

Self-Management, Satisfaction With Family Functioning, and the Course of Psychological Symptoms in Emerging Adults With Spina Bifida

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Objective To explore psychological symptoms in emerging adults with spina bifida (SB) and their association with self-management and satisfaction with family functioning. **Methods** Longitudinal data were collected at 2 time points, 15 months apart, in 48 individuals with SB. Reliable change indices and paired samples *t*-tests assessed change in anxiety and depressive symptoms. Hierarchical regression models explored the contributions of SB severity, family satisfaction, and self-management in explaining change in psychological symptoms. **Results** No significant group level differences in psychological symptoms were found across time in participants (Mean age 22 years), but significant individual-level change in anxiety symptoms ($n = 13$) and depressive symptoms ($n = 9$) was observed. Improved satisfaction with family functioning was associated with decreased anxiety symptoms ($b = -0.30$, $p = .02$), and increased SB self-management was related to reduced depressive symptoms ($b = -0.63$, $p = .01$). **Conclusions** Changes in self-management and satisfaction with family functioning may influence the course of psychological symptoms.

Key words emerging adulthood; family functioning; psychological symptoms; self-management; spina bifida.

Spina bifida (SB), a neural tube defect characterized by the improper closure of the spine early in embryonic development, is one of the more common birth defects worldwide with 1,500 infants born with SB every year in the United States (Canfield et al., 2006). As the result of significant advances in health care during the past 4 decades, nearly 75% of people with SB are now expected to live into adulthood (Bowman, McLone, Grant, Tomita, & Ito, 2001). Individuals with SB experience a wide range of neurological, orthopedic, cognitive, and physical deficits (Zebracki, Zaccariello, Zelko, & Holmbeck, 2010) and often require ongoing rehabilitation, condition management, and psychosocial support in their daily lives (Webb, 2010). Health and psychosocial challenges are evident throughout

the life span (Sawyer & Macnee, 2010), but emerging adulthood, conceptualized as a distinct developmental period that occurs between the ages of 18 and 25 years (Arnett, 2000), is a particularly complex and vulnerable time for this population (Essner & Holmbeck, 2010; Holmbeck, et al., 2010a).

The transition from adolescence into emerging adulthood for individuals with SB is characterized by a developmental push toward independence in the context of ongoing health needs, restricted experiences with self-management, and limited community integration (Bellin et al., 2011; Buran, Sawin, Brei, & Fastenau, 2004; Zebracki et al., 2010), giving rise to the potential for psychological distress. Previous studies have shown that

adolescents with SB are at higher risk for experiencing internalizing symptoms than their typically developing peers (Appleton et al., 1997; Holmbeck et al., 2010b), and this vulnerability appears to persist into adulthood. A small but growing body of research with emerging adults identified high rates of anxiety and depressive symptoms (Bellin et al., 2010; Kalfoss & Merckens, 2006), but the underlying mechanisms associated with the development of psychological distress in individuals with SB are not well understood (Schellinger, Holmbeck, Essner, & Alvarez, 2012).

In the bio-neuropsychosocial model of adjustment described by Holmbeck and Devine (2010), the psychological functioning of individuals with SB is affected by biological (e.g., SB severity), neuropsychological (e.g., executive functioning), and social (e.g., family functioning) factors that evolve and exert different influences over time. Investigations of psychological functioning in individuals with SB have primarily focused on the adolescent developmental period, but findings from these prior inquiries provide insights into how characteristics of the family environment may impact the development of psychological symptoms. Low maternal acceptance, high behavioral control, and high psychological control emerged as risk factors for depressive symptoms in a sample of adolescents with SB (Schellinger et al., 2012). Because the family context wields a strong social influence in this population (Holmbeck & Devine, 2010), even as they transition from adolescence into early adulthood (Bellin et al., 2010), dissatisfaction with family interactions may similarly increase vulnerability to psychological symptoms in emerging adults.

Challenges in meeting the developmental milestones associated with emerging adulthood, including obtaining employment and living independently in the community, may also predispose emerging adults with SB to psychological distress (Zebracki et al., 2010; Zukerman, Devine, & Holmbeck, 2011). Compared with typically developing peers, they are less likely to leave home, attend college, and be employed (Zukerman et al., 2011). For individuals with a complex disability, the development of self-management skills is essential to facilitate a successful transition into adulthood (Betz, 2004; Friedman, Holmbeck, DeLucia, Jandasek, & Zebrack, 2009; Sawin, Bellin, Roux, Buran, & Brei, 2009). However, our previous research with emerging adults with SB identified limited independence in the management of their condition (Bellin et al., 2011) and found low self-management competencies to be associated with preventable conditions, such as urinary tract infections, and increased healthcare utilization (Mahmood, Dicianno, & Bellin, 2011). It is possible that SB severity is a contributing factor to the observed discrepancies in

psychosocial functioning between young adults with SB and their peers, as higher spinal lesions are associated with poorer motor independence (Hetherington, Dennis, Barnes, Drake, & Gentili, 2006) and decreased self-management skills (Bellin et al., 2011).

In summary, although leading scholars in SB research consistently emphasize the need for research on psychosocial outcomes from a life span perspective (Holmbeck et al., 2010a; Sawyer & Macnee, 2010), emerging adulthood is an understudied area. Guided by the bio-neuropsychosocial model of adjustment in individuals with SB (Holmbeck & Devine 2010), the intent of the study is to advance knowledge of anxiety and depressive symptoms in emerging adults with SB and to provide a preliminary understanding of the longitudinal effects of SB severity and changes in satisfaction with family functioning and self-management skills on psychological symptoms. It was hypothesized that (a) anxiety and depressive symptoms would increase from Time 1 to Time 2 and (b), after controlling for the effects of SB severity, change in family satisfaction and self-management would explain variation in depressive and anxiety symptoms across time.

Methods

Participants

Participants were part of a larger 3-year, three-wave study of health outcomes (preventable conditions such as pressure ulcers and urinary tract infections), health care utilization, and psychosocial adaptation (psychological symptoms and quality of life) in emerging adults with SB (Bellin et al., 2010, 2011; Mahmood et al., 2011). This study uniquely focuses on longitudinal data for depressive and anxiety symptoms collected at Time 1 and Time 2. The initial data cohort at Time 1 consisted of 61 participants recruited from five geographically diverse SB clinics sites in the United States. Three serve individuals with SB from birth through adulthood; two only provide clinical care to an adult population (≥ 18 years) (No differences in key demographics or study measures were found, so participants were combined for the analysis). Study eligibility criteria included: (a) primary diagnosis of SB, (b) 18–25 years of age based current theory of emerging adulthood (Arnett, 2000), (c) residence in catchment areas of participating sites, and (d) capacity to understand study instruments, which was assessed using an adapted version of the MacArthur Competence Assessment Tool (Bellin et al., 2010).

Procedure

The study was reviewed and approved by the institutional review boards associated with the participating clinics and

by the Professional Advisory Council of the Spina Bifida Association. Recruitment occurred via mailed letter of invitation and face-to-face contact during routine SB clinic visits. The mailed letters included an "opt out" postcard for the young adults to indicate their desire to not be contacted by study staff. Follow-up phone calls to screen for study eligibility and interest occurred approximately two weeks after the mailed letters of invitation. Following informed consent, participants were administered a self-report questionnaire of demographic questions and standardized measures of psychological symptoms and self-management described later in the text. Research staff performed a chart review to obtain SB clinical data. On completion of Time 2 data collection, participants received a \$40.00 gift card as an acknowledgment of their time. Per the study protocol, a copy of all de-identified study packets was sent to the project Principal Investigator for data management and analysis.

Of the original 168 eligible individuals who were contacted by study staff, 64 (38%) agreed to participate in the study. Face-to-face recruitment during routine SB clinic visits occurred at three sites and was notably more effective (25 out of 33; 76% acceptance rate) than recruitment solely via mail and phone contact (39 out of 135; 29% acceptance rate). This discrepancy in enrollment rates reflects difficulties related to reaching the young adults by phone to ascertain study eligibility and interest. It is also possible that executive functioning difficulties that impair activity initiation and follow-through contributed to the lower enrollment rates for the mail and phone recruitment procedures (Zebracki et al., 2010). Three individuals failed the competence screening, resulting in a final Time 1 sample of 61 young adults with SB.

Time 1 and Time 2 data were successfully collected approximately 15 months apart for 48 of the original 61 participants (79% retention rate). Three participants withdrew from the study because of the length of data collection procedures, and the remainder either moved out of the study area or was lost to follow-up. Attrition analyses demonstrated no significant differences in key demographics (e.g., gender, age, employment), SB clinical features (e.g., myelomeningocele vs. other type of SB), or study outcomes (e.g., depressive and anxiety symptoms, satisfaction with family functioning, self-management) for participants who completed both Time 1 and Time 2 data points and those who completed Time 1 only.

Measures

Spina Bifida Severity

Because of the small sample size limiting the number of variables entering the analysis, a SB severity index was

formed based on the work of Hommeyer, Holmbeck, Wills, & Coers (1999) and included the following variables: (a) shunt status (1 = no, 2 = yes); (b) myelomeningocele (1 = no, 2 = yes); (c) lesion level (1 = sacral, 2 = lumbar, 3 = thoracic); and (d) ambulation status (1 = no assistance, 2 = needs assistive devices to walk, 3 = wheelchair use). Scores range from 4 to 10, with higher levels reflecting greater severity. The validity of the severity index was previously established by Hommeyer and colleagues (1999) who observed a significant association with health professionals' rating of SB severity ($r = 0.60$, $p < .001$; Time 1 Cronbach's $\alpha = 0.70$). Internal consistency of the index in this sample is 0.69. SB severity scores ranged from 4 to 10 ($M = 7.70$, $SD = 1.68$).

Satisfaction With Family Functioning

The Family APGAR offered a self-report assessment of how satisfied participants were with family interaction (Austin & Huberty, 1989). The scale measures five dimensions of family functioning: Adaptation, Partnership, Growth, Affection, and Resolve (five items; e.g., "I am satisfied that my family accepts and supports my wishes to take on new activities or directions" and "I am satisfied with the way my family expresses affection and responds to my emotions."). Higher scores on the Family AGPAR (items range from 1 = Never to 5 = Always) reflect greater levels of family satisfaction. The measure has established reliability and validity for use with individuals with SB (Sawin, Brei, Buran, & Fastenau, 2002; Sawin, Buran, Brei, & Fastenau, 2003); internal consistency in this sample was 0.91 at Time 1 and 0.94 at Time 2.

Self-Management

The Adolescent Self-Management and Independence Scale II (AMIS II) was used as an index of the participant's level of self-management (Buran, Brei, Sawin, Stevens, & Neufeld, 2006). The AMIS II is a structured clinical interview designed to systematically collect information about participant SB knowledge and management behaviors, as well as skills for general activities of daily living. Confirmatory factor analysis supports two factors—(a) Self-management: Condition (seven items; i.e., managing SB medication, SB knowledge, SB complication prevention, personal safety, advocacy, accessibility, and family involvement in managing SB) and (b) Self-management: Independent living skills (10 items; i.e., managing money, transportation, making money, community living skills, ordering supplies, managing insurance, household skills, health care appointments, social communication, and general problem solving). The fit statistics support

a good fit of the data to this model (reliabilities ranged from $r = 0.72$ to $r = 0.89$; Buran et al., 2006). Study staff rate participant descriptions of their self-management activities on a 7-point response category (1 = *total assistance* to 7 = *complete independence*). Similar to the process used for other functional assessment tools, inter-rater reliability was established with standard case scoring by data collectors on two cases developed by one of the AMIS II developers before beginning Time 1 data collection and again before Time 2 data collection ($r = 0.90$). Good internal reliability for the AMIS II was found in this sample (Self-management: Independent living skills was 0.90 at Time 1 and 0.85 at Time 2; Self-management: Condition was 0.86 at Time 1 and 0.81 at Time 2).

Psychological Symptoms

The Hopkins Symptom Checklist (HSCL-25) was administered as a self-report measure of psychological distress (Hesbacher, Rickels, Morris, Newman, & Rosenfeld, 1980). It is comprised of a 15-item depressive symptoms scale and a 10-item anxiety symptoms scale, with items ranging from 1 (*Not at all*) to 4 (*Extremely*). A mean item score of ≥ 1.75 is used as the cut-point for clinically significant symptoms on each of the scales (Winokur, Winokur, Rickels, & Cox, 1984). Following the Institution Review Board protocol, participants who scored above the clinical cut-point at each data collection period were referred to local mental health services. The HSCL-25 has an acceptable degree of sensitivity and specificity to formal psychiatric diagnostic criteria (Veijola et al., 2003), and has been previously used as a screening instrument for psychological symptoms in adults with SB residing in the United States and internationally (Kalfoss & Merckens, 2006). The anxiety symptoms subscale demonstrated an appropriate level of internal consistency (0.80 at Time 1 and 0.80 at Time 2), as did the depressive symptoms subscale (0.90 at Time 1 and 0.91 at Time 2). A moderate association among participants' depressive and anxiety symptoms was observed at Time 2 ($r = 0.69$, $p < .001$), which was consistent with the Time 1 relationship ($r = 0.61$, $p < .001$).

Data Analysis

Data analyses were run using Predictive Analytics Software SPSS (PASW version 18, 2009). The first set of analyses included descriptive statistics and examination of individual-level differences (i.e., change/difference scores) across time (Rogosa, Bradt, & Zimowski, 1982). There are several statistical techniques appropriate for analyzing change over time, including analysis of change scores based on raw data, analysis of residualized change, and repeated measure analysis (Everitt & Pickles, 2004;

Hand & Taylor, 1987). Residual analysis focuses on differences between observed and predicted Time 2 scores using Time 1 scores as a covariate. However, the analysis of residuals answers a different research question than the one proposed in this study in that it examines individual-level change relative to the entire group, whereas analysis of change scores examines individual-level change relative to the individuals themselves. Furthermore, analysis of change scores can be used to model individual-level change in situations where some participants' scores are increasing while other participants' scores decrease or stay static. Rogosa (1988, p. 180) argued that the use of change scores represents an "unbiased estimate of true change." There are limitations to the use of change scores (i.e., reliability and correlation of scores at different time points), but these issues are frequently exaggerated (Gottman & Rushe, 1993) and primarily associated with designs that include between-group analyses instead of only within-group comparisons (Allison, 1990). Rogosa et al. (1982) and Chiou & Spreng (1996) have argued that the reliability of change scores is maximized when (a) reliability is high for each individual component measure (e.g., pretest and posttest), and (b) the correlation between component measures is moderate. As detailed earlier, all measures had acceptable internal consistency at both time points. Additionally, correlations between Time 1 and Time 2 scores (i.e., test-retest reliability) fell in the moderate-to-high range: APGAR (0.66), Self-management: Condition (0.73), Self-management: Independent living (0.82), Anxiety symptoms (0.67), and Depression symptoms (0.57).

Change scores for the study variables were derived by subtracting Time 1 scores from Time 2 scores; positive values indicated an increase in scores over time, and negative values indicated a decrease in scores over time. Reliable Change Indices (RCI) were used to assess the statistical significance of individual-level variation in anxiety and depressive symptoms and were calculated as the difference in scores between time points divided by the standard error of the difference in scores between time points (Jacobson & Traux, 1991). RCI values more than ± 1.96 indicate statistically significant differences at $\alpha = 0.05$. Tests of differences in mean scores in anxiety and depressive symptoms at Time 1 and Time 2 were conducted using paired samples *t*-tests.

Finally, after establishing that the assumptions of multiple regression were met (e.g., normal distribution, linearity, independence, and homoscedasticity of residuals), two hierarchical regression analyses were run to provide a preliminary understanding of the contribution of change in family satisfaction and self-management in explaining differences in anxiety and depressive symptoms over time.

In both analyses, SB severity was entered in Model 1, and change scores for satisfaction with family functioning and the self-management factors were entered in Model 2. The total variance accounted for by the factors (Model R^2), and the significance of additional explained variance associated with each step of the model were examined (Model $R^2\Delta$).

An a priori power analysis using $\alpha=0.05$ and $\beta=0.20$ was conducted using G*Power (v. 3.0.10, 2007). For the proposed paired samples *t*-tests, the necessary sample size was 12 participants for detecting a large effect (Cohen's $d=0.8$). Tests of large effect sizes for correlations ($r=0.5$) required 21 participants. A sample size of 40 was required for the proposed multiple regression analysis with four predictors in the model and a large effect size of $f\text{-square}=0.35$ (Dattalo, 2008).

Results

At Time 2, the mean age of the sample was 22.04 years ($SD=2.16$; range 19–26 years). The participants were primarily Caucasian ($n=37$, 77%), and a slight majority was female ($n=26$, 54%). Thirty-one (64.6%) of the emerging adults reported residence at the home of their parents/guardians or in a supervised living setting (e.g., group home). The highest level of education achieved at Time 2 varied among participants, but the majority had graduated high school or had obtained their GED ($n=24$, 51.0%). Fourteen were in college or a technical/vocational school (29.8%), six were in high school (2.8%), two had completed college (4.3%), and one had dropped out of high school (2.1%). The majority of participants were unemployed ($n=26$, 54.2%), and those who were employed on either a part-time ($n=17$, 35.4%) or full-time basis ($n=5$, 10.4%) held low-wage positions (e.g., guest services, sheltered workshop).

More than two-thirds had hydrocephalus requiring shunt placement ($n=33$, 68.8%), with an average of 2.95 ($SD=2.68$) surgical revisions to the shunt. Chart reviews performed by study staff revealed that the vast majority of participants had a primary diagnosis of myelomeningocele, the most severe form of SB ($n=41$, 85.5%), which is consistent with rates reported in other studies with this population (e.g., Boudos & Mukherjee, 2008; Zukerman et al., 2011). Other SB diagnoses included lipomyelomeningocele ($n=5$, 10.5%), and meningocele ($n=1$, 2.1%). A lumbar level of lesion (LOL) was most frequently reported in the medical chart ($n=27$, 56.3%), followed by a sacral LOL ($n=15$, 31.3%) and thoracic LOL ($n=6$, 12.5%).

Descriptive Analyses

Descriptive statistics for study variables are summarized in Table I. The sample mean score for the Family APGAR measure of family satisfaction remained consistent across time points ($t=0.26$, $p=.79$), but examination of individual change scores reflected some variation, ranging from -13 to $+7$ ($M=0.14$, $SD=3.88$). In contrast, both self-management subscale means at Time 2 were higher than what was observed at Time 1, reflecting an increase in self-management related to independent living skills ($t=5.01$, $p<.001$) and SB management ($t=3.57$, $p=.001$). Mean item scores were also calculated for the self-management factors to enhance understanding of where the participants fell on continuum for independence as measured by the AMIS II. Based on a possible range of 1–7, scores ranged from 2.20 to 6.90 ($M=4.88$, $SD=1.28$) for Self-management: Independent living skills and from 2.71 to 6.86 ($M=5.35$, $SD=1.18$) for Self-Management: Condition. According to the AMIS II scoring criteria (Buran et al., 2006), the participants continue to require “supervision/stand-by prompting” in SB self-care activities and “assistance/prompting” in skills related to activities of daily living.

At Time 2, 14 participants (29.2%) endorsed clinical levels of anxiety symptoms, and 15 (31.3%) reported depressive symptoms above the cut-point on the Hopkins Symptoms Checklist (Hesbacher et al., 1980). No statistically significant differences in proportions ($p>.05$) were found between these rates, and those observed at Time 1 for the full sample of 61 participants, in which 31.1% ($n=19$) reported scores above the clinical cut-off for anxiety symptoms and 41.0% ($n=25$) fell in the clinical range for depressive symptoms. Table II delineates consistent and discordant findings for clinical levels of anxiety and depressive symptoms among study participants across the two time points. At Time 2, there were no significant differences by gender in clinical levels of anxiety ($\chi^2=0.07$, $p>.05$) or depressive symptoms ($\chi^2=0.49$, $p>.05$), nor were gender differences observed in changes in anxiety ($t=-0.23$, $p>.05$) or depressive symptoms ($t=0.51$, $p>.05$) from Time 1 to Time 2. Similarly, SB type (myelomeningocele vs. other) did not differentiate differences in anxiety ($t=-0.40$, $p>.05$) and depressive symptoms ($t=-0.76$, $p>.05$) across time. However, change in anxiety symptoms from Time 1 to Time 2 was significantly associated with change in satisfaction with family functioning ($r=-0.36$, $p=.01$), with increased satisfaction with family functioning associated with decreased anxiety symptoms. In addition, change in depressive symptoms over time was related to SB severity ($r=0.29$, $p=.048$) and

Table I. Descriptive Statistics ($N = 48$)

Variable	Mean (SD)			Sample range (Scale range)		
	Time 1	Time 2	Change	Time 1	Time 2	Change
SB severity	7.70 (1.68)	NA	NA	4–10	NA	NA
SM: Independent living	42.04 (16.13)	48.77 (12.75)	6.75 (9.32)	17–70 (10–70)	22–69 (10–70)	–7 to +33
SM: Condition	34.04 (9.37)	37.42 (8.72)	3.38 (6.57)	7–49 (7–49)	15–49 (7–49)	–13 to +22
Family satisfaction	19.97 (4.48)	20.02 (4.88)	0.14 (3.88)	6–25 (5–25)	8–25 (5–25)	–13 to +7
Anxiety symptoms	15.84 (4.41)	15.39 (4.26)	0.46 (3.52)	10–25 (10–40)	10–26 (10–40)	–7 to +8
Depressive symptoms	25.52 (8.14)	25.27 (8.09)	–0.25 (7.73)	15–47 (15–60)	15–45 (15–60)	–24 to +18

Note. SM = Self-management.

Table II. Clinical Levels of Anxiety and Depressive Symptoms Across Time

	Anxiety symptoms	Depressive symptoms
Below cut-point at Time 1 and Time 2	28 (58.3%) RCI = 1(–) (3%)	24 (50.0%) RCI = 1(–) (4%)
Above cut-point at Time 1 and below cut-point at Time 2	6 (12.5%) RCI = 6(–) (100%)	9 (18.8%) RCI = 4(–) (44%)
Below cut-point at Time 1 and above cut-point at Time 2	5 (10.4%) RCI = 3(+) (60%)	4 (8.3%) RCI = 2(+) (50%)
Above cut-point at Time 1 and Time 2	9 (18.8%) RCI = 1(–) and 2(+)(33%)	11 (22.9%) RCI = 2(–) (2%)
Total	48 (100%) RCI = 13 (27%)	48 (100%) RCI = 9 (18%)

Note. The top set of numbers in each cell is relative to the total sample size ($N = 48$). The bottom set of numbers reflects the number of significant ($p < .05$). RCIs relative to the sample size of the cell. (+) indicates a positive RCI and (–) indicates a negative RCI.

change in Self-management: Condition ($r = -0.35$, $p = .01$). Improved self-management of SB from Time 1 to Time 2 was associated with a decrease in depressive symptoms, and greater SB severity was associated with an increase in depressive symptoms across time. No evidence of multicollinearity among study variables entering the regression models was observed (Table III); the only significant correlation among the predictors was for Self-management: Condition and Self-management: Independent living skills ($r = 0.71$, $p < .001$), but the association was below the standard cut-off value of 0.8 for multicollinearity (Cohen, Cohen, West, & Aiken, 2003).

Change scores for the psychological distress variables were normally distributed and ranged from -7 to $+8$ ($M = 0.46$, $SD = 3.52$) for anxiety symptoms and from -24 to $+18$ ($M = -0.25$, $SD = 7.73$) for depressive symptoms, with positive values indicating an increase in symptoms from Time 1 to Time 2 and negative values reflecting a decrease in symptoms over time (Figure 1). RCI revealed eight participants (17%) had statistically significant decreases in anxiety symptoms from Time 1 to Time 2, and five individuals (10%) endorsed significant increases over time ($RCI > \pm 1.96$, $p < .05$). Significant decreases in

depressive symptoms were found for five individuals (10%) across time points, and four of the emerging adults (8%) reported significantly higher depressive symptoms at Time 2 compared with Time 1 ($RCI > \pm 1.96$, $p < .05$). Paired samples t -tests revealed no significant differences in group mean scores on the HSCL-25 subscales for anxiety symptoms at Time 1 and Time 2 ($t = 0.90$, $p = .37$) or depressive symptoms over time ($t = 0.23$, $p = .82$).

Multiple Regression Analysis

Change in Anxiety Symptoms

As shown in Table IV, Model 1 was not significant ($R^2 = 0.03$, $F_{(1,47)} = 1.36$, $p = .25$), but Model 2, with the inclusion of the additional independent variables, yielded a significant small-to-moderate effect size (Cohen, 1988) of $R^2 = 0.19$ ($F_{(4,47)} = 2.99$, $p = .03$, 95% CI 0.01, 0.37). In the final model, only change in satisfaction with family functioning was a significant predictor of differences in anxiety symptoms ($b = -0.30$, $t = -2.37$, $p = .02$). This finding suggests that predicted change scores for anxiety symptoms will move further from zero in a negative direction (lower anxiety symptoms at Time 2 than Time 1),

as change scores for family satisfaction move further from zero in a positive direction (higher family satisfaction at Time 2 than Time 1). Specifically, for each 1-unit increase in family satisfaction over time (i.e., satisfaction with family functioning is higher at Time 2 than Time 1), there is a 0.30-unit decrease in change scores for anxiety symptoms.

Change in Depressive Symptoms

Model 1 of the hierarchical regression yielded a statistically significant R^2 of 0.08 ($F_{(1,47)} = 4.12, p = .048, 95\% \text{ CI } 0.01, 0.22$). SB severity was a significant predictor of change in depressive symptoms over time ($b = 1.28, t = 2.03, p = .048$); however, the relationship became non-significant when self-management and satisfaction with family functioning entered the model. The change in R^2 from Model 1 to Model 2 was statistically significant ($R^2\Delta = 0.20, F_{(3,43)} = 3.92, p = .015$), yielding a final model R^2 of 0.28 ($F_{(4,47)} = 4.16, p = .006, 95\% \text{ CI } 0.09, 0.44$), which is classified by Cohen (1988) as a moderate effect size. Change in Self-Management: Condition was the

only significant predictor in the final model ($b = -0.63, t = -2.87, p = .006$). As was the case in the interpretation of the significant regression coefficient in the anxiety symptoms model, the interpretation of the significant result for changes in self-management is based on both the magnitude of the change and the direction of the change relative to zero. The negative sign of the coefficient indicates that positive change scores for self-management of SB (higher scores at Time 2 than Time 1) are associated with negative change scores for depressive symptoms (lower scores at Time 2 than Time 1). Specifically, we expect that as change scores for the Self-Management: Condition factor move 1 unit from zero in a positive direction (increase from Time 1 to Time 2), that change scores for depressive symptoms will have a 0.63 point move from zero in a negative direction (decrease from Time 1 to Time 2).

Discussion

The purpose of this study was to advance knowledge of the course of psychological symptoms in emerging adults with SB and to offer a preliminary understanding of the longitudinal effects of condition severity, satisfaction with family functioning, and self-management on depressive and anxiety symptoms. Study findings did not support an overall increase in anxiety or depressive symptoms across time for the group, but the rates of psychological symptoms at Time 2 remained high, with over a quarter of participants endorsing clinical levels of anxiety symptoms, and nearly a third were above the cut-point for depressive symptoms. A comparison sample of typically developing peers was not

Table III. Intercorrelations Among Study Variables (N = 48)

	1	2	3	4	5	6
1. SB severity	—					
2. Δ SM: Independent living	0.13	—				
3. Δ SM: Condition	-0.03	.71**	—			
4. Δ Family satisfaction	0.05	0.05	0.16	—		
5. Δ Anxiety symptoms	0.17	-0.07	-0.26	-.36*	—	
6. Δ Depressive symptoms	.29*	-0.05	-.35*	-0.21	.46**	—

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

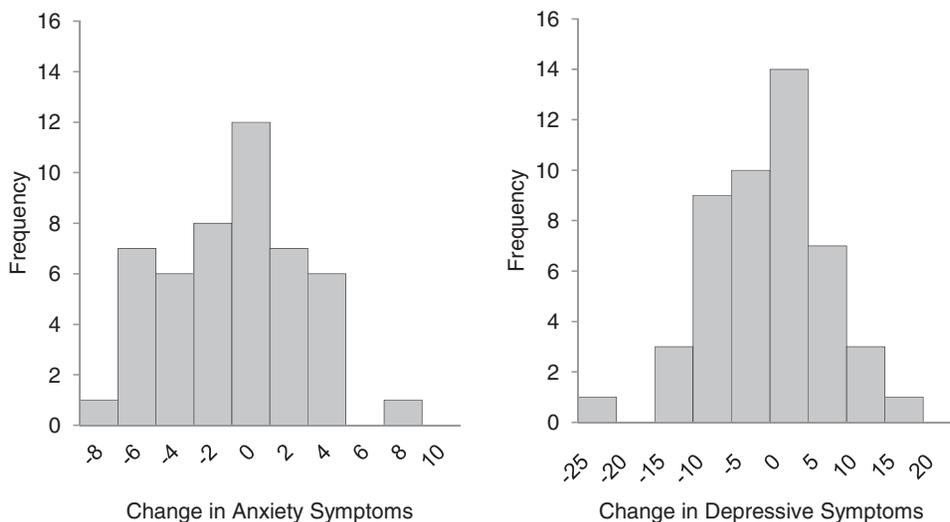


Figure 1. Distribution of change scores for anxiety and depressive symptoms.

included in this study, but findings from the National Health Interview Survey identified 5.3% of individuals aged 18–24 years in the general population experienced two or more depressive symptoms in the previous month (Child Trends, 2010), which suggests that the observed rates of psychological distress in the emerging adults with SB are elevated. The high number of participants who fell in the clinical range for psychological symptoms at both time points is particularly concerning because, per study protocol, each was referred to local mental health services for treatment following Time 1 data collection. However, this study did not track access to care nor duration or type of therapy received (e.g., pharmacological, counseling).

The persistence of anxiety and depressive symptoms in this sample underscores the critical need for integrating mental health screening into clinical encounters with this population, as they transition from pediatric oriented health care into adult health care systems. However, previous research suggests that comprehensive, multidisciplinary models of health care delivery for emerging adults with a complex and pervasive disability like SB are not as well developed as for other chronic health populations (Sawyer & Macnee, 2010). Additional barriers to assessment and referral for mental health treatment relate to the limited number of screening tools validated for use with the young adults with SB who may present with mild-to-profound cognitive impairment (Holmbeck et al., 2010b) and the lack of mental health therapies adapted for individuals with an intellectual disability and practitioners to carry out these adapted interventions (Dykens, 2007).

Another finding from this study suggests that SB severity is not a driving force of change in psychological symptoms during emerging adulthood. Condition severity did not predict change in anxiety symptoms from Time 1 to Time 2, and although a main effect for SB severity on depressive symptoms was initially observed, the relationship became nonsignificant when the effects of family satisfaction and the self-management factors were controlled for. Perhaps specific clinical indicators of SB severity (e.g., mobility status, presence of hydrocephalus), and not the summative effect captured by the severity index, are associated with variation in anxiety and depressive symptoms in emerging adulthood. Alternatively, the young adult's perception of the impact of SB on his or her life, and not the objective measure of condition severity, may be more strongly related to the course of anxiety and depressive symptomology.

This study also highlights the continued central role that the family context holds in the lives of individuals with SB as they progress through early adulthood. Self-reported

increases in satisfaction with family functioning over time were associated with decreases in anxiety symptoms from Time 1 to Time 2. The observed relationship may reflect that young adults with SB experience social isolation (Barf et al., 2007; Devine, Holmbeck, Gayes, & Purnell, 2012; Roux, Sawin, Bellin, Buran, & Brei, 2007) have low rates of transitioning from home to independent residence in the community (Bellin et al., 2011; Bowman et al., 2001), and consequently, have not individuated from their families in ways that would be expected for emerging adults. Developmental theory suggests that, beginning in adolescence and continuing through early adulthood, peers become increasingly important, offering opportunities for social interactions outside of the family and leading to decreased family time (Larson, Richard, Moneta, Holmbeck, & Duckett, 1996). For emerging adults who experience a delayed individuation process or a limited peer social network, positive family interactions characterized by shared decision making, support for individual growth, and open expression of feelings—as measured by the Family APGAR (Austin & Huberty, 1989)—may be especially important for their psychological health.

Results also provide preliminary support for fostering self-management skills to protect against psychological distress in emerging adults with SB. Specifically, an increase in SB management competencies from Time 1 to Time 2 was significantly associated with a decrease in depressive symptoms across time. Although parental intrusiveness and overprotection in the management of SB may be adaptive early on when the medical care needs exceed the developing child's capabilities (Holmbeck et al., 2002), our finding is consistent with previous messages to encourage independence early on (Betz, 2004; Loomis, Javornisky, Monahan, Burke, & Lindsay, 1997), with health professionals supporting families in the planned transfer of SB care responsibilities from the parent to the adolescent. Sawin and colleagues (2009) previously described a model of shared decision making in the gradual shift of SB management based on a comprehensive assessment of the adolescent's knowledge, skills, goals, and deficits.

It is also helpful to place the observed relationship between self-management of SB and depressive symptoms in the context of developmental theory, which identifies attending college, leaving home, and obtaining employment as key milestones associated with emerging adulthood (Arnett, 2000). Although these achievements may similarly be viewed as hallmarks of a positive transition experience from adolescence into emerging adulthood for individuals with SB (Holmbeck & Devine, 2010; Zebracki et al., 2010), young adults with a complex and pervasive health condition like SB may also have some unique

Table IV. Hierarchical Regression Results

	Model	B	SE	Beta	95% CI	R ²	R ² Δ
Change in anxiety symptoms							
1	(Constant)	-3.16	2.39		(-7.99, 1.63)	.03	.03
	SB severity	0.35	0.30	0.17	(-0.26, 0.96)		
2	(Constant)	-2.79	4.28		(-7.34, 1.75)	.22*	.19*
	SB severity	0.33	2.51	0.16	(-0.25, 0.92)		
	Δ SM: Independent living	0.06	0.07	0.15	(-0.09, 0.21)		
	Δ SM: Condition	-0.17	0.45	-0.31	(-0.38, 0.05)		
	Δ Family satisfaction	-.29*	0.12	-0.33*	(-0.55, -0.04)		
Change in depressive symptoms							
1	(Constant)	-10.10*	4.97		(-20.10, -0.09)	.08*	.08*
	SB severity	1.28*	0.63	0.29*	(0.01, 2.55)		
2	(Constant)	-8.05	4.63		(-17.39, 1.29)	.28*	.20*
	SB severity	1.07	0.59	0.24	(-0.13, 2.26)		
	Δ SM: Independent living	0.26	0.15	0.32	(-0.05, 0.57)		
	Δ SM: Condition	-0.63	0.22	-0.55*	(-1.07, -0.19)		
	Δ Family satisfaction	-.30*	0.26	-0.16	(-0.82, 0.21)		

Note. SM = Self-management; * $p < .05$.

indicators of a successful transition process. Becoming independent in the monitoring and management of SB care is perhaps an equally salient milestone, and even a necessary precursor to achieving the more “typical” milestones of emerging adulthood for this population. Once a young adult is proficient in handling SB care needs, including medication management, prevention of secondary conditions (pressure ulcers and urinary tract infections), and addressing accessibility challenges in the community, he or she may be better positioned to individuate from the family unit, live independently, and obtain employment (Verhoef et al., 2006). Although the emerging adults in this sample had an increase in their self-management skills from Time 1 to Time 2, they continued to require supervision/stand-by prompting in managing their condition and assistance/prompting for their independent living skills. Davis, Shurtleff, Walter, Seidel, & Duguay (2006) found individuals with SB tend to be 2–5 years delayed in developing autonomy skills compared with their typically developing peers. Thus, it may be that the parameters of emerging adulthood may need to be both reconceptualized and extended for individuals with a complicated and pervasive health condition like SB.

Limitations

The study sample and methodology present several limitations to the interpretation of key findings. In particular, the small sample size restricted the number of variables entering the models and the types of analyses run. For example, we were underpowered to probe for a potential interaction effect for SB severity and SB self-management on change in

depressive symptoms. It is also important to emphasize that conclusions drawn from study findings are tentative because causality cannot be determined from two data points. Our confidence in the proposed directionality of the associations between satisfaction with family functioning, self-management, and psychological symptoms would be increased through latent growth curve modeling that requires at least three data points. Adequately powered longitudinal research in the future could explore whether improved self-management skills over time results in decreased depressive symptoms and whether this reduction in psychological symptoms in turn promotes further achievements in SB self-care.

Other sample-related limitations include the attrition rate and potential for selection bias. We observed a moderate participant attrition rate from Time 1 to Time 2. Although no significant group differences in psychological symptoms were found for participants who completed both data points versus those who were lost to follow-up, it is possible that increased depressive and anxiety symptomatology contributed to attrition. Selection bias may have also influenced our sample composition in that individuals with profound intellectual disabilities were excluded from participating. Thus, the models predicting change in psychological symptoms may not hold with emerging adults with SB who have more severe cognitive impairments. However, the clinical features of SB in our participants closely parallel what was reported for a longitudinal cohort of adolescents with SB in which 71% had shunted hydrocephalus, 83% with myelomeningocele, and 59% reporting a lumbosacral or lumbar LOL (Zukerman, et al., 2011).

Our reliance on self-report measures also precludes our ability to rule out common method variance as an explanation for the observed significant associations among psychological symptoms, satisfaction with family functioning, and self-management (Kelly, Zebracki, Holmbeck, & Gershenson, 2008). Because emerging adults with SB may overestimate their level of functioning in handling condition-specific tasks and more general activities of daily living, it would be helpful to include objective measures (e.g., direct observation) and additional reporters (e.g., parents) of the participants' level of self-management. However, previous research has shown cross-informant consistency in the reporting of the AMIS II subscales among transition-age individuals with SB and their parents (Sawin et al. 2006). Last, the influence of executive functioning, defined as a "series of higher-order cognitive skills employed in problem solving" (Zebracki et al., 2010, p. 186), was not explored in this research. However, executive functioning abilities consistently emerged as significant predictors of psychosocial functioning in a cohort of 18- and 19-year-olds with SB (Zukerman et al., 2011) and may be critical to fostering independence in self-care for this population.

Despite these limitations, the current study is one of the first longitudinal investigations of psychological symptoms in this vulnerable population. With an unprecedented number of individuals with SB surviving into emerging adulthood and beyond, it is essential to deliver health services that address their ongoing medical needs and maximize their psychosocial functioning. Our research provides a preliminary understanding of how condition severity, satisfaction with family functioning, and self-management may influence the course of depressive and anxiety symptoms in emerging adults with SB.

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