores, watching TV, curfew). Each item requires three responses. The family member first responds whether the issue was discussed during the last 2 weeks. If an issue was discussed, the respondent estimates how often it was discussed, and on a 5-point-Likert scale ranging from 1 = *calm* to 5 = *angry* rates the intensity of these discussions. A mean conflict intensity score was calculated for those items that had been discussed. Because intensity ratings were provided only for the particular items endorsed by the respondent, an alpha could not be calculated for this variable. This questionnaire was completed by the mother, father, and child and was administered at all four waves of data collection.

As described above, trained research assistants coded videotaped interaction tasks on a variety of dimensions, using a macro-coding scheme adapted for this project by

Holmbeck, Belvedere, Gorey-Ferguson, and Schneider (1994), and based on a system developed by Smetana and colleagues (1991). Observed level of conflict within each dyad (mother-child, MC; father-child, FC; and mother-father, MF) was coded on a 5-point Likert scale (1 = almost not at all, 5 = very much) at each wave of data collection. Intraclass correlations that assessed interrater reliabilities were computed at each time point for all observational data. As interrater reliabilities for dyadic conflict were low for some time points (spina bifida group, range .48 to .79, $M = .64$; comparison group, range .45 to .82, $M = .68$), this variable was excluded from subsequent analyses.

Overall level of family conflict was assessed using an abbreviated version of the Family Environment Scale (FES; Moos & Moos, 1981), a 63-item measure of perceived family social climate. The family conflict subscale is comprised of 9 items. Parents were asked to rate each item (e.g., "we fight a lot in our family"), in terms of its applicability to their own family, on a 4-point Likert scale ranging from 1 = *strongly disagree* to 4 = *strongly agree*. For the current study, parental perceptions of family conflict from Time 2 to Time 4 were included, as data from Time 1 was measured using a different metric (i.e., true-false). This measure has demonstrated predictive validity and has been validated for use with chronically ill children (Kronenberger & Thompson, 1990; Loomis, Javornisky, Monahan, Burke, & Lindsay, 1997). For mother-reported conflict, alphas ranged from .71 to .81 ($M = .75$) for the spina bifida group, and .76 to .84 ($M = .81$) for the comparison group. Alphas for father-reported conflict ranged from .64 to .73 ($M = .69$) for the spina bifida group, and .72 to .83 ($M = .78$) for the comparison group.

Family cohesion. Three indexes of family cohesion were assessed including: (a) self-reports of overall level of family cohesion, (b) observed family cohesion, and (c) degree of observed cohesion between parents. Overall level of family cohesion was also assessed using the abbreviated version of the FES (Moos & Moos, 1981). The family cohesion subscale is comprised of 9 items. Parents were asked to rate each item (e.g., "there is a feeling of togetherness in our family") on a 4-point Likert scale ranging from 1 = *strongly disagree* to 4 = *strongly agree*. As with family conflict, parental perceptions of family cohesion from Time 2 to Time 4 were included (Mother report α —spina bifida group: range .70 to .80, $M = .76$; comparison group: range .77 to .84, $M = .80$; Father report α —spina bifida group: range .59 to .77, $M = .71$; comparison group: range .80 to .82, $M = .81$).

Observed family cohesion was coded using the macro-coding scheme and was assessed using the following codes: (a) level of family impairment (reverse scored), (b) degree to which the family was disengaged (reverse scored), (c) openness and warmth, and (d) ability to reach a resolution or agreement. Across the four waves of data collection, scale alphas ranged from .91 to .92 ($M = .92$) for the spina bifida group, and .90 to .96 ($M = .92$) for the comparison group. Interrater reliabilities ranged from .76 to .85 ($M = .81$) for the spina bifida group, and .73 to .90 ($M = .82$) for the comparison group.

Observed cohesion between parents during family interactions was also measured. Parental cohesion, or the degree to which parents presented as a united front, was reflected in their level of agreement on issues, supportiveness of each other's thoughts and ideas, and joint presentation of clear expectations to their child. Time 1 through Time 4 interrater reliabilities ranged from .53 to .69 ($M = .62$) within the spina bifida group. Due to low interrater reliabilities in the comparison group (range .04 to .64, $M = .47$), this variable was excluded from subsequent analyses.

Family stress. The Family Inventory of Life Events (FILE) assesses the frequency of life events and their impact on the family system (Olson et al., 1985), and was utilized as a measure of family stress. The current study utilized an extended version of this form, including the original 71 items regarding life events, such as marital relations, deaths, and moves, and 19 additional items designed by another investigator to capture additional relevant stressors (Judy Garber, personal communication, October 1993; see Holmbeck, Coakley et al., 2002). For each item, respondents were asked to specify whether a particular event had occurred within the past 12 months (i.e., "yes" = 1 or "no" = 0); the sum total of stressful life events that had occurred was used for the purposes of the current study. Parental perceptions of family stress were solicited at all four waves of data collection. For mother report, alphas ranged from .74 to .81 ($M = .78$) in the spina bifida group, and .80 to .88 ($M = .84$) in the comparison group. For father report, alphas ranged from .71 to .86 ($M = .80$) in the spina bifida group, and .82 to .85 ($M = .84$) in the comparison group.

Results

Overview of Data Analytic Approach

Five unique outcomes were assessed (family conflict intensity, FES family conflict, observed family cohesion, FES family cohesion, and family stress). Because data from multiple reporters were collected, a total of 10 "sets" of analyses were conducted. Given our interest in modeling developmental trajectories of various family-level characteristics, growth curve models were estimated using the mixed procedure in SAS statistical software (for examples, see DeLucia & Pitts, 2006; Singer, 1998). Models were structured to highlight the potential impact of our primary theoretical predictor variable, spina bifida status, on developmental trajectories of these family-level processes, as well as the moderating influences of SES, gender, and PPVT scores.

Our analytical approach was modeled closely after that described and illustrated by DeLucia and Pitts (2006). In the literature on longitudinal data analyses, these models have been referred to as growth curve models (Rogosa, Brandt, & Zimowski, 1982), hierarchical linear models (Bryk & Raudenbush, 1987), and random effects regression models (Gibbons et al. 1993; to name a few). Terminology varies by discipline and software preferences. The essential feature of the model is the researcher's ability to model the change process at both the aggregate and individual levels, and to

explicitly predict variability in the change process as a function of theoretical predictor variables. Our analytical approach unfolded in the following series of steps.

First, we estimated unconditional growth models to determine the functional form of growth in these various family processes. In all growth models described below, the "time" variable is youth age, which was centered at age 9 to represent the average age on the first assessment occasion. Our final growth models include a mixture of three general growth forms: (a) intercept only, (b) linear, and (c) quadratic. Intercept-only models are flat in that the predicted level of the outcome remains constant over time (for an example, see Figure 3). Linear models display some constant rate of change over time (i.e., every one unit increase in age is associated with a constant change in the outcome; for an example, see Figure 4). Quadratic models display trajectories that curve or bend (for an example, see Figure 2). In this analytical framework, it is possible to estimate both "fixed" and "random" trajectory components. Fixed trajectory components provide information about the average trajectory component (e.g., the average trajectory intercept). To the extent that significant individual-level variability exists around these average trajectory components (e.g., trajectory intercepts vary across study participants), this variability can be explicitly modeled in the form of random effects.¹ As we present each analysis we discuss the growth form (e.g., linear) and the specification of fixed and random trajectory components.

Moreover, this individual-level variability in the trajectory components can also be predicted from theoretically meaningful predictor variables. In the analyses that follow we were primarily interested in effects of illness status on the trajectory components. In other words, we were interested in testing whether growth trajectories of various family processes varied significantly as a function of illness status (e.g., whether increases in family stress were more dramatic in families of youth with spina bifida relative to families of comparison youth). As described above, prior cross-sectional work with these data suggested that three additional predictors be considered: (a) youth gender, (b) family SES, and (c) youth verbal ability. The possible moderating influence of these predictors on the illness status-trajectory component association was also examined. When present, significant interactions were probed and graphically displayed following the methods of Aiken and West (1991). Nonsignificant interactions were trimmed from final models.

Modeling Growth Over Time in Family Processes

Family conflict intensity. To reduce nonnormality, mother, father, and child report data were transformed by taking the natural logarithm of the original scales. The best-fitting growth model for mother-reported family conflict intensity was an intercept-only model (including both fixed and random intercepts). In other words, on average, mothers perceived levels of conflict intensity that were stable over time. Although significant variability in intercepts was detected (i.e., mothers varied significantly with

respect to their perceived level of conflict intensity), this variability was not explained by any of the predictor variables.

In contrast to the stable pattern of family conflict intensity described by mothers, the growth models for both father and child report of conflict intensity were quadratic. For father report, growth models included fixed and random effects for trajectory intercepts, linear, and quadratic components. Illness status interacted with SES in predicting variability in both the linear (estimate [est] = 0.008, standard error [SE] = 0.003, p -value [p] = .019) and quadratic (est = -0.001, SE = 0.001, p = .016) components. To probe these significant interactions we plotted growth curves by illness status at low (-1 *SD*), average (*M*), and high (+1 *SD*) values of SES (see Figure 1). At average and high values of SES, the simple group effects did not predict significant variability in the linear and quadratic effects (i.e., these trajectory components did not vary significantly as a function of illness status). At low values of SES, however, the simple group effects for both linear and quadratic components were significant (est = -0.154, SE = 0.058, p = .008; est = 0.022, SE = 0.009, p = .015, respectively). Comparison youth from low SES families displayed no growth in family conflict intensity. For youth with spina bifida, however, there was a significant and negative linear trend (est = -0.099, SE = 0.038, p = .010) and a significant and positive quadratic trend (est = 0.014, SE = 0.006, p = .023). As reflected in Figure 1, this pattern indicates an initial decrease in conflict intensity (captured by the linear component), followed by an increase (captured by the quadratic component).

For child report of conflict intensity, trajectory intercepts and linear components were estimated as both fixed and random effects. Because individual-level variability in the rates of trajectory curvature, captured by the random quadratic component was nonsignificant, the quadratic component was estimated as a fixed effect only (est = 0.007, SE = 0.003, p = .018). Illness status significantly predicted variability in linear components (est = -0.042, SE = 0.017, p = .014). At age 9, the linear component was negative and significant for the youth with spina bifida (est = -0.054, SE = 0.019, p = .005); for comparison youth, however, the linear component was nonsignificant. Although trajectory intercepts were not significantly different at age 9, by age 12, as the trajectories diverged over time, comparison youth had significantly higher levels of family conflict intensity (est = 0.440) than did youth with spina bifida (est = 0.340). By age 15, this difference was more pronounced (see Figure 2).

In summary, this pattern indicates that although youth with and without spina bifida report similar levels of family conflict intensity during pre- and early adolescence, their trajectories are quite different over time (see Figure 2).

¹ The best-fitting growth model (intercept-only versus linear) was determined by comparing the -2LL values from competing nested models (see Snijders & Bosker, 1999). All relevant statistics are available on request from the third author.

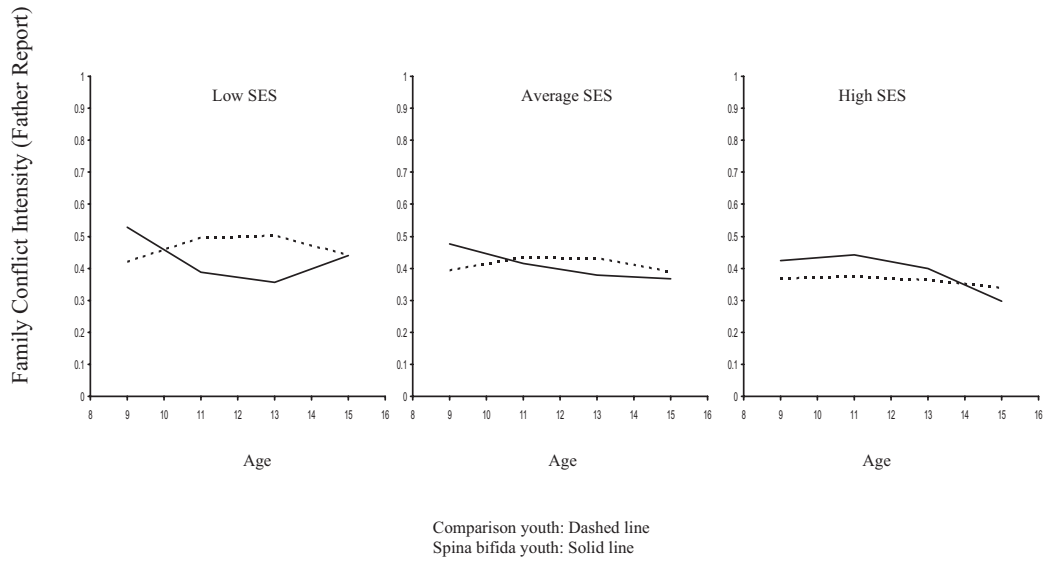


Figure 1. Illness status by socioeconomic status (SES) interaction in predicting conditional linear and quadratic growth rates of father report of family conflict intensity.

For youth with spina bifida, family conflict intensity decreases during pre- to early adolescence and stabilizes around age 12. In contrast, family conflict intensity is relatively constant during pre- to early adolescence for

comparison youth, and increases around age 12 through midadolescence.

FES family conflict. Mother and father perceived trajectories of family conflict were flat in nature, and included

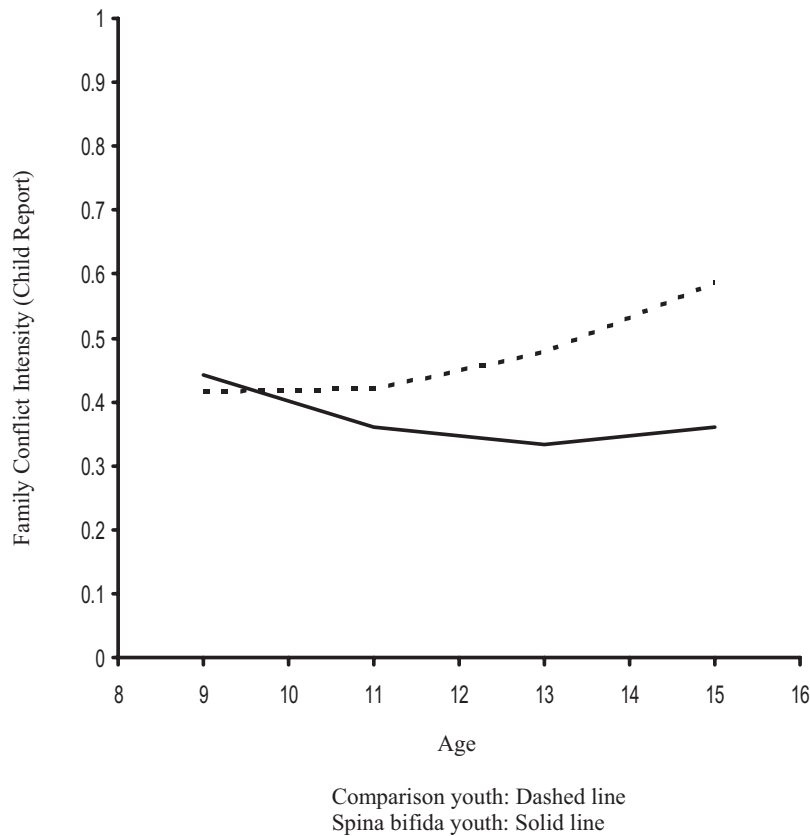


Figure 2. Illness status in predicting intercepts and conditional linear growth rates of child report of family conflict intensity.

fixed and random effects for trajectory intercepts only. For mother report, illness status was not a significant predictor of trajectory intercepts and the average trajectory intercept was 2.109. For fathers, however, illness status significantly predicted variability in family conflict intercepts (est = -0.24 , $SE = 0.074$, $p = .0017$). Fathers of youth with spina bifida reported significantly lower levels of overall family conflict (est = 2.00) than did fathers of comparison youth (est = 2.24, see Figure 3).

Observed family cohesion. To reduce nonnormality, observed family cohesion was transformed by taking the natural logarithm of the original scales. Growth over time was linear. Intercepts and linear components were modeled as fixed effects, but only intercepts were modeled as random effects. Average linear components varied significantly by illness status (est = 0.02, $SE = 0.008$, $p = .013$). Although both groups reported significant declines in family cohesion, these declines were less dramatic for families of youth with spina bifida (est = -0.017) than for families of comparison youth (est = -0.037 , see Figure 4).

FES family cohesion. The average trajectories of mother and father perception of family cohesion were stable over time with mothers (est = 3.04) and fathers (est = 2.95) reporting similar levels of family cohesion. Significant variability in the trajectory components was not associated with the predictor variables.

Family stress. Mothers and fathers reported on levels of family stress. Based on mother reports, growth over time in family stress was linear and included both fixed and random intercept and linear components. A significant illness status

by SES interaction was detected in predicting variability in intercepts (est = 0.23, $SE = 0.09$, $p = .01$). As can be seen in Figure 5, although at low levels of SES the difference between the group intercepts is statistically significant (est = -4.21 , $SE = 1.75$, $p = .018$), this difference is attenuated at higher levels of SES (and no longer significant). It is worth noting that at higher levels of SES the comparison group “crosses-over” the spina bifida group in that they experience lower levels of family stress on average. As can also be seen in the plot, comparison youth have a negative linear slope (est = -0.31 , $SE = 0.16$, $p = .04$). For youth with spina bifida, however, the association between age and life stress was relatively flat.

Father-reported growth over time in family stress was flat, including both fixed and random intercept components. Similar to mother-report models illness status interacted with SES in predicting variability in trajectory intercepts (est = 0.226, $SE = 0.097$, $p = .022$). Figure 6 shows a pattern of results conceptually similar to those observed for mother-report models. At low levels of SES, fathers of comparison youth reported higher levels of family stress than did fathers of youth with spina bifida. At average values of SES, the effect is attenuated and at higher values of SES, comparison youth “cross-over” youth with spina bifida and report lower levels of family stress.

Discussion

The purpose of this study was to compare changes in family processes occurring during the transition into ado-

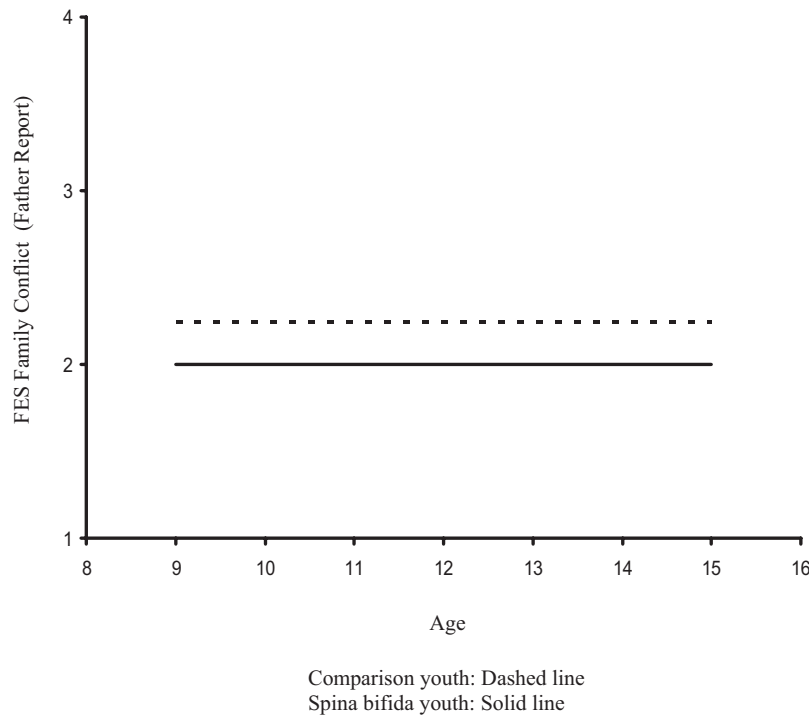


Figure 3. Illness status in predicting intercepts of father report of Family Environment Scale (FES) family conflict.

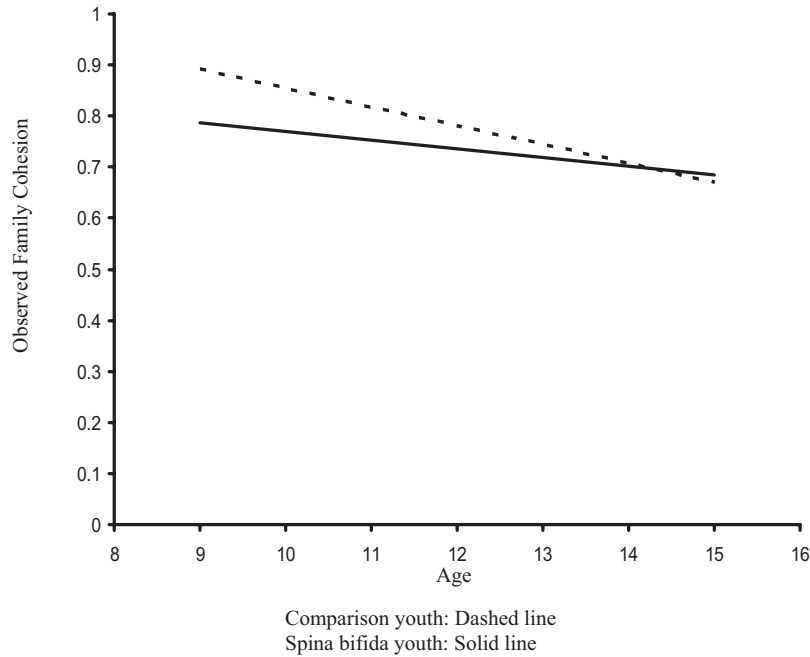


Figure 4. Illness status in predicting linear growth rates of observed family cohesion.

lescence for families of youth with and without spina bifida. Trajectories of change in family processes were described across four waves of longitudinal data collection, when youth were 9 to 15 years of age, using growth curve modeling procedures. Measures of family functioning included family conflict, cohesion, and stress. Specifically, analyses were conducted to test whether illness status would predict variability in family processes. In addition, potential moderators (child gender, SES, and verbal ability) of the association between illness status and family functioning were examined.

It was predicted that illness status (i.e., presence of spina bifida) would significantly predict individual variability in family functioning. Specifically, families of children without a chronic illness were expected to demonstrate increases in family conflict and decreases in family cohesion over time, consistent with typical adolescent development. In contrast, changes in family processes in families of youth with spina bifida were expected to occur later or to a lesser degree. In addition, families of youth with spina bifida were expected to report higher levels of stress than families in the comparison group, overall. Stress in families of adolescents

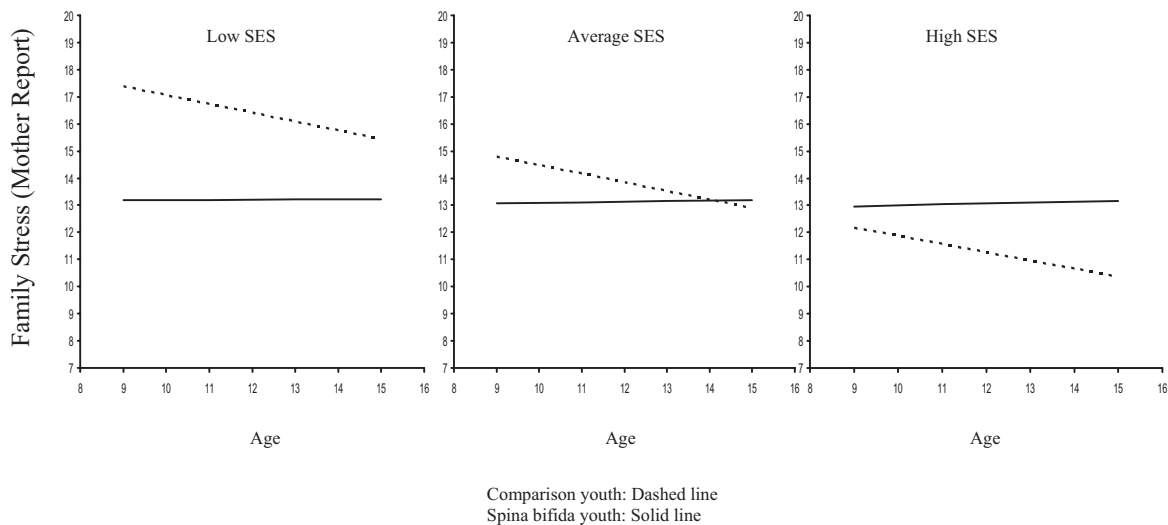


Figure 5. Illness status by socioeconomic status (SES) interaction in predicting intercepts of mother report of family stress.

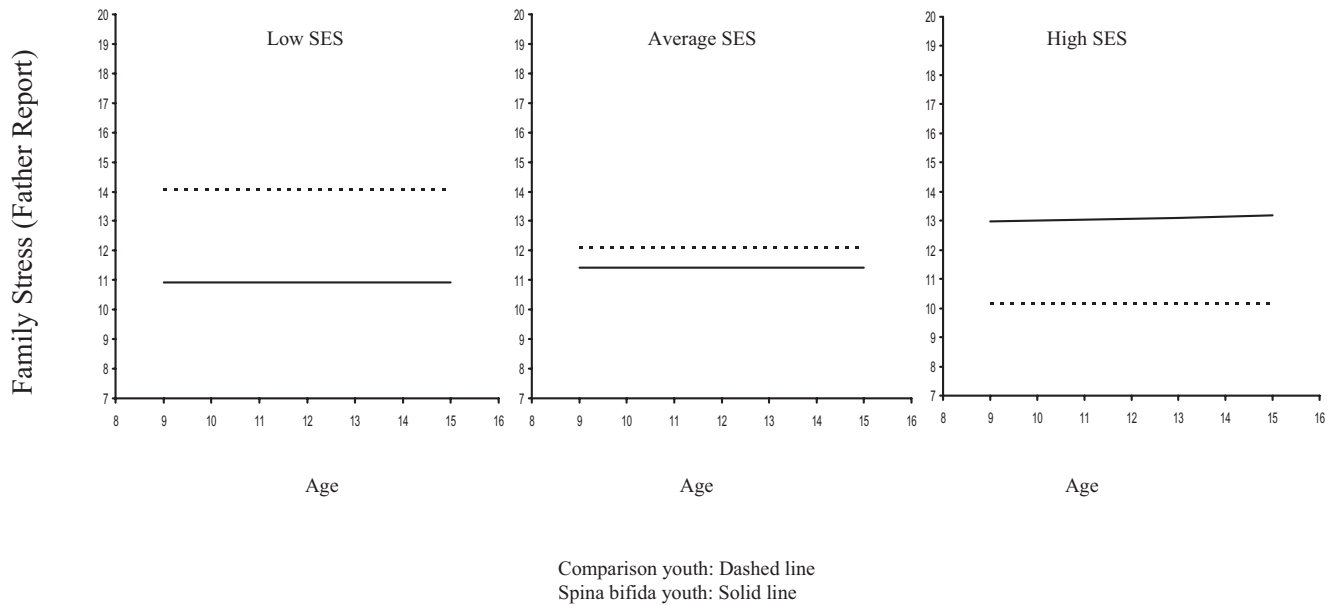


Figure 6. Illness status by socioeconomic status (SES) interaction in predicting intercepts of father report of family stress.

without spina bifida was expected to increase over time, in conjunction with other normative changes in family adjustment. In the context of low SES and youth verbal ability, families of youth with spina bifida were expected to demonstrate the highest levels of risk for discrepant developmental patterns (e.g., higher overall levels of stress and decreased sensitivity to normative developmental changes). Child gender was not expected to moderate the relationship between illness status and trajectories of family processes.

With respect to the hypothesized differences in developmental trajectories between groups, significant results were generally consistent with expectations. Findings indicated that families of youth with spina bifida may demonstrate a smaller degree of change or deviations in patterns of change in family processes than are typically observed in youth negotiating the transition to adolescence (Coakley et al., 2002). For some analyses, SES moderated the relationship between illness status and developmental trajectories of family functioning. In contrast, differences in developmental trajectories between groups did not vary according to child gender or verbal ability. Finally, results were found to differ somewhat depending on methodology (i.e., questionnaire versus observational data) and reporter.

The literature on adolescent development has suggested that family conflict and cohesion represents aspects of family functioning critical to individual maturation and adjustment (Cox & Brooks-Gunn, 1999). Family conflict is expected to increase during early adolescence as parents and children negotiate changes in level of responsibility for everyday tasks (Arnett, 1999; Laursen et al., 1998). Contrary to expectations, some of our findings suggested that trajectories of family conflict are largely stable over time (e.g., for father report of overall family conflict). On the other hand, child report of conflict intensity followed the

expected developmental pattern. Specifically, as commonly reported in the literature (Laursen et al., 1998), typically developing youth reported increases in conflict intensity during the transition to adolescence. Interestingly, youth with spina bifida did not report such increases. Similar group differences were found for low SES fathers' reports of conflict intensity. Given that findings for conflict intensity differed from those for reports of overall levels of conflict, it may be that the group differences in developmental trajectories only emerge when assessing the emotional intensity of conflict (Laursen et al., 1998), rather than when assessing the overall frequency of conflict.

The results also suggested that significant group differences in family conflict were generally consistent with study hypotheses. Specifically, families of youth with spina bifida demonstrated lower levels of family conflict over time (i.e., father report of overall family conflict, child report of conflict intensity). This may indicate that youth with spina bifida were less likely to challenge their parents' authority regarding who had decision-making jurisdiction over important family-related issues (Smetana, 1995).

Considering the multiple tasks associated with spina bifida, individuating from parents may be overwhelming or may undermine the possibility of optimal family functioning and medical management. The literature on families of youth with type 1 diabetes lends support to the importance of continued parental involvement in medical management throughout adolescence (Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997). Thus, for youth with spina bifida, perturbations in the level of family conflict consistent with typical adolescence may occur more gradually or, alternatively, may lag behind typically developing peers and occur later in adolescence. A recent study conducted on this sample found that adolescents with spina bifida demon-

strated delays in the development of independent behavior (Friedman, Holmbeck, DeLucia, Jandasek, & Zebracki, 2009), lending some support to this hypothesis; however, studies assessing youth in families in later adolescence and emerging adulthood are sorely needed.

Findings related to family cohesion indicated changes consistent with the expected adolescent developmental trajectory (i.e., decreased cohesion) or no changes in cohesion over time for both groups. Observational data indicated that changes in family processes consistent with typical adolescent development may occur to a lesser degree in the context of spina bifida. In families of typically developing youth, levels of family cohesion were observed to decrease more dramatically over time than in families of youth with spina bifida. Again, these results indicate that families of youth with spina bifida may be less responsive to developmental change during the early years of adolescence, perhaps because of the continued complex challenges involved with managing a medical condition. Management of day-to-day tasks in families of youth with spina bifida may necessitate a higher level of interdependence and close sharing of responsibilities between parent and child, thus precluding large developmental shifts expected to occur during adolescence. Further research, however, is needed to clarify associations between trajectories of family functioning and long-term psychosocial adjustment in the context of chronic illness. These associations are likely to support the disruption-resilience model indicating particular areas of strength and vulnerability characteristic of families affected by chronic illness. For example, although the patterns of family functioning described herein may be optimal for management of physical health, they also may imply increased risk in terms of independent functioning (Friedman et al., in press) and peer relationships.

Surprisingly, findings regarding trajectories of family stress were contrary to expectations. Depending on the variable or group under investigation, family stress was found to either decrease or remain stable throughout adolescence. Furthermore, spina bifida status was not associated with higher levels of stress. Findings that did emerge suggested that group differences depended on the level of SES. Specifically, levels of family stress were similar across both groups in families of high and average SES. In the context of low SES, the presence of spina bifida appeared to function as a protective factor. Specifically, for families of low SES, parents of youth without a chronic illness reported higher levels of stress than parents of youth with spina bifida. Perhaps, for these families, coping with stressors associated with low SES on a daily basis may serve to decrease attention to or perceptions of stress related to a chronic illness. Findings of past research have supported the notion that adjusting to socioeconomic strain may be more difficult than adjusting to the demands of caring for a child with special needs (Holmbeck, Coakley, et al., 2002).

The complex relationships that emerged between SES and family functioning lend support to Thompson's stress and coping model as well as the disruption-resilience model of pediatric adjustment (Costigan et al., 1997; Wallander et al., 2003). SES appears to be an important variable to

consider when studying adolescent development and family processes although its associations with adjustment may not always be straightforward. In the context of low SES, families of youth with chronic illness may demonstrate either higher levels of risk or resilience depending on the specific variable of interest.

As stated previously, findings varied according to reporter and method and did not consistently reflect the expected patterns of change in family functioning during the transition to adolescence. For example, in families of typically developing youth, parents generally perceived family conflict and cohesion to be stable over time. On the other hand, children in these families perceived the expected developmental increases in family conflict. Similarly, decreases in cohesion based on an observational measure were more dramatic in the comparison sample. Discrepancies across assessment methods are common and well documented (Holmbeck, Li, Schurman, Friedman, & Coakley, 2002), and may vary according to informant characteristics, contextual factors, and whether variables of interest are inferred as opposed to observed (Achenbach, 2006). For example, perhaps children's perceptions of increasing family conflict were reflective of a more internal process (e.g., increasing desire for autonomy) that had not yet been manifested behaviorally in the family context. Understanding the differential utility of various assessment methods and their associations with child and family adjustment is an area worthy of future investigation with high relevance to clinicians working with families and youth.

There are several limitations of the current study that should be noted. First, samples sizes were relatively small. Use of larger sample sizes would allow for a more detailed investigation of within group differences and other variables that may impact family processes, such as illness severity, puberty, and specific aspects of neuropsychological functioning. Second, the current study was conducted with an ethnically homogenous sample. Inclusion of more Latino participants in future research is warranted given the high prevalence rate of spina bifida in this population (Lary & Edmonds, 1996). Third, the current study failed to account for the presence of other children in the family, aside from matching children according to their birth order. Given that siblings also impact family dynamics and that sibling roles may change in families where one child is chronically ill, future investigations of family development should incorporate the role of siblings. Fourth, the current study investigated family processes in youth from ages 8 to 15 years. Future research with an expanded age range could address questions uncovered by the current investigation (e.g., are developmental processes in adolescents with spina bifida simply delayed or are they qualitatively different?) Fifth, exploring associations between family process trajectories and various aspects of psychosocial adjustment would help to inform intervention and clinical practice. Finally, developmental constructs (e.g., family conflict) assessed in the current study were operationally defined consistent with a typical developmental perspective to facilitate comparisons with youth without chronic illness. Although informative, it is important to note that such an approach may overlook

significant variation that is only relevant to families of youth with chronic physical conditions. For example, it will be important to examine whether families of youth with a chronic illness argue about issues pertaining to chronic illness management and what role these disagreements play in the development of self-care over time.

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