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# Depressive Symptoms in Adults with Spina Bifida

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# Abstract

**Purpose/Objective**—To examine the prevalence of depressive symptoms in adults with spina bifida and identify contributing factors for depressive symptomatology.

**Research Method/Design**—Retrospective Cohort Study. Data collection was conducted at a regional adult spina bifida clinic. A total of 190 charts from adult patients with spina bifida were included. The main outcome measures were the Beck Depression Inventory-II (BDI-II) and the mobility domain of the Craig Handicap Assessment Reporting Technique Short Form (CHART-SF).

**Results**—Of the 190 participants, 49 (25.8%) had BDI-II scores (14+) indicative of depressive symptomatology. Sixty-nine (36.3%) of all participants were on antidepressants for the purpose of treating depressive symptoms, and 31 (63.3%) of those with clinical symptoms of depression were on antidepressants. The total number of participants with a history of depressive symptoms may be as high as 45.7% if both participants with BDI-II scores 14+ and those with antidepressant use specifically for the purposes of depression treatment are combined. In this population, lower CHART-SF mobility score, expressing "emotional concerns" as a reason for the visit on an intake sheet, and use of antidepressant medications were significantly associated with depressive symptoms.

**Conclusions/Implications**—Depressive symptomatology appears to be common and undertreated in this cohort of adults with spina bifida, which may warrant screening for emotional concerns in routine clinic appointments. Significant depressive symptoms are associated with fewer hours out of bed and fewer days leaving the house. Additional research is needed to assess the impact of interventions directed towards mobility on depression and in the treatment of depression in this patient population.

### Keywords

Spina Bifida; Rehabilitation; Mobility; Depression; Adult

### Introduction

Spina bifida (SB), a congenital condition defined by incomplete closure of the neural tube, impacts approximately 1,500 to 2,000 infants in the United States each year (National Institute of Neurological Disorders and Stroke (NINDS), 2013). This congenital condition has historically led to high rates of mortality in newborns (Davis et al., 2005), but major advances in medicine over the past four decades have significantly improved survival rates into adulthood and overall life expectancy (Bowman, McLone, Grant, Tomita, & Ito, 2001; Davis et al., 2005; Dillon, Davis, Duguay, Seidel, & Shurtleff, 2000; Hunt, 1997; McDonnell & McCann, 2000a; Ouyang, Grosse, Armour, & Waitzman, 2007; Shurtleff, 2000; Wong & Paulozzi, 2001). However, individuals with SB often encounter ongoing and complex health and rehabilitative needs, as well as impairments in cognitive and psychosocial functioning. Delays in skill development for independence, self-management, and community integration are also evident among adolescents (age 10-19) and emerging adults (age 18-25) Arnett, 2000; Bellin et al., 2011; Sawin et al. 2009). Cross-sectional research on psychosocial challenges experienced by adults (age 25+) with SB suggests social seclusion, decreased employment opportunities, low rates of independent living, physical pain, and health risk behaviors including poor eating choices and a sedentary lifestyle are prevalent and may heighten risk for distress (Bellin et al., 2011; Bellin, Dicianno, et al., 2013; Dicianno et al., 2008; Holmbeck et al., 2010; Sawyer & Macnee, 2010; Soe, Swanson, Bolen, Thibadeau, & Johnson, 2012; Zebracki, Zaccariello, Zelko, & Holmbeck, 2010).

The limited literature available on mental health outcomes in the SB population identifies an increased risk for internalizing disorders among adolescents compared with typically developing peers, as well as to peers with a disability (Appleton et al., 1997; Holmbeck et al., 2010; Holmbeck & Devine, 2010). Adolescents with SB report greater anxiety and lower overall quality of life than their peers with an early-onset spinal cord injury (Flanagan, 2013). Preliminary studies reveal as many as 13% to 18% of adolescents (Sawin, Brei, Buran, & Fastenau, 2002), and 41% to 48% of emerging adults with SB present with depression scores above the clinical cutoff on The Hopkins Symptom Checklist (Bellin et al., 2010; Kalfoss & Merkens, 2006). In contrast, 11% of adolescents in the general population experience a major depressive episode before adulthood (National Institute of Mental Health [NIMH], n.d.) and 10.9% of emerging adults have depression symptoms defined as meeting Behavioral Risk Factor Surveillance System criteria for either major

depression or 'other depression' (Centers for Disease Control and Prevention (http://www.cdc.gov/chronicdisease/), 2010).

These disparities have generated calls for longitudinal studies that delineate the trajectories of mental health outcomes from a lifespan perspective (Holmbeck & Devine, 2010). Yet, the majority of mental health research in SB has focused on child, adolescent, and emerging adult developmental periods. Since findings from the general population suggest that depressive episodes are more likely in adults who were symptomatic in adolescence (Harrington, Fudge, Rutter, Pickles, & Hill, 1990; Rao et al., 1995), identifying risk and protective mechanisms associated with psychological functioning is the first step in developing tailored clinical programs for this vulnerable population.

Evidence suggests higher risk for psychosocial symptoms is associated with both clinical features of SB (e.g., severity) and functional limitations (Wallander & Varni, 1998). Decreased capacity for independence in the community was associated with more psychological symptoms in a sample of 97 Australian adults with SB (Hayter & Dorstyn, 2013). Longitudinal research with a younger cohort of 48 emerging adults (mean age 22 years) with SB residing in the US similarly identified a significant relationship between self-management and symptomatology, whereby an increase inself-management skills over time was associated with decreased depressive symptomatology (Bellin, Dosa, et al., 2013). However, functional independence scores failed to differentiate Canadian adults with and without depression symptomatology, but the lack of statistical significance may be due to the small sample size [n = 7] (Berbrayer, 2013). In summary, research on mental health outcomes among those with SB has been limited in the scope of factors included in models, included small samples, and primarily focused only on individuals in the adolescent and emerging adulthood developmental period.

This study aims to address these gaps in science by examining the prevalence of depressive symptoms and factors associated with depressive symptoms in a large sample of community-based adults with SB in the US. Since more severe physical limitations are thought to negatively impact functional independence, quality of life, and depressive symptoms (Dicianno et al., 2008; Hayter & Dorstyn, 2013; Hetherington, Dennis, Barnes, Drake, & Gentili, 2006; Zukerman, Devine, & Holmbeck, 2011; Dicianno, Gaines, Collins, & Lee, 2009), it was hypothesized that clinical factors indicative of greater SB severity (higher lesions, positive shunt history) and decreased mobility would be significantly associated with depression symptoms.

# Methods

The local Institutional Review Board approved all procedures for this study. A retrospective review was conducted of charts from one university adult outpatient SB clinic directed by a physiatrist. This clinic provides routine care as the only regional SB clinic for adults. All data were collected as part of routine clinical practice but were also analyzed as part of this study. This dataset was also used in previous work (Dicianno, Gaines, Collins, & Lee, 2009; Garcia & Dicianno, 2011; Stepanczuk, Dicianno, & Webb, 2014). Data gathered at every visit included the following self-assessment surveys: Beck Depression Inventory-II [BDI-II]

(Kuhner, Burger, Keller, & Hautzinger, 2007), Craig Handicap Assessment Reporting Technique Short Form [CHART-SF] (Walker, Mellick, Brooks, & Whiteneck, 2003), and an intake form collecting the reason(s) for the visit. Each participant in this study completed all three surveys during one singular visit; therefore, the surveys were gathered for each individual at one point in time. All data were gathered from comprehensive annual visits rather than from follow up visits related to a specific medical issue. All clinical visits took place between 8/1/2005 and 6/22/2011.

Age, sex, race, shunt history (yes/no), and medications were also gathered from patient charts. Motor level of lesion (LOL) was defined as the highest motor level on physical exam that had antigravity strength and was grouped as cervical, thoracic, lumbar, sacral, and normal. It has been shown that higher LOL correlates with neurobehavioral outcomes in a wide variety of domains (Fletcher et al., 2005).

### Inclusion Criteria

Participants were included if they met these criteria: (1) primary diagnosis of spina bifida cystica or occult spina bifida with an underlying neurological abnormality, and (2) 18+ years of age.

### Exclusion Criteria

Participants' charts were excluded if the patient was deceased or if they had insufficient data for analysis. A proxy was permitted to physically help patients complete the BDI-II if they had trouble writing but was asked not to answer the questions for the individual. After excluding 15 charts of patients who were deceased and 30 charts for incomplete data (i.e. total BDI-II score could not be calculated), a total of 190 participants were included in the study.

# Measures

The BDI-II is a screening questionnaire consisting of 21 questions with each answer scored from 0 to 3, with 0 indicating no active symptoms and 3 representing the most severe symptoms. The total score ranges from 0–63. BDI-II as a screening tool for depressive symptoms has been utilized and validated across diverse populations (Kjaergaard, Arfwedson Wang, Waterloo, & Jorde, 2013; Kuhner et al., 2007). It has been demonstrated to be particularly useful in populations at high risk for depression, such as those with complex medical conditions like SB (Sharp & Lipsky, 2002).

The CHART-SF (Walker et al., 2003) contains 19 questions that measure 6 functional dimensions (mobility, occupational, cognitive, economic, social, and physical independence). Each dimension is scored 0–100, where 100 represents independent functioning. CHART-SF is validated as a measure of impairment as a total score or as individual dimension scores (Segal & Schall, 1995; Whiteneck, Charlifue, Gerhart, Overholser, & Richardson, 1992).

An intake form was used to ask patients the reason(s) for their visit. They were asked to check a box indicating one or more concerns related to physical, medical, social, and

community functioning (See Table 1). Multiple responses and free text responses were allowed. Individuals were allowed to rank their concerns or give them equal weight. The responses were treated as ordinal variables in the analysis.

During patient visits, the physiatrist documented medical history of clinical depression and purposes for all medications taken. In the chart review, use of antidepressants, antiepileptic medications, pain medications (narcotics, NSAIDs, corticosteroids, tricyclics), and anxiolytics was recorded. Given the potential for overlap between treatment of pain and seizures with depression or anxiety, antidepressant medication use was counted as a treatment for depressive symptoms only for individuals who corroborated having a history of depression during their appointment (all patients are routinely asked this question), or for those who had a history of depressive symptoms or formal mental health diagnosis previously documented in their charts. Patients on antidepressant medications purely for the treatment of pain were not tallied as having a history of depressive symptoms if a history of depressive symptoms was not corroborated by the patient or his or her chart. However, concomitant use of an antidepressant medication for both pain and depressive symptoms was counted.

# Analysis

IBM SPSS Statistics version 21 was used for data analysis. Descriptive analyses were performed. Initially, a multiple linear regression model was attempted but the data were skewed (Shapiro Wilk test, p < 0.0001) and residual plots were non-random. There were a substantial number of patients (N = 52) who had BDI-II scores of 0. Thus, multinomial logistic regression modeling was utilized with BDI-II total score as the dependent variable. Participants were grouped into four depressive symptom categories based on their BDI-II score: (1) No to Minimal (0–13), (2) Mild (14–19), (3) Moderate (20–28), and (4) Severe (29–63). This scoring method is recommended by the test authors as a means of minimizing false negatives (Beck). Previous studies in samples with chronic conditions also have used this scoring system (Carney, Ulmer, Edinger, Krystal, & Knauss, 2009; Gannotti, Minter, Chambers, Smith, & Tylkowski, 2011; Rodriguez et al., 2013). "No to Minimal" was used as the reference category. The variance inflation factors ranged from a low of 1.004 to a high of 1.041. The regression was run using a stepwise approach with the following independent variables: age, sex, race, shunt history (yes/no), antidepressant use (yes/no), anxiolytic use (yes/no), reason for visit, LOL as an ordinal variable (Lumbar LOL was used as the reference variable due to the large group membership to all depressive symptom categories), and CHART-SF dimension scores. Collinear variables were not included in the model. The case-to-variable ratio for each input was favorable at >10:1(Hosmer & Lemeshow, 2004). Significance was defined as a p-value less than or equal to 0.05. Criteria for selecting the optimal regression model was overall model significance and the model accuracy rate.

### Results

The mean age was 33.6 (SD = 11.1) years (median 31.0, mode 26, range 18–77 years). The mean BDI-II score for the entire population was 8.9 (SD = 10.8). The majority of

participants, 141 (74.2%), had a total score less than 14, and thus fell into the category of "No to Minimal" symptoms, while 59 (31%) of the 141 had a BDI-II score of 0. The remaining 49 (25.8%) participants' scores fell into one of the three categories suggestive of the presence of depressive symptoms: 20 (10.5%) were "Mild," 13 (6.8%) were "Moderate," and 16 (8.4%) were "Severe." Additional demographic data are listed in Table 2.

Overall, the most frequently endorsed items on the BDI-II were low energy (52.6%), sleep disturbances (46.6%), and fatigue (43.6%)

The overall regression model was significant (Tables 3–4). Independent variables that were significantly associated with depression score (overall analysis of effects) were having "emotional concerns" as a reason for the visit (p = 0.0006), CHART-SF Mobility score (p = 0.0149), and use of an antidepressant medication (p = 0.0004). Table 4 displays individual analyses of maximum likelihood estimates with associated *p* values. The remaining independent variables, including LOL and shunt status, were not significantly associated with depression score. The classification accuracy of this model was significant with group membership prediction of 60.5%, which is larger than membership distribution by chance alone, estimated at 45.3% (The classification accuracy rate was 60.5% which was greater than or equal to the proportional by chance accuracy criteria of 56.6% [1.25 × 45.3% = 56.6%]).

The mean CHART-SF mobility dimension score for participants without depressive symptoms (scoring <14 on the BDI\_II) was 78.6 (SD = 28.5), for those with relevant depressive symptoms (scoring 14+) was 64.2 (SD = 31.2), and specifically for the "Severe" group (scoring 29+) was 54.6 (SD = 33.7).

# Discussion

This study helps advance science by describing depressive symptom prevalence and correlates of symptomatology in a large sample of adults with SB residing in the US. A valuable contribution of this analysis is our enhanced understanding of depressive symptoms experienced by a broader range of adults, inclusive of emerging and older adults, compared to previous US based research. Over a quarter [n = 49/190, 25.8%] of the adults in this study had depressive symptoms (BDI-II 14+), which is comparable to rates in younger adults with SB (Bellin et al., 2010; Hayter & Dorstyn, 2013; CDC, 2010). A total of 27.0% of those scoring in the normal range (BDI-II 0–13) [n = 38/141] were on antidepressants for prior depressive symptoms. Therefore, the number of patients with a history of depressive symptoms may be as high as 45.7% [n = 87/190] if both participants with BDI-II 14+ and those with antidepressant use specifically for the purposes of depression treatment are combined. A scoring method that minimized false negatives was used; however, even if higher cut-offs had been used, the high prevalence suggests screening for depressive symptoms is warranted in clinical encounters with this population.

Our finding that severe depression symptoms is significantly associated with emotional concerns as a reason for a visit is particularly noteworthy since many clinicians do not address psychological functioning with patients—either because they are uncomfortable

asking, they forget, or they do not have time to administer a full survey (Simon & VonKorff, 1995). It is therefore possible that a single question about whether patients have "emotional concerns" may serve as a screening tool that could be specific for those with severe symptoms. However, more extensive screening is needed to detect those with mild or moderate symptoms. Single item symptom indicators and screening tools have been a focus of research (Sawin & Bellin, 2010) in the SB population in areas such as quality of life, but not yet in the area of depression. Developing effective screening processes are the first step in achieving the goal of "Healthy People 2010" to reduce the proportion of adults with depressive symptoms that prevent them from being active. ('Healthy People 2010. http://fodsupport.org/documents/HealthyPeople2010DisabilityChapter.pdf. Accessed March 1, 2015.,')

This study also showed that low CHART-SF mobility score was significantly associated with severe depression score. While associations between mobility and depression have been previously studied in the broader population of adults with various mobility impairments (Hughes, Nosek, & Robinson-Whelen, 2007; Myaskovsky et al., 2011), we were particularly interested in the SB population given the pediatric onset of physical limitations. To our knowledge, there are no other comparable investigations in adults with SB. A low mobility dimension score reflects fewer hours out of bed and fewer days leaving the house, possibly implying that barriers to care and ambulation are associated with depressive symptoms. The finding that decreased mobility is associated with severe depressive symptoms is supported by a previous study that found full-time wheelchair users to have a reduced quality of life compared to ambulators and part-time wheelchair users (Dicianno, Bellin, & Zabel, 2009). Although social integration has been demonstrated to be uniformly low regardless of SB ambulation ability (Dicianno, Gaines, et al., 2009), social avoidance due to depressive symptoms may explain why the CHART-SF mobility dimension instead is associated with depression. Taken together, these findings suggest that treatments aimed to improve mobility may play a role in reducing depressive symptoms, or alternatively, that treating depression could have a positive impact on mobility.

A third clinically important finding is that use of an antidepressant medication was associated with moderate and severe depressive symptoms, but not mild symptoms. Mild symptoms often do not warrant treatment with medications, but many individuals with moderate and severe symptoms who are being treated pharmacologically continue to be symptomatic and thus may be undertreated. It was not possible to determine whether participants were taking their medications consistently More attention to modifying or improving treatment plans for individuals already identified as having depressive symptoms may be warranted.

The hypothesis that SB severity indicators (higher LOL and shunt history) would be associated with depression score was not supported. In other research, a higher LOL (e.g., lumbar and above) is generally associated with greater deficits in self-management competencies (Bellin et al., 2011) and functional independence (Hetherington et al., 2006). These limitations have been found to create barriers to community participation, negatively impact quality of life (Cate, Kennedy, & Stevenson, 2002) and self-worth (Sawin, Buran, Brei, & Fastenau, 2003), and heighten vulnerability to distress. It is likely that depression

correlates with LOL only indirectly because of the LOL's effect on mobility. Since adequate self-management skills appear to have a protective effect on depressive symptoms (Bellin, Dosa, et al., 2013), tailored skill-building interventions for independence and self-management may protect against depressive symptoms.

Of the BDI-II symptoms reported, low energy (53%), sleep disturbance (47%), and fatigue (44%) were the most common. The frequency of passive suicidal thoughts, i.e. "I have thoughts of killing myself but would not carry them out" on the BDI-II was one of the least frequently reported symptoms at 12.6%. No individuals indicated active thoughts, i.e. "I would like to kill myself" or "I would kill myself if I had the chance." Low energy and fatigue could be explained by the increased energy demands for ambulation. Inevitably, some overlap with depressive symptomatology and sleep disturbance exists, but sleep disturbances are also prevalent in SB compared to the general population (Edelstein, Cirino, Hasher, Fletcher, & Dennis, 2012). Chiari II malformation is common in SB and is associated with central apnea, central hypoventilation syndrome, and obstructive apnea (Kirk, Morielli, & Brouillette, 1999). Thus, a targeted review of systems should likely include questions about suicidal thoughts and sleep. Crisis plans should be in place for any individuals with active suicidal thoughts. Sleep apnea should be ruled out if clinically indicated.

### Limitations

Results from this study cannot be generalized to all adults with SB. The distribution of age in this population was skewed toward younger ages, with the majority falling between 18–30 years old. This cohort is also disproportionately Caucasian; however, much of the research in self-management and psychological symptoms in SB has included a high percentage of Non-Hispanic Caucasian participants (Buran, Sawin, Brei, & Fastenau, 2004; Dicianno, Gaines, et al., 2009; Holmbeck et al., 2010; Zukerman et al., 2011). To our knowledge, this is one of few studies to evaluate such a large cohort of participants with SB with ages extending into older adulthood.

The scores seen on the BDI-II were quite variable. A relatively large number of participants had a BDI-II total score of zero, which is common on the BDI-II and may indicate poor lowend specificity, or responding in a "fake good" manner (Beebe, Finer, & Holmbeck, 1996). Another less likely explanation is that patients have a high degree of emotional resiliency and sufficient coping mechanisms (Hayter & Dorstyn, 2013). On the other hand, those reporting higher scores may have been over-reporting symptoms, which has been previously been demonstrated with pain scores and psychological symptoms in participants with physical disabilities and chronic pain (Engel, Wilson, Tran, Jensen, & Ciol, 2013; Gendelman et al., 2009). Likewise, somatic symptoms can also inflate BDI-II score (Thombs et al., 2010). However, the percent of participants in this study with BDI-II 14+ is high, even when compared to what has been demonstrated in conditions like diabetes (Gendelman et al., 2009), suggesting that symptoms were less likely due to somatic complaints alone. Finally, a total of 30 charts were excluded due to incomplete BDI-II scores. If cognitive impairments prevented some individuals from understanding the questions, then the results may be less applicable to this group. Having a proxy assist with

survey completion could also influence the results. In this study, however, only 2 individuals had motor impairments (e.g. cervical level of lesion) that impacted writing ability. More work is needed to determine whether asking about "emotional concerns" as a reason for the visit could be a sensitive screening for individuals who cannot complete a full survey.

It is also important to note that a mean age of 33.6 (SD = 11.1) years upon presentation implies that adult providers outside the pediatric SB clinic initiated many of the treatments. This may have resulted in under-treatment of symptoms during the transition period.

### Conclusions

This study is one of the first to describe depressive symptoms experienced by individuals with SB of a broad range of ages extending into adulthood. Adults with SB in this sample have higher rates of depression symptoms compared to the general population, with 25.8% considered to have depressive symptomatology based on BDI-II. Data suggest that low CHART-SF mobility scores and prior or concomitant use of antidepressants are significantly associated with depressive symptoms. More work is needed to determine how interventions to treat depression or improve mobility may impact depressive symptoms in patients with SB longitudinally. Furthermore, the results suggest that physiatrists and other clinicians should systematically screen patients for emotional concerns or lack of interest, as these symptoms may be useful in detecting some cases of depressive symptomatology.

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# Abbreviations

(SB)	Spina Bifida
(BDI-II)	Beck Depression Inventory-II
(CHART-SF)	Craig Handicap Assessment Reporting Technique Short Form
(LOL)	Level of Lesion

### References

- Appleton PL, Ellis NC, Minchom PE, Lawson V, Boll V, Jones P. Depressive symptoms and selfconcept in young people with spina bifida. Journal of pediatric psychology. 1997; 22(5):707–722. Retrieved from: http://jpepsy.oxfordjournals.org. [PubMed: 9383931]
- Arnett JJ. Emerging adulthood: A theory of development from the late teens through the twenties. American Psychology. 2000; 55:469–480.
- Beck, AT.; Steer, RA.; Brown, GK. Manual for the Beck Depression Inventory-II. San Antonio, TX: Psychological Corporation; 1996.

Beebe DW, Finer E, Holmbeck GN. Low-end specificity of four depression measures: Findings and suggestions for the research use of depression tests. Journal of personality assessment. 1996; 67(2): 272–284. [PubMed: 8828189]

- Bellin MH, Dicianno BE, Levey E, Dosa N, Roux G, Marben K, Zabel TA. Interrelationships of sex, level of lesion, and transition outcomes among young adults with myelomeningocele. Developmental medicine and child neurology. 2011; 53(7):647–652. [PubMed: 21410695]
- Bellin MH, Dicianno BE, Osteen P, Dosa N, Aparicio E, Braun P, Zabel TA. Family satisfaction, pain, and quality-of-life in emerging adults with spina bifida: A longitudinal analysis. American journal of physical medicine & rehabilitation. 2013; 92(8):641–655. [PubMed: 23867887]
- Bellin MH, Dosa N, Zabel TA, Aparicio E, Dicianno BE, Osteen P. Self-management, satisfaction with family functioning, and the course of psychological symptoms in emerging adults with spina bifida. Journal of pediatric psychology. 2013; 38(1):50–62. [PubMed: 22976508]
- Bellin MH, Zabel TA, Dicianno BE, Levey E, Garver K, Linroth R, Braun P. Correlates of depressive and anxiety symptoms in young adults with spina bifida. Journal of pediatric psychology. 2010; 35(7):778–789. [PubMed: 19880443]
- Berbrayer DPR. Depression and functional independence, education, and employment in adults with spina bifida case control quantitative study. PM & R : the journal of injury, function, and rehabilitation. 2013; 5(9 Suppl):S200.
- Bowman RM, McLone DG, Grant JA, Tomita T, Ito JA. Spina bifida outcome: A 25-year prospective. Pediatric neurosurgery. 2001; 34(3):114–120. [PubMed: 11359098]
- Buran CF, Sawin KJ, Brei TJ, Fastenau PS. Adolescents with myelomeningocele: Activities, beliefs, expectations, and perceptions. Developmental medicine and child neurology. 2004; 46(4):244– 252. [PubMed: 15077702]
- Carney CE, Ulmer C, Edinger JD, Krystal AD, Knauss F. Assessing depression symptoms in those with insomnia: An examination of the Beck Depression Inventory second edition (BDI-II). Journal of psychiatric research. 2009; 43(5):576–582. [PubMed: 18954876]
- Cate IM, Kennedy C, Stevenson J. Disability and quality of life in spina bifida and hydrocephalus. Developmental medicine and child neurology. 2002; 44(5):317–322. [PubMed: 12033717]
- Centers for Disease Control Prevention (CDC). Current depression among adults--- United States, 2006 and 2008. Morbidity and Mortality Weekly Report. 2010; 59(38):1229–1235. Retrieved from: http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5938a2.htm. [PubMed: 20881934]
- Davis BE, Daley CM, Shurtleff DB, Duguay S, Seidel K, Loeser JD, Ellenbogan RG. Long-term survival of individuals with myelomeningocele. Pediatric neurosurgery. 2005; 41(4):186–191. [PubMed: 16088253]
- Dicianno BE, Bellin MH, Zabel AT. Spina bifida and mobility in the transition years. American journal of physical medicine & rehabilitation. 2009; 88(12):1002–1006. [PubMed: 19935183]
- Dicianno BE, Gaines A, Collins DM, Lee S. Mobility, assistive technology use, and social integration among adults with spina bifida. American journal of physical medicine & rehabilitation. 2009; 88(7):533–541. [PubMed: 19542778]
- Dicianno BE, Kurowski BG, Yang JM, Chancellor MB, Bejjani GK, Fairman AD, Sotirake J. Rehabilitation and medical management of the adult with spina bifida. American journal of physical medicine & rehabilitation. 2008; 87(12):1027–1050. [PubMed: 18923330]
- Dillon CM, Davis BE, Duguay S, Seidel KD, Shurtleff DB. Longevity of patients born with myelomeningocele. European journal of pediatric surgery : official journal of Austrian Association of Pediatric Surgery. 2000; 10(1 Suppl):33–34.
- Edelstein K, Cirino PT, Hasher L, Fletcher JM, Dennis M. Sleep problems, chronotype, and diurnal preferences in children and adults with spina bifida. Journal of biological rhythms. 2012; 27(2): 172–175. [PubMed: 22476778]
- Engel JM, Wilson S, Tran ST, Jensen MP, Ciol MA. Pain catastrophizing in youths with physical disabilities and chronic pain. Journal of pediatric psychology. 2013; 38(2):192–201. [PubMed: 23033363]
- Flanagan A, Kelly EH, Vogel LC. Psychosocial outcomes of youth with early onset spinal cord injury and those with spina bifida. Pediatric Physical Therapy. 2013; 25(4)
- Fletcher JM, Copeland K, Frederick JA, Blaser SE, Kramer LA, Northrup H, Dennis M. Spinal lesion level in spina bifida: A source of neural and cognitive heterogeneity. Journal of neurosurgery. 2005; 102(3 Suppl):268–279. [PubMed: 15881750]

- Garcia AM, Dicianno BE. The frequency of lymphedema in an adult spina bifida population. Am J Phys Med Rehabil. 2011; 90(2):89–96. [PubMed: 21173682]
- Gannotti ME, Minter CL, Chambers HG, Smith PA, Tylkowski C. Self-concept of adults with cerebral palsy. Disability and rehabilitation. 2011; 33(10):855–861. [PubMed: 20804447]
- Gendelman N, Snell-Bergeon JK, McFann K, Kinney G, Paul Wadwa R, Bishop F, Maahs DM. Prevalence and correlates of depression in individuals with and without type 1 diabetes. Diabetes Care. 2009; 32(4):575–579. [PubMed: 19171719]
- Harrington R, Fudge H, Rutter M, Pickles A, Hill J. Adult outcomes of childhood and adolescent depression: I. Psychiatric status. Archives of general psychiatry. 1990; 47(5):465–473. [PubMed: 2184797]
- Hayter MR, Dorstyn DS. Resilience, self-esteem and self-compassion in adults with spina bifida. Spinal Cord. 2014; 52(2):167–171. [PubMed: 24322213]
- Hetherington R, Dennis M, Barnes M, Drake J, Gentili F. Functional outcome in young adults with spina bifida and hydrocephalus. Child's nervous system : ChNS : official journal of the International Society for Pediatric Neurosurgery. 2006; 22(2):117–124.
- Holmbeck GN, DeLucia C, Essner B, Kelly L, Zebracki K, Friedman D, Jandasek B. Trajectories of psychosocial adjustment in adolescents with spina bifida: A 6-year, four-wave longitudinal followup. Journal of consulting and clinical psychology. 2010; 78(4):511–525. [PubMed: 20658808]
- Holmbeck GN, Devine KA. Psychosocial and family functioning in spina bifida. Developmental disabilities research reviews. 2010; 16(1):40–46. [PubMed: 20419770]
- Hosmer, DW.; Lemeshow, S. 2nd ed.. Hoboken, NJ: John Wylie & Sons, Inc; 2004. Applied Logistic Regression.
- Hughes RB, Nosek MA, Robinson-Whelen S. Correlates of depression in rural women with physical disabilities. Journal of obstetric, gynecologic, and neonatal nursing : JOGNN / NAACOG. 2007; 36(1):105–114.
- Hunt GM. The median survival time in open spina bifida [Letter to the editor]. Developmental medicine and child neurology. 1997; 39(8):568. [PubMed: 9295857]
- Kalfoss MH, Merkens MJ. A comparative study of quality of life among adults with spina bifida [Oral presentation from the 50th Annual Meeting of the Society for Research into Hydrocephalus and Spina Bifida]. Cerebrospinal Fluid Research. 2006; 3(1 Suppl):S31.
- Kirk VG, Morielli A, Brouillette RT. Sleep-disordered breathing in patients with myelomeningocele: The missed diagnosis. Developmental medicine and child neurology. 1999; 41(1):40–43. [PubMed: 10068048]
- Kjaergaard M, Arfwedson Wang CE, Waterloo K, Jorde R. A study of the psychometric properties of the Beck Depression Inventory-II, the Montgomery and Asberg Depression Rating Scale, and the Hospital Anxiety and Depression Scale in a sample from a healthy population. Scandinavian journal of psychology. 2013
- Kuhner C, Burger C, Keller F, Hautzinger M. Reliabilität und Validität des revidierten Beck-Depressions-inventars (BDI-II) [Reliability and validity of the revised Beck Depression Inventory (BDI-II). Nervenarzt. 2007; 78(6):651–656. [PubMed: 16832698]
- McDonnell GV, McCann JP. Why do adults with spina bifida and hydrocephalus die? A clinic-based study. European journal of pediatric surgery : official journal of Austrian Association of Pediatric Surgery. 2000a; 10(1 Suppl):31–32.
- McDonnell GV, McCann JP. Issues of medical management in adults with spina bifida. Child"s nervous system : ChNS : official journal of the International Society for Pediatric Neurosurgery. 2000b; 16(4):222–227.
- Myaskovsky L, Burkitt KH, Lichy AM, Ljungberg IH, Fyffe DC, Ozawa H, Boninger ML. The association of race, cultural factors, and health-related quality of life in persons with spinal cord injury. Archives of physical medicine and rehabilitation. 2011; 92(3):441–448. [PubMed: 21353826]
- National Institute of Mental Health (NIMH). (n.d.). Depression in children and adolescents fact sheet. Retrieved from NIMH website: http://www.nimh.nih.gov/health/publications/depression-inchildren-and-adolescents/index.shtml

- National Institute of Neurological Disorders and Stroke (NINDS). Spina bifida fact sheet. Bethesda, MD: National Institutes of Health; 2013. (NIH Publication No. 13-309) Retrieved from NINDS website: http://www.ninds.nih.gov/disorders/spina\_bifida/spina\_bifida\_FS.pdf
- Ouyang L, Grosse SD, Armour BS, Waitzman NJ. Health care expenditures of children and adults with spina bifida in a privately insured U.S. population. Birth defects research. Part A: Clinical and molecular teratology. 2007; 79(7):552–558.
- Rao U, Ryan ND, Birmaher B, Dahl RE, Williamson DE, Kaufman J, Nelson B. Unipolar depression in adolescents: Clinical outcome in adulthood. Journal of the American Academy of Child & Adolescent Psychiatry. 1995; 34(5):566–578. [PubMed: 7775352]
- Rodriguez EM, Dunn MJ, Zuckerman T, Hughart L, Vannatta K, Gerhardt CA, Compas BE. Motherchild communication and maternal depressive symptoms in families of children with cancer: Integrating macro and micro levels of analysis. Journal of pediatric psychology. 2013; 38(7):732– 743. [PubMed: 23616622]
- Sawin KJ, Bellin MH. Quality of life in individuals with spina bifida: A research update. Developmental disabilities research reviews. 2010; 16(1):47–59. [PubMed: 20419771]
- Sawin KJ, Bellin MH, Roux G, Buran CF, Brei TJ. The experience of self- management in adolescent women with spina bifida. Rehabilitation Nursing. 2009; 34:26–38. [PubMed: 19160922]
- Sawin KJ, Brei TJ, Buran CF, Fastenau PS. Factors associated with quality of life in adolescents with spina bifida. Journal of holistic nursing : official journal of the American Holistic Nurses" Association. 2002; 20(3):279–304.
- Sawin KJ, Buran CF, Brei TJ, Fastenau PS. Correlates of functional status, self-management, and developmental competence outcomes in adolescents with spina bifida. SCI nursing : a publication of the American Association of Spinal Cord Injury Nurses. 2003; 20(2):72–85.
- Sawyer SM, Macnee S. Transition to adult health care for adolescents with spina bifida: Research issues. Developmental disabilities research reviews. 2010; 16(1):60–65. [PubMed: 20419772]
- Segal ME, Schall RR. Assessing handicap of stroke survivors. A validation study of the Craig Handicap Assessment and Reporting Technique. American journal of physical medicine & rehabilitation. 1995; 74(4):276–286. [PubMed: 7632384]
- Sharp LK, Lipsky MS. Screening for depression across the lifespan: A review of measures for use in primary care settings. American family physician. 2002; 66(6):1001–1008. Retrieved from: http:// www.aafp.org. [PubMed: 12358212]
- Shurtleff DB. 44 years experience with management of myelomeningocele: Presidential address, Society for Research into Hydrocephalus and Spina Bifida. European journal of pediatric surgery : official journal of Austrian Association of Pediatric Surgery. 2000; 10(1 Suppl):5–8.
- Simon GE, VonKorff M. Recognition, management, and outcomes of depression in primary care. Archives of family medicine. 1995; 4(2):99–105. Retrieved from: http://www.clockss.org/clockss/ Archives\_of\_Family\_Medicine. [PubMed: 7842160]
- Soe MM, Swanson ME, Bolen JC, Thibadeau JK, Johnson N. Health risk behaviors among young adults with spina bifida. Developmental medicine and child neurology. 2012; 54(11):1057–1064. [PubMed: 22937873]
- Stepanczuk BC, Dicianno BE, Webb TS. Young adults with spina bifida may have higher occurrence of prehypertension and hypertension. Am J Phys Med Rehabil. 2014; 93(3):200–206. [PubMed: 24088776]
- Thombs BD, Ziegelstein RC, Pilote L, Dozois DJ, Beck AT, Dobson KS, Abbey SE. Somatic symptom overlap in Beck Depression Inventory-II scores following myocardial infarction. The British journal of psychiatry : the journal of mental science. 2010; 197(1):61–66. [PubMed: 20592436]
- Walker N, Mellick D, Brooks CA, Whiteneck GG. Measuring participation across impairment groups using the Craig Handicap Assessment Reporting Technique. American journal of physical medicine & rehabilitation. 2003; 82(12):936–941. [PubMed: 14627930]
- Wallander JL, Varni JW. Effects of pediatric chronic physical disorders on child and family adjustment. Journal of child psychology and psychiatry, and allied disciplines. 1998; 39(1):29–46.
- Whiteneck GG, Charlifue SW, Gerhart KA, Overholser JD, Richardson GN. Quantifying handicap: A new measure of long-term rehabilitation outcomes. Archives of physical medicine and

rehabilitation. 1992; 73(6):519–526. Retrieved from: http://www.archives-pmr.org. [PubMed: 1622299]

- Wong LY, Paulozzi LJ. Survival of infants with spina bifida: A population study, 1979-94. Paediatric and perinatal epidemiology. 2001; 15(4):374–378. [PubMed: 11703686]
- Zebracki, K.; Zaccariello, M.; Zelko, F.; Holmbeck, GN. Adolescence and emerging adulthood in individuals with spina bifida: A developmental neuropsychological perspective. In: Donders, J.; Hunter, SJ., editors. Principles and Practice of Lifespan Developmental Neuropsychology. Cambridge, England: Cambridge University Press; 2010. p. 183-194.
- Zukerman JM, Devine KA, Holmbeck GN. Adolescent predictors of emerging adulthood milestones in youth with spina bifida. Journal of pediatric psychology. 2011; 36(3):265–276. [PubMed: 20855288]

### Impact

- Although studies have described depressive symptoms in individuals with spina bifida below age 25, this study extends these findings into adults over age 25 (and up to age 77). This represents a fairly new cohort, given that only in recent decades have individuals with spina bifida begun to have life expectancy that extends into adulthood.
- This study adds to the literature by demonstrating that depressive symptoms are common and potentially undertreated in the adult spina bifida population.
- An implication for clinical practice is that screening adults with spina bifida with a single question about having emotional concerns is warranted.

Reason for visit as selected by patients on an intake sheet.

Patients' Reasons for Visit				
Reason for Visit	N (%)			
Medical Issues	112 (58.9)			
Wheelchair, Bracing or Equipment Issues	62 (32.6)			
Medication Issues	51 (26.8)			
Employment Issues	35 (18.4)			
Physical Assistance Needs	32 (16.8)			
Transportation Issues	32 (16.8)			
Emotional Concerns	22 (11.6)			
Housing Issues	18 (9.5)			
Relationship or Sexuality Issues	16 (8.4)			
Financial Issues	15 (7.9)			
Educational Issues	6 (3.2)			
Legal Concerns	3 (1.6)			
Substance Use Concern	1 (0.5)			

Note. Sum is more than 100% because more than one response was allowed.

Demographics and outcome variables collected in the study. CHART-SF dimension scores ranges from 0–100, with 100 indicating full ability or independence in that dimension.

Variable	N (%) or (SD)			
Gender				
Male	87 (45.8%)			
Female	103 (54.2%)			
Ethnicity				
Hispanic	2 (1.1%)			
Non-Hispanic	188 (98.9%)			
Race				
African American	4 (2.1%)			
Asian	1 (0.5%)			
Caucasian	183 (96.3%)			
Race Unanswered	2 (1.1%)			
BDI-II Category				
No to Minimal (0-13)	141(74.2%)			
Mild (14-19)	20 (10.5%)			
Moderate (20-28)	13 (6.8%)			
Severe (29–63)	16 (8.4%)			
CHART-SF*				
• Mobility	74.3 (32.4)			
• Physical Independence	75.8 (38.0)			
• Economic	44.3 (41.5)			
• Social	70.7 (32.4)			
• Cognitive	34.6 (30.3)			
Occupational	46.9 (38.9)			
Antidepressant Use for Depressiv	ve Symptoms at time of chart revie			
No	121 (63.7%)			
Yes	69 (36.3%)			
• No to Minimal	38 of 141 (27.0%)*			
• Mild	9 of 20 (45.0%)*			
• Moderate	11 of 13 (84.6%)*			
• Severe	11 of 16 (68.8%)*			
* Percent use per	r depression category			
Level of Lesion				
Lumbar	131 (69.9%)			
Thoracic	36 (18.9%)			
Sacral	15 (7.9%)			

Demographics, CHART-SF, and Psychological Variables			
Variable N (%) or (SD)			
Normal	6 (3.2%)		
Cervical	2 (1.1%)		

Odds Ratio Estimates for independent variables.

Odds Ratio Estimates						
Effect	BDI-II category	Odds Ratio	95% Wald			
			Confidence Limits			
CHART-SF Mobility	Mild	0.989	0.973	1.004		
CHART-SF Mobility	Moderate	0.99	0.969	1.01		
CHART-SF Mobility	Severe	0.97	0.951	0.989		
Antidepressant use	Mild	2.091	0.774	5.647		
Antidepressant use	Moderate	15.841	3.237	77.516		
Antidepressant use	Severe	6.803	1.809	25.581		
Emotional concern	Mild	5.421	1.501	19.574		
Emotional concern	Moderate	2.541	0.427	15.119		
Emotional concern	Severe	16.816	4.181	67.632		

# Analysis of Maximum Likelihood Estimates for independent variables

Analysis of Maximum Likelihood Estimates								
Independent Variable	<b>BDI-II</b> Category	Beta	Standard Error	pValue				
CHARTSF-Mobility	Mild	-0.0114	0.00799	0.1549				
CHARTSF-Mobility	Moderate	-0.0104	0.0106	0.3280				
CHARTSF-Mobility	Severe	-0.0307	0.00980	0.0017				
Antidepressant Use	Mild	0.7378	0.5068	0.1455				
Antidepressant Use	Moderate	2.7626	0.8102	0.0006				
Antidepressant Use	Severe	1.9174	0.6758	0.0045				
Emotional Concerns	Mild	1.6902	0.6551	0.0099				
Emotional Concerns	Moderate	0.9327	0.9099	0.3053				
Emotional Concerns	Severe	2.8223	0.7101	<.0001				

 $Overall\ model\ p<0.0001,\ R-Square\ 0.2742,\ Max-rescaled\ R-Square\ 0.3354$