

Mother–Adolescent Agreement Regarding Decision-Making Autonomy: A Longitudinal Comparison of Families of Adolescents with and without Spina Bifida

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Objective Longitudinal comparison of mother and adolescent agreement regarding decision-making autonomy for adolescents with and without spina bifida (SB). **Methods** Forty-two mother–adolescent dyads of adolescents with SB and 55 comparison dyads reported on who was responsible for decision-making across five waves of data collection, beginning at age 8 or 9 years through age 16 or 17 years. **Results** The proportion of tasks that dyads agreed were decided by adolescents increased over time for both samples beginning at age 12 or 13 years, but appeared to be delayed by roughly two years for youth with SB and was lower for youth with SB from lower socioeconomic (SES) backgrounds. Mothers and adolescents with low SES demonstrated higher proportions of tasks that dyads agreed were decided by mothers. **Conclusions** SB and low SES are risk factors for lower levels of agreed-upon decision-making autonomy. Future studies should examine how parent–adolescent agreement regarding autonomy relates to psychosocial outcomes.

Key words adolescence; decision-making autonomy; parent–adolescent agreement; spina bifida.

Achieving autonomy is a key developmental milestone of adolescence. The current study prospectively examined behavioral autonomy, defined as one's ability to make independent decisions and regulate his/her own behaviors (Feldman & Wood, 1994; Hill & Holmbeck, 1986; Silverberg & Gondoli, 1996). Specifically, this study examined mother–adolescent agreement regarding the acquisition of decision-making autonomy from late childhood through adolescence for a sample of youth with spina bifida (SB) and a comparison sample of typically developing adolescents. This topic is especially relevant for adolescents with SB, as recent findings have suggested a delay in autonomy for these youth, which has implications for future self-care and independence (Davis, Shurtleff, Walker, Seidel, & Duguay, 2006; Friedman, Holmbeck, DeLucia, Jandasek, & Zebracki, 2009). Research examining

both parental and adolescent perceptions of autonomy acquisition for youth with SB can provide guidelines for appropriate autonomy development during adolescence and the transition to young adulthood.

SB is a common birth defect, affecting 18 in every 100,000 newborns (Centers for Disease Control and Prevention [CDC], 2008). The condition is characterized by an incomplete closure of the spinal column during the early weeks of pregnancy. Children with SB often face a multitude of physical and medical challenges, including urinary, bowel, orthopedic, and neurological difficulties. The medical regimen and self-care tasks required to maintain optimal health can be demanding, including catheterization, bowel programs, shunt monitoring, and skin checks (Charney, 1992). Additionally, children with SB often have specific neuropsychological complications,

including difficulties with visual-spatial, organizational, and mathematical skills (Fletcher et al., 2004; Wills, Holmbeck, Dillon, & McLone, 1990).

Behavioral autonomy is a process that evolves gradually over several years, wherein caregivers relinquish responsibilities and decision-making authority throughout the adolescent developmental period (Holmbeck, 1996; Spear & Kulbok, 2004). Behavioral autonomy is expected to increase over the course of adolescence in typically developing youth, with older adolescents demonstrating greater independence in decision-making (Dowdy & Kliewer, 1998; Holmbeck, 1996). Behavioral autonomy is typically measured using adolescent or parent report on an autonomy inventory. Study findings have suggested that parents and adolescents view the sequence of autonomy acquisition similarly, though adolescents tend to expect autonomy at earlier ages than parents expect (Dekovic, Noom, & Meeus, 1997; Feldman & Quatman, 1988). Discrepancies in parent–adolescent perceptions of autonomy are important to examine as outcomes during critical developmental periods, such as adolescence, because they may prompt adaptive developmental changes in parent–adolescent roles and responsibilities as children age (Holmbeck et al., 1996; Holmbeck, Li, Schurman, Friedman, & Coakley, 2002). Moreover, discrepancies in parent–adolescent perceptions of decision-making responsibility may prompt conflict in family relationships or, for youth with chronic illness, conflict related to self-care and medical management (Holmbeck, 1996; Miller & Drotar, 2003).

The method through which parent–adolescent discrepancies are examined varies across studies (Holmbeck, Li et al., 2002). A discrepancy can be examined as a dichotomous variable (i.e., parent and adolescent either agree or disagree regarding who is responsible for making decisions regardless of whether ratings are in the direction of more or less decision-making autonomy for adolescents) or by examining the direction of the discrepancy (i.e., both the parent and adolescent believe that they are responsible or the parent reports that the adolescent is responsible whereas the adolescent reports that the parent is responsible). Different types of agreements and discrepancies have been linked to different outcomes, suggesting that the direction of agreement/disagreement is important (Anderson, Auslander, Jung, Miller, & Santiago, 1990; Butner et al., 2009; Miller & Drotar, 2003).

Researchers commonly utilize summary scores as the basis for comparing parent and child perceptions and determining if there is a discrepancy (i.e., a discrepancy is computed by subtracting the total score of one respondent from the total score of the other respondent). Although this

strategy allows for an examination of the direction of agreement or discrepancy, the use of a summary score is limited in that it provides only an average or overall sense of each individual's perspective and precludes a more nuanced examination of items on which reporters disagree. In fact, using this method, it is possible for two reporters to have the same total summary score (thus yielding a difference score of 0) but disagree on every item. An examination of agreement or discrepancy at the item-level avoids such distortions of the underlying data (for an example of item-level analysis, see Anderson et al., 1990, 2009).

Although the primary purpose of this study was to evaluate group (SB vs. comparison) differences in parent–adolescent agreement regarding decision-making autonomy, we also wanted to consider other factors that might influence parent–adolescent agreement (e.g., socioeconomic status [SES]). Because no literature exists for predictors of parent–adolescent *agreement* regarding decision-making autonomy, we focused on findings related to behavioral autonomy with typically developing youth as a useful starting point. Research has shown that authoritarian parenting styles are more common in families from lower SES backgrounds (e.g., Dornbusch, Ritter, Leiderman, & Roberts, 1987; Hoff, Laursen, & Tardif, 2002). Authoritarian parents tend to emphasize obedience and respect for authority, expecting rules to be followed without discussion or explanation (Baumrind, 1991). Authoritarian parents also tend to view decision making regarding adolescent tasks as falling within their own jurisdiction (Smetana, 1995); therefore, it is likely that parents from low SES backgrounds would report that they themselves are responsible for decision making for most tasks involving their adolescents. Adolescents may or may not agree with their parents; however, SES may influence how parents and adolescents perceive and report on who is responsible for decision-making autonomy. Additionally, low SES has been identified as a risk factor for a range of adjustment difficulties in children with SB (Holmbeck et al., 2003). Therefore, SES appears to be a salient factor to examine related to parent–adolescent agreement regarding decision-making autonomy. Intellectual functioning is another relevant factor that likely impacts the process of decision-making autonomy, especially for youth with SB. Previous studies of youth with SB have reported verbal IQ scores within the low average range (e.g., Wills et al., 1990). In line with such studies, we expected our sample of youth with SB to have lower verbal ability scores compared to typically developing youth, and therefore included this variable as a covariate in all analyses.

The main purpose of the current study was to examine changes over time in the proportion of items for which

parents and adolescents agreed that the parent or adolescent was responsible for decision-making autonomy with regard to personal issues (e.g., “how I spend my money”) and behavioral expectations (e.g., “whether I do chores around the house”) for adolescents with and without SB. For each item, parents and adolescents separately reported on who decided—the parent, the parent with adolescent input, the adolescent with parent input, or the adolescent. Agreement regarding decision-making autonomy was examined at each wave of data collection using: (1) the proportion of items where mothers and adolescents agreed that mothers were responsible for decision making (“agree, mother”), (2) the proportion of items where the dyads disagreed and each member of the dyad believed that he or she himself decided (“disagree, self”), (3) the proportion of items where the dyads disagreed and each member of the dyad believed that the other member decided (“disagree, other”), and (4) the proportion of items where respondents agreed that the adolescent decided (“agree, adolescent”; see Figure 1). We recognized that agreement regarding decision-making autonomy and autonomy were not completely independent issues; if agreement that the adolescent was responsible for decision making was high, it was likely that the adolescent’s decision-making autonomy was also high. Therefore, just as autonomy was expected to increase during adolescence, it was hypothesized that the proportion of items where the dyads agreed that adolescents had decision-making autonomy would increase over time for all youth; however, for adolescents with SB, the proportion of items where

dyads agreed that the adolescent had decision-making autonomy was expected to lag behind typically developing peers. Similarly, we expected that the proportion of items where the dyads agreed that mothers had decision-making autonomy would decrease over time, but less so for youth with SB. Given the salience of SES, especially for youth with SB, SES was considered as a predictor of parent–adolescent agreement regarding decision-making autonomy. It was expected that lower SES would be associated with a higher proportion of items in which parents and adolescents would agree that parents were responsible for decision making.

Method
Participants

Participants in this study were part of a larger, longitudinal study exploring family functioning and psychosocial aspects of development in children with and without SB (Holmbeck et al., 2003). Families of children with SB were recruited from three hospitals and a statewide SB association, and families from the comparison group were recruited from schools at which participating children with SB were enrolled. Data collection occurred every two years after the Time 1 data collection. This study examined data collected through the first five time points (ages 8/9, 10/11, 12/13, 14/15, and 16/17 years) from mother and child questionnaires. During the Time 1 data collection, participants included 68 families with a child aged 8 or 9 years who had SB and a matched comparison group of 68 families with a typically developing child (see Holmbeck et al., 2003 for details on matching and recruitment; samples were matched on 10 demographic variables, including age, gender, and SES). At Time 2, 67 (99% of original sample) SB and 66 (97% of original sample) comparison (C) families participated; at Time 3, 64 (94%) SB and 66 (97%) C families participated; at Time 4, 60 (88%) SB and 65 (96%) C families participated; and at Time 5, 52 (76%) SB and 61 (90%) C families participated. For all data analyses in this study, only families in which both the mother and the child completed the measure of interest at every time point were included, which resulted in 42 SB and 55 C families (62% and 81% of the original sample, respectively). Families of children with SB had higher attrition rates, $\chi^2(1) = 4.24$, $p < .05$, and were less likely to be included in analyses due to attrition or failure to complete the measure of interest at all five time points, $\chi^2(1) = 6.08$, $p < .05$.

Table I shows the demographics collected at Time 1 for the original full sample and this reduced sample of mothers and children who completed the measures of

		Adolescent Report			
		Parent Decides	Parent Decides with Adolescent Input	Adolescent Decides with Parent Input	Adolescent Decides
Mother Report	Parent Decides	1	2	3	4
	Parent Decides with Adolescent Input	Agree, Mother Category 1 5 6		Disagree, Self Category 2 7 8	
	Adolescent Decides with Parent Input	9	10	11	12
	Adolescent Decides	Disagree, Other Category 3 13 14		Agree, Adolescent Category 4 15 16	

Figure 1. Strategy for combining mother and adolescent data.

Table I. Demographics of Original (Full) and Completer (Reduced) Samples at Time 1

Characteristic	Original (Full) sample			Completer (Reduced) sample		
	SB <i>n</i> = 68	Comparison <i>n</i> = 68	SB vs. Comparison	SB <i>n</i> = 42	Comparison <i>n</i> = 55	SB vs. Comparison
Age, <i>M</i> (<i>SD</i>)	8.34 (0.48)	8.49 (0.50)	<i>t</i> (134) = -1.75	8.38 (0.49)	8.49 (0.51)	<i>t</i> (95) = -1.08
Gender						
% Male	54.41	54.41	$\chi^2(1) = 0.00$	52.38	54.55	$\chi^2(1) = 0.05$
% Female	45.59	45.59		47.62	45.45	
Ethnicity						
% White	82.35	91.18	$\chi^2(1) = 2.30$	90.48	90.91	$\chi^2(1) = 0.01$
% Other	17.65	8.82		9.52	9.09	
PPVT-R, <i>M</i> (<i>SD</i>)	92.49 (18.49)	108.97 (15.06)	<i>t</i> (133) = 5.68**	97.24 (15.78)	110.13 (15.37)	<i>t</i> (95) = -4.05**
Maternal age, <i>M</i> (<i>SD</i>)	37.74 (5.19)	37.74 (4.84)	<i>t</i> (134) = 0.00	37.90 (4.62)	37.96 (4.75)	<i>t</i> (95) = 0.06
% Married	80.88	69.12	$\chi^2(1) = 2.51$	78.60	72.70	$\chi^2(1) = 0.44$
Hollingshead SES, <i>M</i> (<i>SD</i>)	43.12 (10.6)	46.46 (10.9)	<i>t</i> (131) = -1.80	43.57 (10.4)	47.97 (10.7)	<i>t</i> (92) = -1.99*

p* < .05; *p* < .01.

interest at each time point. There were no differences in age, gender, ethnicity, maternal age, or maternal marital status for families included in the analyses versus those not included due to missing data for either the SB or Comparison groups. However, families in the comparison sample from high SES backgrounds were more likely to complete the measures over time relative to comparison families from low SES backgrounds, $\chi^2(1) = 4.2$, $p < .05$, whereas the difference between families from high or low SES backgrounds in the SB sample was not significant, $\chi^2(1) = 3.5$, $p > .05$. Additionally, children with SB who were included in analyses had higher receptive language abilities as measured by the Peabody Picture Vocabulary Test-Revised (PPVT-R) compared to those who were not included, $t(65) = 2.87$, $p < .01$, whereas there were no significant differences in PPVT-R scores in the comparison sample, $t(66) = 1.31$, $p > .05$.

All analyses were conducted with the reduced sample of families with complete data across all time points. As seen in Table I, slightly more half of the participants in the SB and comparison groups were male. Most of the participants were Caucasian (90% of SB group; 91% of C group). Participants also identified as African American (5% of SB group), Asian (4% of C group), Hispanic (2% of SB group), and other (2% of SB group; 5% of C group). There were no significant differences between groups in age, gender, ethnicity, maternal age, or parental marital status (see Table I). As expected, children with SB scored lower on average on the PPVT-R relative to children in the comparison sample, and PPVT-R score was used as a covariate in all analyses. Although the SB and comparison groups did not differ on SES at Time 1 in the full sample, in the reduced sample comparison families had slightly higher

Hollingshead SES scores as compared to families of children with SB. This difference in SES scores between the SB and comparison families appears to be due to differential attrition by families of typically developing youth with lower SES.

Of the 42 participants with SB, medical chart data indicated that 78.6% had myelomeningocele (MM), 16.7% had lipomeningocele, and 4.8% had another type of SB. Lesion levels were reported as 31.0% sacral (least severe), 61.9% lumbosacral or lumbar, and 7.1% thoracic (most severe). Sixty-four percent of the participants with SB had a shunt to treat hydrocephalus and on average had experienced 3.79 ($SD = 5.52$) shunt revision surgeries prior to Time 1. Maternal report at Time 1 was used to determine ambulation status: 26.2% ambulated without assistance, 64.3% ambulated using of braces, and 9.5% ambulated using a wheelchair. Within our group of participants with MM, lesion level, shunt status, and ambulation status are similar to other samples of youth with SB (e.g., Fletcher et al., 2005; Parkin et al., 1997). However, our sample of youth with SB included individuals with lipomeningocele, a less severe form of SB, and therefore the sample in this study had less medical severity as compared to other research samples that only include individuals with MM.

Measures

Demographics

The Parent Demographic Questionnaire (PDQ), developed for this study, was used to assess factors such as the child's age, the parents' education level, and the parents' occupation.

SES

The Hollingshead Four Factor Index of socioeconomic status was used to assess SES (Hollingshead, 1975). SES was derived by assigning a score to mothers' and fathers' occupations and education level. Education and occupation scores were combined and these scores were averaged across caregivers to calculate the family SES. In the case of single-parent families, or two-parent families in which only one parent was employed, that individual's score was used to represent the family. Higher scores reflect higher SES.

Medical Information

The Medical History and Adherence Questionnaire was used to assess shunt status, surgical history, and the primary orthopedic device used.

Agreement Regarding Behavioral Autonomy

The extent of the adolescent's independent decision making in the family context was assessed using a modified version of the Steinberg Decision-Making Questionnaire (SDMQ; Steinberg, 1987). Mothers and adolescents responded to 15 items assessing family decision-making responsibility for non-medical personal issues and behavioral expectations (e.g., in which clubs or hobbies the adolescent is involved; at what time must the adolescent be home). Reporters indicated whether parents or adolescents made the final decision about each issue or expectation in their household. Each item was rated as follows: (1) parent tells adolescent what to do, (2) parent and adolescent discuss the issue, but parent has the final say, (3) parent and adolescent discuss the issue, but adolescent has the final say, (4) the adolescent decides, or (5) not applicable. The original SDMQ provides only three choices (numbers 1, 2, and 4 above). The third choice, the parent and adolescent discuss but the adolescent has the final say, was added to capture a fuller range of possible responses. A response of "not applicable" was treated as missing data, as agreement or disagreement regarding responsibility for decision making cannot be calculated if the issue is perceived as not applicable. Within the SB group, alphas ranged from .69 to .93 ($M = .78$) for adolescent report and .80 to .92 ($M = .87$) for mother report across the five time points. Within the comparison group, alphas ranged from .76 to .88 ($M = .81$) for adolescent report and .61 to .83 ($M = .70$) for mother report across the five time points.

At each time point, mother and adolescent responses were compared at the item level. Responses from each dyad were placed into 1 of 16 combinations (four possible adolescent responses \times four possible mother responses; see Figure 1). These 16 combinations were then merged

into four categories to show agreement or disagreement for who is primarily responsible for decision making about each issue: (1) "agree, mother"—adolescent and mother agree that mother decides, (2) "disagree, self"—adolescent reports that the adolescent decides and the mother reports that the mother decides, (3) "disagree, other"—adolescent reports that the mother decides and the mother reports that the adolescent decides, (4) "agree, adolescent"—adolescent and mother agree that the adolescent decides. For each dyad, the proportion of the total responses that fell into each category was calculated to control for the number of questions answered (given that some items were viewed as not applicable for some adolescents). For example, in response to Item 1, if a mother were to say "parent decides" and the adolescent responded "adolescent decides with parent input," the dyad would receive a tally in box "3" for Item 1. The same procedure would be repeated for Items 2 through 15. Each of the four agreement/disagreement categories would be scored by summing the total number of scores within it (e.g., scores in boxes 3, 4, 7, and 8 would be summed to yield a total score for Category 2, "disagree, self") and then dividing by the total number of items completed (maximum = 15). This strategy provided a proportion of responses for each of the four categories (proportions could range from 0 to 1). For each dyad, adding the proportion of items in all four categories would equal 1. A supplementary online table shows the intercorrelations among the proportion of items in each category at each time period for each group (see Supplementary Digital Content 1). These proportions were utilized in all analyses.

Proxy for Verbal Intellectual Functioning

The PPVT-R (Dunn & Dunn, 1981), a test of receptive language abilities, was used to estimate the child's verbal intellectual functioning at Time 1. The PPVT-R has high levels of validity and reliability, correlating moderately with other measures of verbal intelligence (Sattler, 2002).

Procedure

This study was approved by university and hospital Institutional Review Boards. At each time point of the study, data were collected during 3-hr home visits by trained graduate and undergraduate research assistants. Informed consent from parents and assent from the adolescent were obtained at each visit. Each family member independently completed a series of questionnaires, including the Decision-Making Questionnaire, and participated in videotaped interaction tasks, which were not examined as part of this study. Families received monetary compensation upon completion of each visit.

Analytic Strategy

Repeated measures ($2 \times 2 \times 5$) analyses of covariance (ANCOVAs) were used to examine the effects of group, SES, and Group \times SES interactions on the proportion of items in each of the four agreement/disagreement categories separately over time, with PPVT-R scores as a covariate. Specifically, four repeated measures ANCOVAs were run—one for each of the four categories (i.e., [1] agree, mother; [2] disagree, self; [3] disagree, other; and [4] agree, adolescent; see Figure 1). The within subjects variable was time (i.e., five waves of data examining proportion of items for the specific category). The between subjects variables were group (i.e., scored 1 for SB group and 0 for C group) and SES (i.e., scored 0 for low and 1 for high). All possible interactions were also examined—Group \times SES, Group \times Time, SES \times Time, and Group \times SES \times Time. To simplify the analyses and the interpretation of the findings, a median split ($SES < 44.00 = 0$; $SES \geq 44.00 = 1$) was used to convert SES into a dichotomous variable. Results are presented by hypothesis. Although we did not have specific hypotheses related to proportion of items for which parents and adolescents disagreed (categories 2 and 3 in Figure 1), we included exploratory results related to the two disagreement categories. A power analysis was conducted prior to running analyses (Cohen, 1988). Based on a medium effect size $f = .25$, $\alpha = .05$, power = .80, and degrees of freedom of the numerator of F ratio (u) = 4, the adjusted sample size was calculated to be 39 per group, indicating that a total sample size of 210 was needed for the within subjects main effect and three-way interactions. Based on a large effect size $f = .40$, $\alpha = .05$, power = .80, and $u = 4$, the adjusted sample size was calculated to be 16 per group, indicating that a total sample size of 95 was required for the within subjects main effect and three-way interactions. Power analyses for between subjects interaction effects (Group \times SES) indicated that a total sample of 146 was needed to detect medium effects and a total sample of 72 was needed to detect large effects. Thus, our sample size of 42 in the SB group and 55 in the C group was sufficient to detect large effect sizes.

Results

Hypothesis 1

It was expected that the proportion of items where the dyads agreed that adolescents had decision-making autonomy would increase over time for all youth, but that adolescents with SB would lag behind their typically developing peers. This hypothesis was tested by examining main and interaction effects of group and time on the

proportion of issues where dyads agreed that the adolescent decided (category 4, “agree, adolescent,” in Figure 1). Mauchly’s tests indicated that the assumption of sphericity was violated for the within-subjects main effect of time, $\chi^2(9) = 26.92$, $p < .001$. Therefore, degrees of freedom were corrected using Huynh–Feldt estimates of sphericity ($\epsilon = .96$). As hypothesized, the proportion of issues where dyads agreed that adolescents were responsible for decision making significantly increased over time for both groups, $F(3.82, 351.48) = 2.71$, $p < .05$. Posthoc pairwise comparisons indicated significant increases between ages 10/11 and 12/13 years, $p < .05$, 12/13 and 14/15 years, $p < .01$, and 14/15 and 16/17 years, $p < .01$. However, there was also a significant Group \times SES \times Time interaction, $F(3.82, 351.48) = 2.79$, $p < .05$. Follow-up two-way repeated measures ANCOVAs were conducted separately for each group to interpret the interaction. For adolescents with SB, there was a marginally significant interaction between SES and time, $F(3.68, 143.58) = 2.48$, $p = .051$, with adolescents with SB and low SES showing lower proportions of issues where dyads agreed that adolescents decided over time as compared to adolescents with SB and high SES (see Figure 2). A significant SES \times Time interaction did not emerge for the comparison sample, $F(4, 208) = 0.87$, $p > .05$ (see Figure 2).

There was a significant between-subjects main effect for group, indicating that adolescents with SB exhibited a lower proportion of issues for which mothers and adolescents agreed that adolescents had decision-making responsibility compared to typically developing youth, $F(1, 92) = 4.20$, $p < .05$.

Hypotheses 2 and 3

It was hypothesized that the proportion of issues where dyads agreed that the mother had decision-making responsibility would decrease over time, but less so for youth with SB (Hypothesis 2). Furthermore, it was hypothesized that dyads from lower SES backgrounds would have a higher proportion of items on which mothers and adolescents agreed that mothers had decision-making responsibility (Hypothesis 3). Hypotheses 2 and 3 were tested simultaneously using a $2 \times 2 \times 5$ (group \times SES \times time) repeated measures ANCOVA for category 1, “agree, mother” (see Figure 1). Specifically, Hypothesis 2 was tested by examining main and interaction effects of group and time on category 1, “agree, mother”, and Hypothesis 3 was tested by examining main and interaction effects of group, SES, and time on category 1, “agree, mother”. Results indicated that although the proportion of issues where dyads agreed that mothers were responsible for decision making decreased over time for both groups, the main effect for

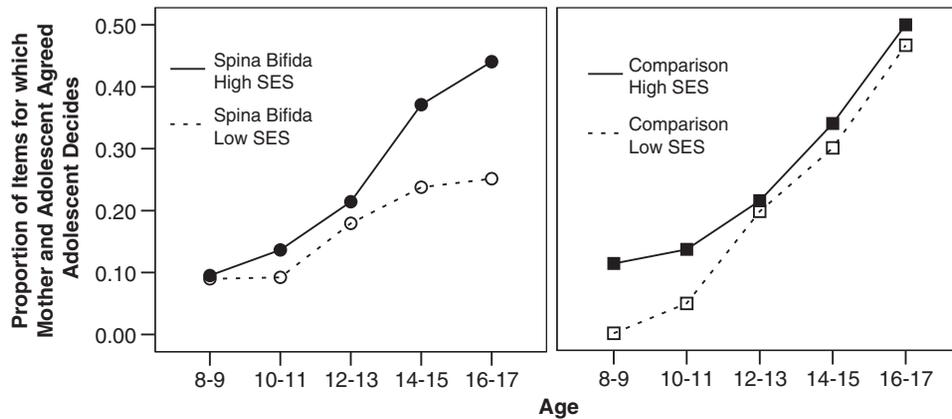


Figure 2. Three-way interaction of Group \times SES \times Time for the proportion of items for which mothers and adolescents agreed that the adolescent decides (category 4, “agree, adolescent,” in Figure 1).

time was only marginally significant, $F(4, 368) = 2.28$, $p = .06$. Additionally, the between-subjects main effect for group status and the Group \times Time interaction effect were not significant, in contrast to Hypothesis 2. With regard to Hypothesis 3, there was a significant main effect for SES, as mothers and adolescents from lower SES backgrounds showed a higher proportion over time of issues where they agreed that mothers decided, $F(1, 92) = 5.38$, $p < .05$. There were no significant SES \times Time or SES \times Group \times Time interactions.

We also visually displayed the data related to Hypotheses 1 and 2 as a timeline for mother–adolescent agreement regarding decision-making autonomy in Figure 3. This figure shows the average proportion of issues for which mothers and adolescents agreed that the mother was responsible (category 1 in Figure 1: “agree, mother”) and the average proportion of issues for which mothers and adolescents agreed that the adolescent was responsible (category 4 in Figure 1: “agree, adolescent”) for each group through all time periods. Points of interest are marked in the figure. Points 1 and 3 indicate the age at which mothers and adolescents agreed that the adolescent decided a higher proportion of issues as compared to the proportion of issues where mothers and adolescents agreed that the mother decided for the comparison group (point 1; ages 14–15 years) and the SB group (point 3; ages 16–17 years), respectively (see Figure 3). Point 2 indicates the age at which mothers and adolescents agreed that the adolescent had decision-making responsibility for more than 50% of the issues for the comparison group (ages 16–17 years). At the final time point (ages 16–17 years), dyads in the SB group had not yet reached the point where they agreed that adolescents had decision-making responsibility for more than 50% of the issues (see Figure 3).

Exploratory Analyses: Disagreement regarding Decision-Making Responsibility

The proportion of issues where dyads disagreed about responsibility for decision-making was generally low and stable across time (means for each group ranged from 0.16 to 0.26 across time periods for category 2, “disagree, self,” and from 0.05 to 0.10 across time periods for category 3, “disagree, other”). Each type of disagreement was examined separately. There were no significant within-subjects or between-subjects main or interaction effects with regard to the proportion of tasks in which the dyad disagreed and each reported that they decided themselves (category 2 in Figure 1, “disagree, self”) or with regard to the proportion of tasks in which the dyad disagreed and each reported that the other decided (category 3, “disagree, other”).

Discussion

The purpose of this study was to examine mother–adolescent agreement regarding decision-making responsibility for personal and behavioral expectation issues from late childhood through adolescence. Results indicated that the proportion of issues for which dyads agreed that the adolescent had decision-making responsibility increased over time for both adolescents with SB and adolescents from the comparison group, with significant increases beginning between ages 10/11 and 12/13 years. Furthermore, typically developing adolescents showed higher proportions of tasks where dyads agreed that the adolescent was responsible, consistent with our first hypothesis. However, there was a Group \times SES \times Time interaction, suggesting that adolescents with SB and low SES showed

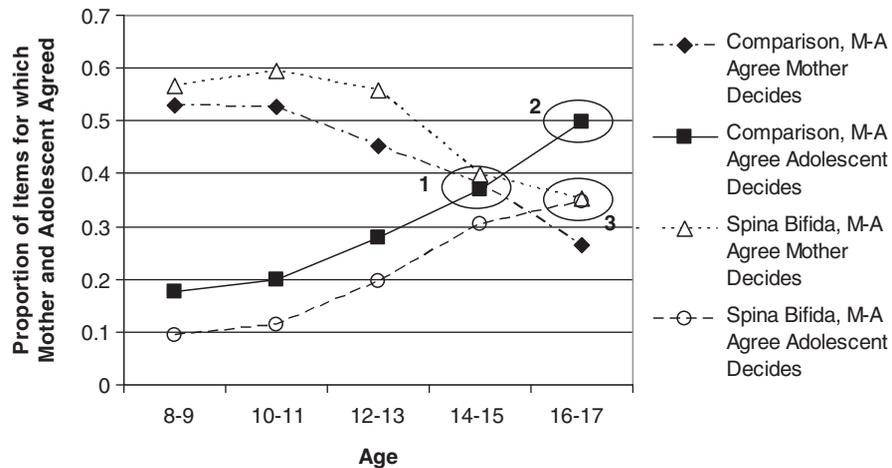


Figure 3. Proportion of items where dyads agreed that the mother decided and where dyads agreed that the adolescent decided for SB and comparison groups longitudinally. M = mother; A = adolescent; 1 = point at which the proportion of issues that mothers and adolescents agreed were decided by the adolescent exceeded the proportion of issues that mothers and adolescents agreed were decided by the mother for the comparison group; 2 = point at which the proportion of issues that mothers and adolescents agreed were decided by the adolescent was the majority (>50%) of issues for the comparison group; 3 = point at which the proportion of issues that mothers and adolescent agreed were decided by the adolescent exceeded the proportion of issues that mothers and adolescents agreed were decided by the mother for the SB group.

the lowest proportions of tasks agreed to be decided by adolescents over time. Contrary to our second hypothesis, the decrease in the proportion of issues for which mothers and adolescents agreed that the mother decided was only marginally significant. This result suggests that mothers and adolescents agreed that mothers maintain decision-making responsibility for some issues throughout adolescence.

Visual examination of the timeline of mother-adolescent agreement regarding decision-making autonomy in Figure 3 revealed that the age at which the dyads agreed that adolescents, rather than mothers, had decision-making responsibility for a greater proportion of tasks, was later for youth with SB (approximately aged 16–17 years) relative to the comparison group (approximately aged 14–15 years). These results are consistent with a general lag in behavioral autonomy found in other studies of youth with SB (Davis et al., 2006; Friedman et al., 2009). Parental intrusiveness, found to be higher for youth with SB (Holmbeck, Johnson et al., 2002), may partly explain the lag in the proportion of issues that mothers and adolescents agreed were decided by adolescents, but this requires further exploration. It is also possible that parents of youth with SB begin transferring decision-making autonomy at the same age as parents of typically developing youth, but that successful transition takes longer and requires repeated teaching of various decision-making skills because of the difficulties in executive function that typically occur in youth with SB (Fletcher & Dennis, 2010; Wills et al., 1990). Independent decision-making might require more parental assistance, which may

partially explain why families of adolescents with SB agree on adolescent responsibility at a later age.

The lower proportions of personal and behavioral expectation issues agreed to be decided by the adolescent found for youth with SB may have important social implications. In general, youth with SB, as compared to typically developing youth, tend to be socially immature and passive, have fewer friends, and have limited social contacts outside of school (e.g., Blum et al., 1991; Ellerton, Stewart, Ritchie, & Hirth, 1996; Holmbeck et al., 2003). A lack of social contact and activities may either be a cause or consequence of lower levels of agreed upon decision-making autonomy for personal and behavioral expectation issues at home. For example, the decision-making questionnaire used in this study examined issues related to spending time with friends, what clothes the adolescent could wear, what clubs or hobbies the adolescent could pursue, TV choices, and curfew decisions. When adolescents and parents agree that the adolescent has decision-making responsibility for a low proportion of these issues, adolescents may be perceived as socially immature by peers and have fewer social contacts. Alternatively, when adolescents are socially immature, a lower proportion of issues agreed to be decided by adolescents may serve an adaptive role, protecting youth from premature decision-making responsibility. Examining associations among parent-adolescent agreement regarding decision-making autonomy and social outcomes is an area for future exploration.

With regard to agreement about maternal decision-making responsibility, SES appeared to be a significant factor for youth with and without SB. Consistent with

our third hypothesis, results suggested that compared to mothers and adolescents from high SES families, dyads from low SES families agreed that mothers made decisions for a higher percentage of tasks during adolescence, which is commonly recognized as a period during which parents transfer decision-making responsibility to adolescents. These results are consistent with the general developmental literature, which indicates that authoritarian parenting styles are more common in families from lower SES backgrounds (e.g., Dornbusch et al., 1987; Hoff et al., 2002) and authoritarian parents tend to be more demanding and controlling of their child's behaviors. Thus, the higher rate of this parenting style that is commonly observed among low SES families may underlie our findings. Examining parenting style in future research would help to clarify this issue.

Exploratory examination of disagreements regarding decision-making autonomy during adolescence indicated that the proportions of issues on which mothers and adolescent disagreed (categories 2 and 3 in Figure 1) were low and did not change significantly across time. The lack of change across time suggests that these discrepancies in mother-adolescent perceptions of decision-making autonomy are present throughout adolescence but are also relatively uncommon. Although the proportions of issues in which disagreements occurred were generally low, these discrepancies may impact important psychosocial and health outcomes (e.g., family conflict, adherence), and these types of associations need to be examined empirically.

In this study, adolescents with SB did not reach the point at which they and their mothers agreed that adolescents were responsible for making decisions about the majority of personal and behavioral issues (i.e., >50% of the 15 items), although the comparison group tended to reach this point at ages 16/17 years. Given that the complexity of personal and behavioral issues may increase during emerging adulthood (a developmental period from ages 18 to 25 years characterized by intense exploration and transitions in vocational, educational, and social domains; Arnett, 2000), it is unclear whether youth with SB will remain on a delayed trajectory, or whether they will fall further behind their peers. Again, greater involvement of parents in decision-making may or may not be adaptive for youth with SB. Research following youth with SB into emerging adulthood is necessary to answer these types of questions.

Several limitations of the current investigation should be noted. First, families of adolescents with SB showed greater attrition during the course of the study, which may limit generalizability of results. Youth with SB and

lower receptive language abilities were less likely to complete the decision-making measure over time, suggesting that our reduced sample was higher functioning than the original sample. Thus, the lag found in our study may actually be an underestimate of functioning in the general population of youth with SB. However, other factors that we did not control for may have influenced attrition and subsequently, the results. Furthermore, although our samples were matched on SES and other demographic characteristics at Time 1, adolescents from lower SES backgrounds were less likely to complete the decision-making measure over time, particularly in the comparison sample, which resulted in "completers" from the comparison group demonstrating higher SES on average in relation to "completers" from the SB group. The comparison families from low SES backgrounds who did not complete the study may have diverged on autonomy outcomes relative to those who completed the study, but there is no way to determine this. On the other hand, the examination of main and interaction effects of SES in our reduced sample helped to clarify the impact of SES on agreement regarding autonomy. Additionally, this sample of youth with SB included youth with MM and other types of SB, which may limit generalizability. Furthermore, given that this sample was ethnically homogeneous, future studies in this area should include a more diverse group of participants. Special efforts should be made to include Latino families because of the high rate of SB among these families (Holmbeck, Greenley, Coakley, Greco, & Hagstrom, 2006; Lary & Edmonds, 1996). Also, results are limited to the types of issues identified in the measure used and may not generalize to other types of decision-making issues. Finally, we used $\alpha = .05$ for all four ANCOVAs conducted and did not have adequate power to detect small effects given our sample size and the complexity of our design.

In sum, results of this study add to the current literature by showing a lag in the proportion of issues where parents and adolescents agreed that the adolescent was responsible for decision-making autonomy for youth with SB relative to comparison youth. We also identified youth with SB and lower SES as being particularly at-risk for lower proportions of tasks where parents and adolescents agree that the adolescent had decision-making responsibility. Furthermore, this study provides a novel approach for examining different types of agreements and discrepancies between adolescents and parents. Future research can utilize the fine-grained methodology employed in this study to examine the impact of different types of autonomy-related agreements and discrepancies on outcomes such as illness-specific family conflicts and medical

regimen adherence. This methodology has the advantage of specifying the direction of the discrepancy at the item level and can be useful for identifying patterns of family communication and processes of transitions for youth with different types of medical conditions. Specifically, category 3, “disagree, other” may indicate areas of decision-making neglect, whereby the parent and adolescent each believe that the other decides about a given issue. When this is the case, it is unlikely that the issue is being attended to well or at all, which could be associated with a risk for nonadherence to a medical regimen. Category 2, “disagree, self” may suggest areas of parental intrusiveness, such as when parents continue to maintain sole decision-making responsibility for issues where the adolescent is capable of assuming responsibility. This type of discrepancy may be associated with difficulties achieving independence in self-care or increased parent–adolescent conflict, which in turn could impact other areas, such as adherence and psychosocial functioning. These associations need to be examined empirically with relevant potential moderators included (e.g., SES and child’s age). If it is the case that these different types of discrepancies are suggestive of specific clinical outcomes, examining parent–adolescent discrepancies can be a useful tool for identifying areas of risk. Future studies should also examine how the lag in the proportion of issues agreed to be decided by adolescents relates to adaptive and maladaptive outcomes for youth with SB.

Supplementary Data

Supplementary data can be found at: <http://www.jpepsy.oxfordjournals.org/>.

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References

- Anderson, B., Auslander, W., Jung, K., Miller, J. P., & Santiago, J. (1990). Assessing family sharing of diabetes responsibilities. *Journal of Pediatric Psychology, 15*, 477–492.
- Anderson, B. J., Holmbeck, G., Iannotti, R. J., McKay, S. V., Lochrie, A., Laffel, L., . . . Laffel, R. (2009). Dyadic measures of the parent–adolescent

- relationship during the transition to adolescence and glycemic control in children with type 1 diabetes. *Families, Systems, & Health, 27*, 141–152.
- Arnett, J. J. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist, 55*, 469–480.
- Blum, R. W., Resnick, M. D., Nelson, R., & St. Germaine, A. (1991). Family and peer issues among adolescents with SB and cerebral palsy. *Pediatrics, 88*, 280–285.
- Butner, J., Berg, C. A., Osborn, P., Butler, J. M., Godri, C., Fortenberry, K. T., . . . Wiebe, D. J. (2009). Parent–adolescent discrepancies in adolescents’ competence and the balance of adolescent autonomy and adolescent and parent well-being in the context of type 1 diabetes. *Developmental Psychology, 45*, 835–849.
- Centers for Disease Control and Prevention [CDC]. (2008). Quick-stats: Spina bifida and anencephaly rates—United States, 1991, 1995, 2000, and 2005. *MMWR Weekly, 57*, 15.
- Charney, E. B. (1992). Neural tube defects: Spina bifida and myelomeningocele. In M. L. Batshaw, & Y. M. Perret (Eds.), *Children with disabilities: A medical primer* (3rd ed., pp. 471–488). Baltimore: Paul H. Brookes Publishing.
- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed.). Hillsdale, NJ: Lawrence Erlbaum Associates.
- Davis, B. E., Shurtleff, D. B., Walker, W. O., Seidel, K. D., & Duguay, S. (2006). Acquisition of autonomy skills in adolescents with myelomeningocele. *Developmental Medicine & Child Neurology, 48*, 253–258.
- Dekovic, M., Noom, M. J., & Meeus, W. (1997). Expectations regarding development during adolescence: Parental and adolescent perceptions. *Journal of Youth and Adolescence, 26*, 253–272.
- Dornbusch, S. M., Ritter, P. L., Leiderman, P. H., & Roberts, D. F. (1987). The relation of parenting style to adolescent school performance. *Child Development, 58*, 1244–1257.
- Dowdy, B. B., & Kliewer, W. (1998). Dating, parent–adolescent conflict, and behavioral autonomy. *Journal of Youth and Adolescence, 27*, 473–492.
- Dunn, L. M., & Dunn, L. M. (1981). *Peabody Picture Vocabulary Test Revised (PPVT-R)*. Circle Pines, MN: American Guidance Service.
- Ellerton, M. L., Stewart, M. J., Ritchie, J. A., & Hirth, A. M. (1996). Social support in children with

- a chronic condition. *Canadian Journal of Nursing Research*, 28, 15–36.
- Feldman, S. S., & Quatman, T. (1988). Factors influencing age expectations for adolescent autonomy: A study of early adolescents and parents. *Journal of Early Adolescence*, 8, 325–343.
- Feldman, S. S., & Wood, D. N. (1994). Parents' expectations for preadolescent sons' behavioral autonomy: A longitudinal study of correlates and outcomes. *Journal of Research on Adolescence*, 4, 45–70.
- Fletcher, J. M., & Dennis, M. (2010). Spina bifida and hydrocephalus. In K. O. Yeates, M. D. Ris, H. G. Taylor, & B. F. Pennington (Eds.), *Pediatric neuropsychology: Research, theory, and practice* (2nd ed., pp. 3–25). New York: Guilford.
- Fletcher, J. M., Dennis, M., Northrup, H., Barnes, M. A., Hannay, H. J., Landry, S. H., . . . Francis, D. J. (2004). Spina bifida: Genes, brain, and development. In L. Glidden (Ed.), *International Review of research in Mental Retardation* (Vol. 29, pp. 63–117). San Diego: Academic Press.
- Fletcher, J. M., Copeland, K., Frederick, J., Blaser, S. E., Kramer, L. A., Northrup, H., . . . Dennis, M. (2005). Spinal lesion level in spina bifida meningocele: A source of neural and cognitive heterogeneity. *Journal of Neurosurgery (Pediatrics)*, 102, 268–279.
- Friedman, D., Holmbeck, G. N., DeLucia, C., Jandasek, B., & Zebracki, K. (2009). Trajectories of autonomy development across the adolescent transition in children with spina bifida. *Rehabilitation Psychology*, 54, 16–27.
- Hill, J. P., & Holmbeck, G. N. (1986). Attachment and autonomy during adolescence. In G. J. Whitehurst (Ed.), *Annals of child development* (Vol. 3, pp. 145–189). Greenwich, DN: JAI Press.
- Hoff, E., Laursen, B., & Tardif, T. (2002). Socioeconomic status and parenting. In M. H. Bornstein (Ed.), *Handbook of parenting: Vol. 2. Biology and ecology of parenting* (2nd ed., pp. 231–252). Mahwah, NJ: Lawrence Erlbaum Associates Publishers.
- Hollingshead, A. A. (1975). Four factor index of social status. Unpublished manuscript, Yale University.
- Holmbeck, G. N. (1996). A model of family relational transformations during the transition to adolescence: Parent–adolescent conflict and adaptation. In J. A. Graber, J. Brooks-Gunn, & A. C. Petersen (Eds.), *Transitions through adolescence: Interpersonal domains and context* (pp. 167–199). Hillsdale, NJ, England: Lawrence Erlbaum Associates, Inc.
- Holmbeck, G. N., Johnson, S. Z., Wills, K. E., McKernon, W., Rose, B., Erklin, S., . . . Kemper, T. (2002). Observed and perceived parental overprotection in relation to psychosocial adjustment in preadolescents with a physical disability: The mediational role of behavioral autonomy. *Journal of Consulting and Clinical Psychology*, 70, 96–110.
- Holmbeck, G. N., Li, S. T., Schurman, J. V., Friedman, D., & Coakley, R. M. (2002). Collecting and managing multisource and multimethod data in studies of pediatric populations. *Journal of Pediatric Psychology*, 27, 5–18.
- Holmbeck, G. N., Westhoven, V. C., Phillips, W. S., Bowers, R., Gruse, C., Nikolopoulos, T., & Totura, C. M. W. (2003). A multimethod, multi-informant, and multidimensional perspective on psychosocial adjustment in preadolescents with spina bifida. *Journal of Consulting and Clinical Psychology*, 71, 782–796.
- Holmbeck, G. N., Greenley, R. N., Coakley, R. M., Greco, J., & Hagstrom, J. (2006). Family functioning in children and adolescents with spina bifida: An evidence-based review of research and interventions. *Journal of Developmental and Behavioral Pediatrics*, 27, 249–277.
- Lary, J. M., & Edmonds, L. D. (1996). Prevalence of spina bifida at birth—United States, 1983–1990: A comparison of two surveillance systems. *Morbidity and Mortality Weekly Reports*, 45, 15–26.
- Miller, V. A., & Drotar, D. (2003). Discrepancies between mother and adolescent perceptions of diabetes-related decision-making autonomy and their relationship to diabetes-related conflict and adherence to treatment. *Journal of Pediatric Psychology*, 28, 265–274.
- Parkin, P. C., Kirpalani, H. M., Rosenbaum, P. L., Fehlings, D. L., Van Nie, A., & Willan, A. R. (1997). Development of a health-related quality of life instrument for use in children with spina bifida. *Quality of Life Research*, 6, 123–132.
- Sattler, J. M. (2002). *Assessment of children: Behavioral and clinical applications* (4th ed.). La Mesa, CA: Jerome M Sattler Publisher.
- Silverberg, S. B., & Gondoli, D. M. (1996). Autonomy in adolescence: A contextual perspective. In G. R. Adams, R. Montemayor, & T. P. Gullotta (Eds.), *Psychosocial development during adolescence* (pp. 12–61). Thousand Oaks, CA: Sage Publications, Inc.

- Smetana, J. G. (1995). Parenting styles and conceptions of parental authority during adolescence. *Child Development, 66*, 299–316.
- Spear, H. J., & Kulbok, P. (2004). Autonomy and adolescence: A concept analysis. *Public Health Nursing, 21*, 144–152.
- Steinberg, L. (1987). Impact of puberty on family relations: Effects of pubertal status and pubertal timing. *Developmental Psychology, 23*, 451–460.
- Wills, K. E., Holmbeck, G. N., Dillon, K., & McClone, D. G. (1990). Intelligence and achievement in children with myelomeningocele. *Journal of Pediatric Psychology, 15*, 161–176.