Correlates of Depressive and Anxiety Symptoms in Young Adults with Spina Bifida*

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Objective Based on social ecological theory, this study was designed to examine the unique relationships between multi-level ecological factors and psychological symptoms in young adults with spina bifida (SB). **Method** A sample of 61 individuals with SB, 18–25 years of age, completed standardized self-report measures of attitude toward SB, satisfaction with family functioning, Chronic Care Model (CCM) services, and depressive and anxiety symptoms. A chart review yielded SB clinical data. **Results** High rates of depressive and anxiety symptoms were found. Hierarchical regression analysis identified the proximal individual (attitude toward SB) and family (satisfaction with family functioning) factors as more strongly related to depressive symptoms than the distal healthcare system factor (CCM services). Self-reported pain was the only ecological factor associated with anxiety symptoms. **Conclusions** Study findings provide a potential foundation for multi-factor screening of young adults with SB at risk for psychological symptoms.

Key words spina bifida; psychosocial functioning; social ecological perspective.

Spina bifida (SB), a congenital neural tube defect, causes extensive health problems including hydrocephalus, Chiari II malformation, impaired sensation, muscle weakness, and paralysis, orthopedic problems such as hip and knee contractures, neurogenic bladder and bowel dysfunction, seizure disorders, and neuropsychological difficulties limiting self-management (Kelly, Zebracki, Holmbeck, & Gershenson, 2008; Mitchell et al., 2004; Tarazi, Zabel, & Mahone, 2008; Verhoef, Bark, van Asbeck, Gooskens, & Prevo, 2004). Although biomedical advances have dramatically increased life expectancy for individuals with SB (Bowman, McLone, Grant, Tomita, & Ito, 2001; Davis et al., 2005), less attention has been placed on supporting psychosocial functioning as these and other young adults with a chronic health condition (CHC) assume the roles and responsibilities of adulthood (Arnett, 1998, 2004; Betz, 2004; Betz & Redcay, 2005; Kinavey, 2007; Liptak, 2003; Reiss & Gibson, 2002; Tarazi, Mahone, & Zabel, 2007). Discrepancies in education, independent living, employment, and autonomy are regularly noted between young adults with a CHC and their peers (Blackorby & Wagner, 1996; Davis, Shurtleff, Walter, Seidel, & Duguay, 2006; Geenen, Powers, & Sells, 2003; Stam, Hartman, Deurloo, Groothoff, & Grootenhuis, 2006).

These gaps in achieving the functional expectations of early adulthood may predispose young adults with a chronic condition like SB to poor psychological functioning (Arnett, 1998, 2004; McDonnell & McCann, 2000; Taleporos & McCabe, 2005; Zashikhina & Hagglof, 2007). Although an elevated risk for depressive symptoms has been documented for individuals with SB in the adolescent period (Appleton et al., 1997; Holmbeck et al., 2009), the prevalence of psychological symptoms in young adults with SB is an understudied area, and knowledge of factors associated with poor psychological functioning is particularly limited (Liptak, 2003). Since mood disorders have previously been shown to further restrict the ability of vulnerable populations to achieve self-management of their health condition (Gadalla, 2008), detecting and understanding factors associated with depression and anxiety in young adults with SB is highly significant. Based on social ecology theory

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(Bronfenbrenner, 1979, 2004), the intent of this multicenter study was to advance knowledge of risk and protective correlates of psychological symptoms in young adults living with SB.

Social ecological theory proposes that human behavior is shaped by both individual and contextual factors (Bronfenbrenner, 1979, 2004; Fraser, 2004). This model further suggests that risk factors heightening vulnerability to poor psychological functioning and protective factors that mitigate the effects of adverse experiences on developing youths are embedded in individual, family, and community social systems (Fraser, Kirby & Smokowski, 2004). A strength-of-association model related to the relative impact of the ecological factors is also described, whereby risk and protective factors more proximal to youths (e.g., individual, family) are considered to exert greater influences on developmental trajectories than distal environmental factors (Friedman, Holmbeck, Jandasek, Zukerman, & Abad, 2004). Social ecology theory has long been proposed for use in understanding adaptation to childhood chronic illness and disability (Kazak, 1989, 1992). More recently, Holmbeck and colleagues expanded the social ecological theoretical framework to account for the impact of SB clinical factors on the developmental outcomes of affected youths (Holmbeck & Shapera, 1999; Kelly, et al., 2008).

The utility of a social–ecological framework for understanding psychological symptoms in young adults is supported by prior studies of adjustment in school-age youths and adolescents with SB. Modest support for relationships among SB clinical factors and psychological functioning has been reported. *SB severity* has been identified as a risk factor for low self-esteem (Sawin, Buran, Brei, & Fastenau, 2003), poor social competence (Hommeyer, Holmbeck, Wills, & Coers, 1999), and restricted quality of life (Cate, Kennedy, & Stevenson, 2002) in youths with SB. The prevalence and experience of *pain* in individuals with SB has also gained attention in recent years (Roebroeck, Jahnsen, Carona, Kent, & Chamberlain, 2009). Oddson, Clancy, and McGrath (2006), for example, observed a direct correlation between the experience of pain and depressive symptoms in a sample of 68 school-age youths with SB.

Other proximal individual and family factors have also been shown to influence psychological functioning in youths with SB. Sawin et al. (2003) observed a protective influence of a *positive attitude toward SB* on self-esteem and interpersonal competence in a sample of 60 adolescents with SB. Their program of research also found a significant relationship between adolescent attitude toward SB and health-related quality of life (Sawin, Brei, Buran, & Fastenau, 2002). Family factors have likewise emerged as important correlates of psychological functioning in youths with SB. One of the earliest studies of the interrelationships among family functioning variables and child outcomes identified family conflict as a risk factor for depression and anxiety in adolescents with SB (Murch & Cohen, 1989). More recent research has highlighted relationships between over-protective parenting styles and depressive symptoms in preadolescents with SB (Holmbeck et al., 2002). However, Sawin and colleagues (2003) identified a protective influence of family cohesion and adolescent *satisfaction with family functioning* on adolescent psychological functioning.

At the more distal healthcare system level, the *Chronic Care Model* (CCM) is recognized as an important clinical framework to enhance patient care and health outcomes (Wagner, et al., 2001). It advances a patient-centered approach to service delivery for individuals with a CHC as reflected by optimizing the organization of health care, clinical information systems, delivery system design, decision support, self-management support, and linkages to community resources (Glasgow, Wagner, et al., 2005). Research with other CHC populations, including diabetes, heart disease, and asthma, has revealed important associations between the receipt of care services based on CCM principles and adaptive health outcomes (Glasgow, Wagner, et al., 2005; Glasgow, Whitesides, Nelson, & King, 2005; Schmittdiel, et al., 2008).

In summary, the psychological functioning of individuals with SB appears to be impacted by diverse ecological factors. However, previous investigations failed to account for the influence of the healthcare system, namely the nature of care delivery, on psychological outcomes. Furthermore, prior studies generally included samples comprised of school-age youths and adolescents living with SB. Less is known about risk and protective correlates of psychological symptoms in young adults with SB. The current study advances our understanding of this population by testing the following hypotheses based on past literature and social ecology theory. We proposed that the combined effects of select SB clinical (SB severity and pain), individual (attitude toward SB), family (satisfaction with family functioning), and healthcare system (CCM services) factors would explain variability in depressive and anxiety symptoms. Additionally, following the work of Friedman and colleagues (2004), a strength-of-association model was explored, whereby it was expected that the proximal individual (attitude toward SB) and family (satisfaction with family functioning) ecological factors would be more strongly related to psychological symptoms than the distal healthcare system factor (CCM services).

Methods

Participants

Participants were part of a larger longitudinal study examining the trajectory of health outcomes and psychosocial adaptation (psychological functioning, self-management, bowel and bladder continence, and quality of life) in young adults with SB (Bellin, 2008). The current study presents the first wave of data (Time 1) collected on psychological functioning. Sixty-one young adults with SB were recruited from five geographically diverse SB clinic sites. Three clinics served individuals with SB from birth through adulthood, while two sites only provided clinical care to an adult population (18 and older).[1] Study eligibility criteria included the following: (a) primary diagnosis of SB; (b) 18–25 years of age; (c) residence in catchment areas of participating sites; and (d) capacity to understand study instruments. The selected age range was informed by current theory on emerging adulthood (Arnett, 2004) and is consistent with prior research on the assumption of the roles and responsibilities of young adulthood for individuals with SB (Davis et al., 2006).

Since individuals affected by SB may present with a range of neurocognitive deficits, from mild executive functioning difficulties to profound intellectual impairments (Rose & Holmbeck, 2007), all eligible participants were screened by study staff for capacity to provide informed consent. An adapted version of the MacArthur Competence Assessment Tool was administered to measure a subject's understanding of the purpose of the project (e.g., *What is the purpose of the research*), activities involved in study participation (e.g., *How many study visits are you asked to participate in*), benefits of participation (e.g., *In what way might you benefit by volunteering to participate in this study*), risks and discomforts associated with participation (e.g., *Tell me about the possible risks associated with participating in this project*), and procedure to withdraw from the study (e.g., *What will you do if you decide that you no longer want to participate in this study*) (Appelbaum & Grisso, 2001). Responses to the five domains of questions were scored on a 0–2 range (0 = inadequate understanding; 1 = partial understanding; 2 = adequate understanding). To be enrolled in the study, participants must have received a total score of 8 or higher, out of a possible score of 10, on the measure.

Of the 168 eligible individuals with SB between the ages of 18 and 25 years who received medical services at the participating sites, 64 (38%) agreed to participate. Three individuals failed the competence screening, resulting in a final sample of 61 young adults with SB. Participants reported a mean age of 21.05 years ($SD = 2.11$), range 18–25 years. A majority was female ($n = 37$, 60.7%) and Caucasian ($n = 47$, 77.0%). Over two-thirds of the young adults with SB had hydrocephalus requiring shunt placement ($n = 42$, 68.9%). The average number of surgical revisions to the shunt was 2.95 ($SD = 2.68$). The vast majority of participants had a primary diagnosis of myelomeningocele, the most severe form of SB[2] ($n = 51$, 81.6%). A lumbar level of lesion (LOL) was most frequently reported in the medical chart ($n = 34$, 55.7%), followed by a sacral LOL ($n = 13$, 31.1%), and thoracic LOL ($n = 8$, 13.1%).

Procedure

The study was reviewed and approved by the Institutional Review Boards associated with the participating SB clinic sites and by the Professional Advisory Council of the Spina Bifida Association. Participants were recruited through mailed letter of invitation and by face-to-face contact during routine SB clinic visits. Once informed consent was obtained, participants completed a self-report questionnaire comprised of demographic (e.g., living and employment status) and health-related questions (e.g., pain) followed by the standardized instruments described below. Participants received a $35.00 gift-card as an acknowledgement of their time. Research staff performed a chart review to obtain SB clinical data. A copy of all de-identified study materials was sent to the project Principal Investigator for data management and analysis.

Measures

SB Clinical Factors: Spina Bifida Severity and Pain

Based on the work of Hommeyer et al. (1999), a SB severity composite was formed from the following variables: (a) shunt status (1 = no, yes = 2); (b) myelomeningocele (1 = no, yes = 2); (c) lesion level (sacral = 1, lumbar = 2, thoracic = 3); and, (d) ambulation status (no assistance = 1, needs assistive devices to walk = 2, wheelchair use = 3). Scores range from 4 to 10, with higher levels reflecting greater severity. The validity of the severity composite was previously established by Hommeyer et al. (1999) who observed a significant association with health professionals' rating of SB severity ($r = .60$, $p < .001$). Internal consistency of the composite in this sample ($\alpha = .68$) is comparable to that reported by Hommeyer and colleagues ($\alpha = .70$).

[1]No differences in key demographics or study measures were found, so participants were combined for the analysis.

[2]No differences in model results were found when the analysis was run with the myelomeningocele group alone.

As an index of pain, participants rated their *worst pain in the last week* using a 10cm horizontal visual analogue scale (1 = no pain to 10 = extreme amount of pain). Previous research on pain in individuals with SB has found the worst pain in the last week, but not the current level of pain, to correlate with depressive symptoms ($r = .51$, $p < .01$) (Oddson et al., 2006).

Individual-Level Factor: Attitude Toward Spina Bifida
The 13-item Child Attitude Toward Illness Scale was developed by Austin and Huberty (1993) to capture feelings and attitudes about a health condition from the perspective of the affected individual (e.g., ''*How often do you feel different from others because you have spina bifida*; *How often do you feel sad about having spina bifida*''). Higher participant scores reflected a more positive attitude toward SB. Construct validity of the measure was supported by significant relationships with self-esteem in adolescents with SB ($r = .62$, $p < .05$) (Sawin et al., 2003) and depression in adolescents with epilepsy ($r = -.55$, $p < .01$) (Dunn, Austin, & Huster, 1999). Following review of the scale by SB expert clinicians, the item ''*How often do you feel spina bifida is your fault*'' was dropped. Since SB is a congenital birth defect, as opposed to other chronic conditions that may develop across the lifespan, this item was considered to be conceptually irrelevant to the SB population. The internal consistency of the 12-item scale administered in this study ($\alpha = .86$) was comparable to what is reported for full scale ($\alpha = .89$) (Heimlich, Westbrook, Austin, Cramer, & Devinsky, 2000).

Family-level Factor: Satisfaction with Family Functioning
The Family APGAR provided an assessment of how satisfied participants were with family interaction (Smilkstein, 1978). The scale measures five dimensions of family functioning: Adaptation, Partnership, Growth, Affection, and Resolve (5 items; e.g., ''*I am satisfied that I can turn to my family for help when something is troubling me*''). Higher scores on the Family APGAR (items range from 1 = Never to 5 = Always) reflect greater levels of family satisfaction. Moderate test-retest reliability ($r = .73$) and internal consistency ($\alpha = .71$) have been reported (Austin & Huberty, 1989). The measure also has established reliability and validity for use with individuals who have SB (Sawin, et al., 2002, 2003).

Healthcare System Factor: Chronic Care Model Services
Participants completed the Patient Assessment of Chronic Illness Care (PACIC) to measure receipt of CCM services (20 items; e.g., ''*Over the past 12 months when I received care for spina bifida, I was asked for my ideas when we made a treatment plan*'') (MacColl Institute for Healthcare Innovation, 2004). Participants rate the characteristics of health services on a 5-point Likert-type scale (1 = None of the time to 5 = Always), with higher scores reflecting services consistent with the principles of the CCM. The PACIC has documented reliability ($\alpha = .96$) and concurrent and construct validity, and has been established for use in a range of chronic conditions (Glasgow, Wagner, et al., 2005; Glasgow, Whitesides, et al., 2005).

Psychological Symptoms
The *Hopkins Symptom Checklist* (HSCL-25) was administered as a self-report index of depressive and anxiety symptoms (Hesbacher, Rickels, Morris, Newman, & Rosenfeld, 1980). The HSCL-25 is derived from the 90-item Hopkins Symptom Checklist (SCL-90) (Derogatis, Lipman, & Covi, 1973) and includes a 15-item depressive symptoms scale and a 10-item anxiety symptoms scale. Items are scored on a Likert scale ranging from 1 (Not at all) to 4 (Extremely). A mean score of ≥ 1.75 is used as a cut-point for each of the scales (Winokur, Winokur, Rickels, & Cox, 1984). Relative to other screening instruments, the HSCL-25 has been found to reflect the urgency with which treatment services are needed (Sandanger et al., 1999), and has a moderate degree of sensitivity and specificity to formal psychiatric diagnostic criteria (Veijola et al., 2003). The HSCL-25 has been validated for use as a screening instrument for psychological symptoms in a range of CHC populations, and has previously been administered to adults with SB (Kalfoss & Merkens, 2006). A moderate association between the depressive and anxiety symptoms factors was observed in the current sample ($r = .61$, $p < .001$).

Data Analysis

Data were screened using SPSS 16.0 Missing Value Analysis program. Less than one percent of data were missing, and no patterns related to the nature of missing data were found. To maximize retention of cases for the analysis, values for randomly missing data dispersed throughout the observations were estimated via regression imputation.

Hierarchical multiple regression analysis was performed to examine the unique contributions of the SB clinical (SB severity and pain), individual (Attitude Toward SB), family (Satisfaction with Family Functioning), and health care (CCM services) factors in explaining variance in depressive and anxiety symptoms. The SB clinical factors were entered on step one of each model. A proximal-to-distal approach was subsequently used to

inform the order of forced entry of factors (Friedman et al., 2004): the individual-level factor was entered on step two, the family factor on step three, and the healthcare system factor on step four. The total variance accounted for by the ecological factors and the change in explained variance associated with each step of the model were examined. Confidence intervals around R^2 were constructed based on the guidelines outlined by Dattalo (2008).

An a priori power analysis indicated that a sample size of $N = 58$ was required for the proposed analysis based on the following parameters: (a) $\alpha = .05$; (b) $\beta = .20$; (c) five predictors in the model; and (d) a medium to large effect size of $f^2 = .25$ (Dattalo, 2008; Faul, Erdfelder, Lang, & Buchner, 2007).

Results

The young adults with SB generally reported restricted experiences with employment and independent living. The majority were unemployed ($n = 37$, 60.7%) or employed in part-time, low wage positions (e.g., cashier, food services provider) ($n = 14$, 23.0%). They primarily resided at home with a parent/caregiver ($n = 41$, 68.3%) or in a supervised environment such as an assisted living setting ($n = 3$, 5.0%). A sub-set of the young adults lived alone ($n = 8$, 13.3%), with a spouse/partner ($n = 3$, 4.9%), or with a roommate ($n = 3$, 4.9%).

Participants averaged 1.73 ($SD = 2.44$, range 0–10) hospitalizations for SB related complications within the last three years and 1.05 ($SD = 1.74$, range 0–10) emergency room visits during the previous 12 months. Urinary tract infections and pressure ulcers were also fairly common in this group of young adults with SB. Participants experienced an average of 3.49 ($SD = 5.10$, range 0–24) urinary tract infections and 1.02 ($SD = 1.43$, range 0–5) pressure ulcers within the last 3 years.

Descriptive data on study instruments are presented in Table I. In each case, a higher score reflects higher levels of the concept being measured. In this sample of young adults with SB, family satisfaction was fairly high as indicated by a mean item score of 4.03 out of a possible score of 5 on the family functioning measure. In general, participants rated the nature of health services to be moderately consistent with the principles of the CCM, as reflected by a mean item score of 3.43 out a possible score of 5 on the PACIC. However, the self-reported feelings and attitudes about SB were less positive and slightly lower than those reported by adolescents with SB (Sawin et al., 2003). Intercorrelations among the explanatory variables revealed no evidence of multicollinearity. Simple correlations ranged from a low of $r = .01$, $p > .05$ (Attitude toward SB and CCM Services) to a high of $r = .43$, $p = .001$ (Attitude toward SB and Satisfaction with Family Functioning).

With regard to the psychological functioning variables, nearly half of the young adults with SB reported psychological symptoms above the clinical cut-off ($n = 30$, 49.2%). In total, twenty-five individuals (41.0%) fell in the clinical range for depressive symptoms and nineteen (31.1%) reported scores above the clinical cut-off for anxiety symptoms. Of the 30 participants who were above the cut-off for psychological symptoms, 16 (53.3%) had scores above the cut point for both depressive and anxiety symptoms, ten (33.3%) had scores in the clinical range for depressive symptoms only, and four (13.3%) had scores in the clinical range for anxiety symptoms only. Following the study protocol, participants who scored in the clinical range were referred to local mental health services.

Although young women with SB may be an especially vulnerable group (Appleton et al., 1997; Sawin et al., 2009; Holmbeck et al., 2009), female gender was not

Table I. Descriptive Analysis of Ecological Factors and Outcome Measures ($n = 61$)

	M	*SD*	Scale range	α	No. of items
SB severity	7.64	1.77	4–10	.68	4
Pain	5.11	3.21	1–10		1
Attitude toward SB[a]	37.15 (3.10)	8.54 (.71)	12–60 (1–5)	.86	12
Family satisfaction[b]	20.16 (4.03)	4.36 (.87)	5–25 (1–5)	.91	5
CCM services[c]	68.69 (3.43)	16.48 (.82)	20–100 (1–5)	.92	20
Depressive symptoms[d]	25.58 (1.71)	7.78 (.52)	15–60 (1–4)	.90	15
Anxiety symptoms[d]	15.88 (1.59)	4.48 (.46)	10–40 (1–4)	.80	10

The total scale score is presented first in each cell, followed by the mean item score in parenthesis to further contextualize findings.

[a]Attitude Toward Illness (Austin & Huberty, 1993).

[b]Family APGAR (Austin & Huberty, 1989).

[c]Patient Assessment of Chronic Illness Care (MacColl Institute for Healthcare Innovation, 2004).

[d]Hopkins Symptoms Checklist (Hesbacher et al., 1980).

associated with an increased risk for clinical levels of depressive symptoms, $\chi^2(1, N=61)=.39$, $p>.05$, or anxiety symptoms, $\chi^2(1, N=61)=.07$, $p>.05$. Employment status (employed versus not employed) likewise did not differentiate individuals above the clinical cutpoint for depressive symptoms, $\chi^2(1, N=61)=.01$, $p>.05$, or anxiety symptoms, $\chi^2(1, N=61)=.07$, $p>.05$. Relationships between living status (supervised living environment *vs* independent living) and clinical levels of depressive symptoms, $\chi^2(1, N=61)=.04$, $p>.05$, and anxiety symptoms, $\chi^2(1, N=61)=1.47$, $p>.05$, were also nonsignificant.

Depressive Symptoms Model

As reported in Table II, the overall model inclusive of the SB clinical, individual, family, and healthcare system factors explained a significant amount of variance in depressive symptoms [Adjusted $R^2=.35$, 95% CI = .18 to 0.53, $F(5, 60)=7.52$, $p<.001$]. Based on the benchmarks established by Cohen (1988) for f^2, where f^2 of 0.02 = small, 0.15 = medium, and 0.35 = large, a large effect size was noted for the depressive symptoms model ($f^2=.54$). The SB clinical factors (severity, pain) accounted for a small but significant percentage of variance in depressive symptoms. As predicted, the addition of the proximal individual level factor (Attitude toward SB) to the model on step 2 [$R^2\Delta=.22$, $F(1, 57)=18.54$, $p<.001$; $f^2=.28$] and family factor (Satisfaction with Family Functioning) on step 3 [$R^2\Delta=.10$, $F(1, 56)=9.04$, $p=.004$; $f^2=.11$] were supported. However, the distal healthcare system factor (CCM services) was non-significant [$R^2\Delta=.00$, $F(1, 55)=0.00$, $p>.05$]. In the final model, a main effect was observed for attitude toward SB ($\beta=-.33$, $p=.006$), satisfaction with family functioning ($\beta=-.34$, $p=.005$), and the experience of pain ($\beta=.29$, $p=.008$). Specifically, a more positive attitude toward SB and greater satisfaction with family functioning were associated with fewer depressive symptoms. However, pain was a risk factor for depressive symptoms in the young adults living with SB.

Anxiety Symptoms Model

Less support was found for the combined effects of the ecological factors in explaining variance in anxiety symptoms (Table III). The overall model inclusive of the SB clinical, individual, family, and healthcare system factors was significant [Adjusted $R^2=.26$, 95% CI = .03 to 0.48, $F(5, 60)=5.11$ $p=.001$], and was in the range of a medium-to large effect size ($f^2=.33$). However, the change in explained variance associated with the addition of the individual [$R^2\Delta=.05$, $F(1, 57)=3.80$, $p=.056$; $f^2=.05$], family [$R^2\Delta=.04$, $F(1, 56)=3.41$, $p=.07$; $f^2=.04$], and healthcare system factors [$R^2\Delta=.01$, $F(1, 55)=0.44$, $p=.51$] to the model were all nonsignificant. In the final model, a main effect was only observed for pain ($\beta=.46$, $p<.001$), with pain level positively associated with anxiety symptoms.

Table II. Hierarchical Multiple Regression Results for Depressive Symptoms Model ($n=61$)

	Predictor	Total R^2 Adjusted	ΔR^2	F	ΔF	df	B	SE	β
Step 1	Spina Bifida severity	.05	.09	2.72	2.72*	2, 58	−.20	.46	−.05
	Pain						.71	.26	.29*
Step 2	Attitude toward SB	.27	.22	8.54**	18.54**	1, 57	−.30	.11	−.33*
Step 3	Family satisfaction	.36	.10	9.57**	9.04*	1, 56	−.61	.21	−.34*
Step 4	CCM services	.35	.00	7.52**	0.00	1, 55	.00	.05	.00

The reported unstandardized and standardized coefficients are from the final regression model.
*$p<.05$; **$p<.001$

Table III. Hierarchical Multiple Regression Results for Anxiety Symptoms Model ($n=61$)

	Predictor	Total R^2 Adjusted	ΔR^2	F	ΔF	df	B	SE	β
Step 1	Spina Bifida severity	.20	.22	8.24**	8.24**	2, 58	−.28	.29	−.11
	Pain						.66	.16	.46**
Step 2	Attitude toward SB	.23	.05	7.03**	3.80	1, 57	−.06	.907	−.12
Step 3	Family satisfaction	.26	.04	6.35**	3.41	1, 56	−.25	.13	−.24
Step 4	CCM services	.26	.01	5.11*	0.44	1, 55	.02	.03	.08

The reported unstandardized and standardized coefficients are from the final regression model.
*$p<.05$; **$p<.001$

Discussion

With increased numbers of individuals with SB surviving into adulthood, it is paramount to address and support both their physical care needs and psychosocial health. This study investigated multi-level risk and protective correlates of psychological symptoms in young adults living with SB. Specifically, it was hypothesized that the combined effects of select SB clinical (SB severity, pain), individual (attitude toward SB), family (satisfaction with family functioning), and healthcare system (CCM services) factors would explain variability in psychological symptoms. Furthermore, a strength-of-association model was tested, whereby it was hypothesized that the more proximal ecological factors (individual, family) would be more strongly related to psychological symptoms than the distal healthcare system factor.

In general, the model tested in this research was supported. The combined effects of the ecological factors accounted for a significant amount of variance in psychological symptoms. A large effect size was noted for the depressive symptoms model ($f^2 = .54$), while the anxiety symptoms model was in the range of a medium-to-large effect size ($f^2 = .33$) (Cohen, 1988). The magnitude of change in explained variance associated with each step of the models was more modest in nature. In the depressive symptoms model, a medium-to-large effect size ($f^2 = .28$) was noted for the individual factor (Attitude toward SB), and a small-to-medium effect size ($f^2 = .11$) was observed for the family factor (Satisfaction with Family Functioning). However, in the anxiety symptoms model, a small effect size was found for the change in explained variance associated with the individual ($f^2 = .05$) and family ($f^2 = .04$) factors. Also, consistent with the predicted direction of relationships among the ecological factors and psychological symptoms, the proximal individual and family factors had stronger associations with depressive symptoms than the distal healthcare system factor (CCM services).

A notable contribution of this research is our enhanced understanding of salient risk and protective factors to address in clinical intervention with young adults living with SB. Findings lend tentative support for a protective influence of a positive attitude toward SB and satisfaction with family functioning on the experience of depressive symptoms. In some respects, the associations are not surprising, as individuals with a CHC who positively perceive proximal aspects of life functioning (e.g., health condition, family) might be expected to report less distress. These observed relationships are consistent with long-standing theory that suggests the adjustment of individuals with a CHC is influenced by how they feel about having a chronic condition, as well as how responsive the surrounding family environment is to their developmental needs (Austin & Huberty, 1993; McCubbin & Patterson, 1983). Relationships between attitude toward disability, family functioning, and psychological adaptation have been previously documented in younger populations with SB (Sawin et al., 2002, 2003). These associations merit further investigation, as they may highlight factors relevant to the prevention and treatment of psychological symptoms in individuals with SB in early adulthood. Since prior research suggests that family functioning is consistently associated with the adjustment of youths with SB (Holmbeck et al., 2002; Sawin et al., 2002, 2003), it is also important to examine whether interventions aimed at improving family interactions during childhood and adolescence influence the subsequent psychological functioning of young adults with SB.

Additional implications relate to the associations between the SB clinical factors and psychological symptoms. Although Wallander and Varni (1995) proposed a direct association between condition severity and adjustment in their theoretical model of adaptation to chronic illness and disability, contrary to our expectations, there was no relationship between SB severity and psychological symptoms. While SB severity variables such as lesion level and shunt status have been previously linked to child adjustment (Holmbeck & Faier-Routman, 1995) and neuropsychological presentation (Dennis, Landry, Barnes, & Fletcher, 2006; Fletcher et al., 2005), there is little evidence from the current study to suggest that these severity variables would be of use in identifying young adults at risk for psychological symptoms. Given prior findings of a robust relationship between characteristics of the family environment and adjustment in individuals with SB (Holmbeck et al., 2002; Sawin et al., 2002, 2003), it is possible that family functioning mediates the relationship between SB severity and psychological symptoms.

However, comparable to the findings of Oddson and colleagues (2006), self-report of recently experienced pain was strongly related to depressive and anxiety symptoms. The young adults identified varied causes of pain, although headaches and back, shoulder and foot discomfort were most frequently reported. Since previous research suggests that clinically significant pain in individuals affected by SB is often under-recognized (Clancy, McGrath, & Oddson, 2005), our findings lend support to regular screening of diverse sources of pain in young adults with SB.

Our findings also add to the growing body of evidence indicating high rates of psychological distress in adults

with SB. The self-report of clinically significant symptoms of depression (41%) and anxiety (31%) in our participants closely matched previous symptom reports of depression (47%) and anxiety (23.5%) in a sample of slightly older adults (mean age 29.5 years) with SB (Kalfoss & Merkens, 2006). However, these estimates in young adults with SB are considerably higher than comparable self-reports of serious psychological distress in adults with disabilities reporting assistive device use (5.4%), activity limitations (11.4%), or both (16.5%) (Okoro et al., 2009). While it is unclear if the high prevalence of psychological distress in this sample occurs secondary to CNS damage, increased vulnerability to stress, or environmental influences (Kalfoss & Alve, 2003), it seems likely that the contributing factors are active in some form before at-risk individuals with SB reach young adulthood. As such, the current data support efforts to increase clinic-based education to foster positive adjustment to SB and adaptive family functioning, as well as to expand routine screening for depression and anxiety in SB clinic visits. However, it remains to be seen if general treatment models based upon evidence-based practices (e.g., cognitive behavioral therapy, functional family therapy) are adequate for young adults with SB, or if condition-specific interventions are necessary. Disability scholars have previously raised concerns about the validity of traditional models of clinical intervention for individuals with a cognitive impairment (Dykens, 2007).

Study findings are limited by several methodological considerations. It is important to note that the observed associations between the ecological factors and psychological symptoms are restricted due to the shared methodologies (e.g., self-report questionnaires) that preclude our ability to rule out common-method variance as an explanation for the significant relationships (Kelly et al., 2008). Furthermore, the directionality of observed relationships cannot be established due to the cross-sectional nature of the data. Longitudinal data, which is presently being collected on this cohort of young adults with SB, may help clarify whether negative perceptions of SB and family life increase vulnerability to psychological symptoms or if the presence of psychological symptoms causes young adults with SB to report negatively upon proximal aspects of their life (health condition, family).

The response rate and sample of convenience present additional methodological concerns. The relatively low response rate of 38% reflects limited participant recruitment via mailed letter of invitation. Three sites exclusively relied on face-to-face recruitment in the spina bifida clinics and successfully enrolled 25 of 33 eligible participants (75.8% response rate). The poor response to mailed study invitations is not surprising given the executive functioning deficits that may create barriers to initiation and follow-through in individuals with SB (Tarazi et al., 2007). Although participants were enrolled from five geographically diverse SB clinic sites, it is possible that the sample characteristics are not representative of the larger population of young adults living with SB, particularly those who have a severe cognitive impairment. However, the clinical presentation of SB in this sample (e.g., level of lesion, shunt status) is comparable to what is reported in other recent studies with young adults with SB (Boudos & Mukherjee, 2008; Verhoef, et al., 2006, 2007) and is consistent with available data from participating clinic sites (Dicianno, Gaines, Collins & Lee, 2009).

The modest sample size also limited the number of variables entering the regression analysis. A post-hoc power analysis was performed with the following parameters: (a) $N = 61$; (b) $\alpha = .05$; (c) $\beta = .20$; (d) five predictors in the model; and (e) a medium to large effect size of $f^2 = .25$ (Dattalo, 2008; Faul et al., 2007). Although the analysis confirmed that the study indeed had ample power to test the main effects hierarchical regression model ($1 - \beta = .8325$), a larger sample would enable meaningful testing of moderating effects of clinical factors (e.g., SB severity) and key demographics (e.g., gender) on the observed relationships between the ecological factors and psychological symptoms (Holmbeck, 1997). Exploratory regression models were run with the SB clinical factors on step 1, the centered ecological factors (Attitude Toward SB, Satisfaction with Family Functioning, Chronic Care Model services) and Gender on step 2, and the interaction terms (e.g., Attitude Toward SB × Gender) on step 3. However, the change in explained variance associated with the interaction terms was nonsignificant in both the depressive symptoms and anxiety symptoms models.

Finally, while the combined effects of the ecological factors in explaining psychological symptoms was supported, additional variance may be accounted for by other individual and contextual factors not included in this study. Future research might explore the effect of cognitive functioning and social perception on psychological symptoms (Dicianno, et al., 2008). Despite these limitations, the unique variance accounted for by the self-report of pain, attitude toward SB, and family satisfaction provides a potential foundation for multi-factor screening of young adults with SB who are vulnerable to psychological symptoms. Identifying mechanisms that elevate risk or protect against poor psychological functioning is essential to foster positive outcomes for young adults with SB.

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