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Characteristics Associated with Depression, Anxiety, and Social Isolation in Adults with Spina Bifida

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Abstract

Objectives: To identify demographic and clinical characteristics associated with depression, anxiety, and social isolation among adults with spina bifida. We hypothesize that lower urinary tract dysfunction is associated with poor psychosocial outcomes.

Methods: An anonymous survey was distributed via Facebook advertising to individuals with congenital urologic conditions. Adults with spina bifida were included in our analysis. Lower urinary tract dysfunction was assessed with the Neurogenic Bladder Symptom Score. Depression, anxiety, and social isolation T-scores were measured using Patient-Reported Outcome Measures Information System instruments. A composite depression-anxiety score was calculated. Separate adjusted linear models assessed the association between lower urinary tract dysfunction and depression, anxiety, composite depression-anxiety, and social isolation.

Results: 195 participants were included. Rates of depression, anxiety, and social isolation were 48%, 47%, and 43%, respectively. Comorbid depression and anxiety occurred in 39% of subjects. On adjusted regression analysis, lower urinary tract dysfunction was associated with depression (p

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< 0.001), anxiety (p < 0.001), composite depression-anxiety (p < 0.001), and social isolation (p = 0.010).

Conclusions: Depression, anxiety, and social isolation are common in individuals with spina bifida relative to the general population, and associated with lower urinary tract dysfunction. Interventions focused on optimizing lower urinary tract symptoms and function, transition-age adults, group psychotherapy, and comorbid depression and anxiety may be of particular value in this population.

Keywords

Spinal dysraphism; Depression; Anxiety; Social isolation; Urology

INTRODUCTION

As the life expectancy of individuals with spina bifida has lengthened (82% 25-year survival probability), increased attention has been dedicated to understanding their psychosocial experiences.[1] Rates of depressive and anxious symptoms in individuals with spina bifida as high as 25–45% and 24–31%, respectively, have been identified.[2–4] Social isolation is also commonplace.[5,6]

However, little is known about the factors associated with psychosocial function in this population.[2] Limited research has identified protective factors against depressive symptoms, such as a positive attitude towards spina bifida, increased self-management, and greater satisfaction with family functioning; risk factors for depressive symptoms, such as pain, have also been described.[2,3,7] Similar protective and risk factors for anxiety symptoms have been identified, including greater satisfaction with family functioning and pain, respectively. [2,3]

Data on the relationship between psychosocial outcomes and lower urinary tract dysfunction, which occurs in 90% of patients with myelomeningocele, is particularly scarce. Intuitively, lower urinary tract dysfunction and psychosocial outcomes may be related in a number of ways. Amongst other disease groups, strong links between physical and mental health have been demonstrated, and individuals with spina bifida are at risk for various urologic morbidities across the lifespan, including recurrent urinary tract infection, urolithiasis, and renal insufficiency, as well as continued high mortality throughout adulthood.[8,9] Individuals with spina bifida are at particularly high risk of experiencing incontinence (46% of adults with myelomeningocele, and 63% with nonmyelomeningocele), which in the general population has been associated with a large burden of depression and anxiety.[10,11] Furthermore, bladder management, which may include bladder catheterization (in approximately 80% of adults), bowel care, clean-up of accidents, and frequent interaction with the health care system, may be burdensome for both patients and caregivers.[10,12] Finally, social engagement may be limited by fear of embarrassment and difficulty conducting bladder care independently outside of the home, as has been documented in other groups.[13] In sum, despite a clear theoretical relationship, to our knowledge no prior study has examined the association between lower urinary tract dysfunction and depression, anxiety, and social isolation in adults with spina bifida.

We aim to identify demographic and clinic characteristics associated with depression, anxiety, and social isolation in adults with spina bifida. We hypothesize that lower urinary tract dysfunction specifically is associated with poor psychosocial outcomes.

MATERIALS AND METHODS

Survey Development and Distribution

An anonymous online survey was developed at the University of California, San Francisco (UCSF) and distributed using Facebook advertising to persons with congenital urologic conditions from 3/22/2018 to 9/30/2018. Facebook advertisement has been used for recruitment in other health-related research studies with good success.[2,7,14] Advertisements were targeted to Facebook users who "liked" or were members of Facebook pages related to the Spina Bifida Association. In addition, Facebook groups related to other congenital urologic conditions were contacted via Facebook messenger and asked to distribute our survey to their members. As incentive for participating, participants were entered in a lottery whereby two participants were selected to receive an iPad mini. Participant recruitment through Facebook has gained popularity amongst researchers due to the platform's widespread use and ability to target advertising to user characteristics, and has been utilized successfully previously, with 86% of studies reporting that samples recruited through Facebook were representative to samples recruited through traditional methods.[14]

Inclusion Criteria

Any individual 13 years old who identified as having a congenital urologic condition was eligible to complete the survey. However, this analysis was restricted to respondents who met the following inclusion criteria: diagnosis of spina bifida, age 18 years, primary residence in the United States, and complete survey data available.

Variables

The independent variable hypothesized *a priori* to be associated with psychosocial outcomes was neurogenic bladder dysfunction as assessed by the Neurogenic Bladder Symptom Score (NBSS), a validated tool for measuring urinary symptoms and consequences in individuals with congenital neurologic bladder.[15] Additional covariates controlled for in our analysis were age, gender, race, household education (highest level of education amongst all household members), household income, insurance, prior surgeries for urologic conditions, ventriculoperitoneal (VP) shunt presence, and physical function (as measured by the PROMIS Physical Function with Mobility Aid instrument v1.0, which is a standardized, validated self-report measure of physical functioning).[16,17] For the purposes of regression analysis, a number of variables were dichotomized: race as white/non-white, household education as lower than college degree/college or higher, total household income as < $100,000/ $100,000, and insurance status as private insurance only/all other (dual, public, or no insurance).

The primary outcomes of depression, anxiety, and social isolation were measured using Patient-Reported Outcome Measures Information System (PROMIS) instruments (Depression 8a Short Form v1.0, Anxiety 8a Short Form v1.0, and Social Isolation 6a Short

Form v2.0, respectively).[16] PROMIS instruments are self-report measures of a given phenomenon. Raw scores are converted to standardized T-scores using a scoring manual, with a mean of 50 and standard deviation of 10, to facilitate comparison to the general population. Higher T-scores indicate higher levels of the phenomenon being measured. To aid in interpretation of scores, the following cut-points are provided: "within normal limits" (T-score 55), "mild" (56–60), "moderate" (61–70), and "severe" (71).[17] With regard to the reference population, PROMIS standardized T-score scales were derived from a large sample that represents the 2000 US General Census population, recruited via traditional sampling techniques.[18] Substantial evidence supports the reliability and construct validity of PROMIS measures with "legacy" measures in diverse populations.[17,18] A composite depression-anxiety score was also calculated by averaging the PROMIS depression and anxiety scores. Composite depression-anxiety measures are useful in adjusted analyses such as ours due to the high comorbidity and statistical intercorrelation between depression and anxiety. Early evidence suggests that composite depression-anxiety scales are valid and responsive measures appropriate for use in clinical research.[19]

Data Analysis

Descriptive statistics were calculated for each variable. For each psychosocial outcome, the mean score was compared to that of a normally distributed US general population sample using a one-way t-test. Additionally, for each psychosocial outcome, the proportion of the sample meeting criteria for a mild to severe outcome (per PROMIS cut-points) was compared to that of a US general population sample using a one-sample test of proportions. The proportion of the US general population sample meeting criteria for a mild to severe outcome was derived by converting published T-score cut-points to percentiles using a standard psychometric conversion table.[20] Bivariate analysis of the association between participant characteristics and outcome variables was examined using Student's t-test, one-way ANOVA, and Pearson's correlation, as appropriate. Separate general linear models assessed the association of the independent variables with each outcome measures (depression, anxiety, composite depression-anxiety, and social isolation). In each model, the independent variables were entered, and a backwards elimination approach was employed until all p-values were 0.2. In the model for social isolation, composite depression-anxiety score was included as an additional covariate. Results were considered significant at a p-value of <0.05. Statistical analysis was performed in Stata 16.0 (Stata Corp., College Station, TX, USA).

Ethical Considerations

The study received IRB approval by the UCSF Committee on Human Research (17–23699).

RESULTS

Of 271 survey respondents, 195 met inclusion criteria for this study. Twenty-four subjects were excluded because they did not have a diagnosis of spina bifida, 51 were excluded secondary to incomplete survey data, and one was excluded due to outlying values.

Participant characteristics are presented in Table 1. The mean age was 40.2 years (SD 12.6), with a range of 18 to 72 years. Females accounted for 75% of participants. The majority of participants (80%) were white; participants who identified as Hispanic/Latino comprised 29% of the non-white group. The mean neurogenic bladder symptom score was 29.1 (SD 11.2), with a range of 8 to 74. With respect to psychosocial outcomes, the mean depression score was 55.3 (SD 10.6), which differed significantly from a mean score of 50 (SD 10) for a US general population sample (p < 0.001).[17] According to the PROMIS score cut-offs, 48% of respondents experienced depression, which differed significantly from 31% of a US general population sample, as estimated by the T-score to percentile conversions described in the methods section (p < 0.001). When classified according to severity, 14% of our sample experienced mild depression, 29% experienced moderate depression, and 5% experienced severe depression. With respect to anxiety, the mean score was 55.0 (SD 11.7), which differed significantly from a mean score of 50 (SD 10) for a US general population sample (p < 0.001). Overall, 47% of participants demonstrated anxiety, which differed significantly from 31% of a US general population sample (p < 0.001). When broken down according to severity, 12% of our sample met criteria for mild anxiety, 28% for moderate anxiety, and 7% for severe anxiety. Considered together, 56% of our sample experienced depression, anxiety, or both; 17% demonstrated only one psychopathology, and 39% experienced both. The mean composite depression-anxiety score was 55.1 (SD 10.6). With respect to social isolation, the mean score was 52.6 (SD 10.3), which differed significantly from a mean score of 50 (SD 10) for a US general population sample (p <0.001). Overall, 43% of respondents met criteria for social isolation, which differed significantly from 31% of a US general population sample (p < 0.001). In our sample, 27% of respondents experienced mild social isolation, 10% moderate social isolation, and 6% severe social isolation.

The results of bivariate analyses are presented in Table 2. Significant associations were demonstrated between depression and higher neurogenic bladder symptom scores, as well as lower household education, lack of prior surgeries for a urologic condition, and lower physical function. Significant associations were noted between anxiety and higher neurogenic bladder symptom scores, in addition to younger age, and lower physical function. With respect to the composite depression-anxiety score, significant associations were found with higher neurogenic bladder symptom scores, younger age, lower household education, and lower physical function. Finally, significant associations existed between social isolation and higher neurogenic bladder symptom scores, as well as younger age, lower household education, lack of prior surgeries for a urologic condition, lower physical function score, and higher composite depression/anxiety scores.

Linear regression demonstrated significant associations between depression and higher neurogenic bladder symptom score (B = 0.30, 95% CI 0.17 – 0.43, p <0.001), and lower household education (B = −2.99, 95% CI −5.77 - −0.21, p = 0.035) (Table 3). The final model accounted for 19% of the variance in depression (R^2 = 0.19, p < 0.001). For anxiety, linear regression analysis found significant associations with higher neurogenic bladder symptom score (B = 0.36, 95% CI 0.22 – 0.49, p <0.001), as well as younger age (B = −0.20, 95% CI −0.33 - −0.08, p = 0.001) and lack of a VP shunt (B = −3.36, 95% CI −6.63 - −0.08, p = 0.044). The final model accounted for 20% of the variance in anxiety (R^2 = 0.20,

p < 0.001). With respect to composite depression-anxiety scores, linear regression analysis showed significant associations with higher neurogenic bladder symptom scores (B = 0.32, 95% CI 0.20 – 0.45, p < 0.001) and younger age (B = –0.15, 95% CI –0.26 - –0.04, p = 0.008). The final model accounted for 22% of the variance in composite depression-anxiety scores ($R^2 = 0.22$, p < 0.001). Finally, the model for social isolation showed significant associations with higher neurogenic bladder symptom score (B = 0.14, 95% CI 0.03 – 0.25, p = 0.010), in addition to younger age (B = –0.12, 95% CI –0.20 - –0.03, p = 0.006), lack of surgeries for a urologic condition (B = –3.31, 95% CI –5.71 - –0.91, p = 0.007), and higher composite depression-anxiety score (B = 0.25, 95% CI 0.19 – 0.30, p < 0.001) (Table 4). The final model accounted for 47% of the variance in social isolation ($R^2 = 0.47$, p < 0.001).

DISCUSSION

The high rates of depression and anxiety amongst individuals with spina bifida in our study are striking, with the majority of individuals experiencing at least one of these conditions. In comparison to prior studies in individuals with spina bifida, the depression rate of 48% in our study is consistent with previously documented rates of 25–45%, whereas the anxiety rate of 47% in our study is notably higher than previously documented rates of 24–31%. [2,4,21] Such high rates of depression and anxiety are concerning, as depression and anxiety are associated with increased risk of suicide, decreased quality of life, impairments in role functioning, and high economic cost.[22–24] Further, depression and anxiety are associated with poor health outcomes, particularly when they co-occur with chronic medical conditions.[25–28] Finally, it is remarkable that 39% of our sample experienced comorbid depression and anxiety. Comorbid depression and anxiety is associated with higher symptom severity, functional impairment, and treatment resistance, relative to either disorder alone. [29,30]

Neurogenic bladder dysfunction was significantly associated with depression, anxiety, composite depression-anxiety, and social isolation in our study. Higher bladder symptomology may reflect more severe disease, discomfort, and functional or social limitations that contribute to poor psychological health. Conversely, psychological distress may aggravate bladder symptoms. Future research should elucidate the direction and mechanism of this relationship, given the high burden of both phenomena in individuals with spina bifida. Clinically, bladder dysfunction can often be managed with a variety of behavioral, medical and surgical interventions, and our findings suggest that practitioners should strive to understand and ameliorate the most bothersome elements of patients' disease when possible. Balancing symptom management and quality of life concerns with renal and bladder health may be a nuanced act, as any provider who has cared for a patient who prefers a chronic indwelling catheter can attest. Furthermore, individuals with spina bifida and bladder dysfunction should receive universal screening, and referral or treatment as appropriate, for mental health concerns.[31]

In addition to bladder dysfunction, younger age was associated with worse psychosocial outcomes (specifically, anxiety, composite depression-anxiety, and social isolation). Younger adults may have fewer skills, resources, and relationships to rely on when coping with difficult circumstances; this is particularly true for individuals with spina bifida, who

commonly experience executive function impairments and acquire autonomy skills two to five years later than their typically-developing peers.[32] Further, young adulthood represents a major life transition that may be particularly challenging for those with complex care needs. Support for patients and families who are approaching or undergoing the transition to adulthood and self-management should include strategies and opportunities for improving mental health and socialization.[31]

Interestingly, physical function was not associated with any psychosocial outcome in the adjusted analyses. Perhaps since physical limitations have been present since birth, individuals have found ways to overcome them, or do not view them as having significant impact on their wellbeing. VP shunt status also appeared to be unrelated to psychosocial outcomes (except in the case of anxiety, which was somewhat counterintuitively associated with *lack* of a shunt). These findings make the consistent significant relationship between bladder dysfunction and psychosocial outcomes all the more notable.

Social isolation was associated with higher composite depression-anxiety scores, which is consistent with known clinical manifestations of these conditions. Group cognitive behavioral therapy—which is as effective as individual cognitive behavioral therapy for depression and anxiety, and may decrease social isolation—may offer particular benefit for this population.[33]

It is noteworthy that the general linear models explained only 19, 20, and 22 percent of the variance in depression, anxiety, and composite depression-anxiety, respectively. This is consistent with research indicating that the pathogenesis of depression and anxiety each involve broad sets of risk factors—including genetics, exposure to adversity, and personality traits—which were unaccounted for in this study.[22]

From methodologic standpoint, this study demonstrates that recruitment of adults with spina bifida via social media is feasible. The demographic and clinical characteristics of our respondents suggest that we captured a different subset of patients than are typically included in studies from the national spina bifida registry.[34] White participants were overrepresented in our study compared to the national registry (82.6% vs. 65.5%), as were female participants (74.9% vs. 52.4%). Further, only 44.6% and 68.7% of our population reported having a VP shunt and urologic surgery, respectively, while data from the same national registry documented that all spina bifida registry patients >25 years old had undergone at least one neurologic procedure (including but not limited to VP shunts) and urologic procedure in their lifetime. Our study thus may have included a healthier subset of spina bifida patients than those in the national registry (which may itself skew towards complex patients, as only patients who attend select specialized spina bifida clinics are enrolled in the national registry).[34]

This study has several limitations. First, the cross-sectional design precludes conclusions regarding causality. Second, the recruitment of participants via Facebook advertising may bias our sample, as individuals with spina bifida who utilize Facebook may differ from those who do not. We cannot know the extent to which this bias exists in our study. Lastly, we did not include numerous factors (such as level of dependence on support systems, cognitive

function data, etc.) in our analysis that may be associated with psychosocial outcomes. To that end, the findings and limitations of this study will guide ongoing prospective data collection through a transitional urology patient registry at our institution.

CONCLUSIONS

The present study contributes to the spina bifida literature by documenting high rates of depression, anxiety, and social isolation in individuals with spina bifida, and identifying an association between each of these psychosocial phenomena and bladder dysfunction. From a methodologic perspective, it demonstrates that recruitment of adults with spina bifida via social media is feasible. Our findings underscore the need for appropriate screening and treatment of mental health conditions, and suggest that interventions focused on bladder dysfunction, transition-age adults, group psychotherapy, and comorbid depression and anxiety may be of particular value in this population. Future research should elucidate the mechanism by which bladder dysfunction and psychosocial outcomes are linked, and develop evidence-based screening protocols and interventions to promote psychosocial wellbeing in individuals with spina bifida. Additionally, further investigation of mental health concerns in minority groups less represented in this cohort is needed.

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Table 1.

Baseline characteristics for 195 study participants

Participant characteristic	Distribution
	N (%) or Mean (SD)
Age (years)	40.2 (12.6)
Gender	
Male	49.0 (25.1)
Female	146.0 (74.9)
Race	
White	161.0 (82.6)
Non-white	34.0 (17.4)
Household education	
Less than college	97.0 (49.7)
College/post-graduate	98.0 (50.3)
Household income	
<$20,000	59.0 (30.2)
$20,000 – $49,999	55.0 (28.2)
$50,000 – $99,999	61.0 (31.3)
$100,000	20.0 (10.3)
Insurance	
None	6.0 (3.0)
Public or dual	115.0 (59.0)
Private only	74.0 (38.0)
Prior surgeries for urologic condition	
No	61.0 (31.3)
Yes	134.0 (68.7)
Ventriculoperitoneal shunt	
No	108.0 (55.4)
Yes	87.0 (44.6)
Physical function score	39.7 (7.6)
Neurogenic bladder symptom score	29.1 (11.2)
Depression score	55.3 (10.6)
Anxiety score	55.0 (11.7)
Composite depression/anxiety score	55.1 (10.6)
Social isolation score	52.6 (10.3)

Table 2.

Bivariate analysis between participant characteristics and psychosocial outcomes, using two-way T-test[a], oneway ANOVA[b], and Pearson's correlation[c] as appropriate

Participant characteristic	Depression		Anxiety		Composite depression/ anxiety		Social isolation	
	Mean (SD) or Pearson correlation	P-value	Mean (SD) or Pearson correlation	P-value	Mean (SD) or Pearson correlation	P-value	Mean (SD) or Pearson correlation	P-value
Age (years)[c]	−0.11	0.121	−0.19	*0.006*	−0.16	*0.022*	−0.25	*<0.001*
Gender[a]								
Male	54.8 (11.3)	0.702	53.5 (13.0)	0.301	54.1 (11.7)	0.447	51.1 (10.7)	0.235
Female	55.4 (10.4)		55.5 (11.3)		55.5 (10.3)		53.1 (10.1)	
Race[a]								
White	55.3 (10.2)	0.938	54.6 (11.3)	0.334	54.9 (10.2)	0.621	52.4 (9.9)	0.664
Non-white	55.1 (12.4)		56.7 (13.6)		55.9 (12.6)		53.3 (12.2)	
Household education[a]								
Less than college	57.5 (10.5)	*0.003*	56.5 (12.1)	0.065	57.0 (10.8)	*0.013*	54.1 (10.3)	*0.043*
College/post-graduate	53.1 (10.2)		53.4 (11.2)		53.3 (10.2)		51.1 (10.1)	
Household income[b]								
<$20,000	56.7 (11.7)		57.3 (12.8)		57.0 (11.6)		55.0 (10.8)	
$20,000 – $49,999	55.1 (10.5)	0.585	54.6 (11.2)	0.248	54.8 (10.4)	0.398	52.8 (10.5)	0.124
$50,000 – $99,999	54.6 (10.2)		53.0 (11.5)		53.8 (10.5)		50.9 (9.5)	
$100,000	53.5 (8.5)		55.2 (10.2)		54.3 (8.3)		50.3 (9.7)	
Insurance[b]								
None	61.0 (14.0)	0.392	59.7 (17.9)	0.532	60.4 (14.8)	0.436	58.3 (12.5)	0.212
Public or dual	55.2 (11.1)		55.1 (12.1)		55.2 (11.1)		53.1 (10.8)	
Private only	54.9 (9.4)		54.3 (10.6)		54.6 (9.5)		51.4 (9.1)	
Prior surgeries for urologic condition[a]								
No	57.6 (10.9)	*0.039*	56.9 (12.4)	0.115	57.2 (11.2)	0.058	56.7 (9.7)	*<0.001*
Yes	54.2 (10.3)		54.1 (11.3)		54.1 (10.2)		50.7 (10.0)	
VP shunt[a]								
No	55.9 (9.9)	0.396	55.7 (12.0)	0.354	55.8 (10.5)	0.350	52.3 (10.1)	0.668
Yes	54.9 (11.4)		54.1 (11.4)		54.3 (10.8)		52.9 (10.6)	
Physical function score[c]	−0.18	*0.010*	−0.16	*0.025*	−0.17	*0.011*	−0.16	*0.025*

Participant characteristic	Depression		Anxiety		Composite depression/anxiety		Social isolation	
	Mean (SD) or Pearson correlation	P-value	Mean (SD) or Pearson correlation	P-value	Mean (SD) or Pearson correlation	P-value	Mean (SD) or Pearson correlation	P-value
Neurogenic bladder symptom score[c]	0.38	*<0.001*	0.38	*<0.001*	0.40	*<0.001*	0.40	*<0.001*
Composite depression/anxiety[c]	-	-	-	-	-	-	0.62	*<0.001*

Table 3.

Multiple linear regression models for depression, anxiety, and composite depression/anxiety

Participant Characteristic	Depression			Anxiety			Composite		
	B	95% CI	*P*-value	B	95% CI	*P*-value	B	95% CI	*P*-value
Age (y)	−0.10	−0.21–0.01	.081	−0.20	−0.33 to −0.08	.001	−0.15	−0.26 to −0.04	.008
Gender									
Male	−			−			−		
Female									
Race									
White	−			−			−		
Non-white									
Household education	−			−			−		
Less than college College/post-graduate	−2.99	−5.77 to −0.21	.035	−			−2.23	−4.99 to 0.51	0.110
Household income	−			−			−		
<$20,000									
$20,000–$49,999									
$50,000–$99,999									
$100,000									
Insurance	−			−			−		
None									
Public or dual									
Private only									
Prior surgeries for urologic condition	−			−			−		
No									
Yes									
VP shunt									
No	−2.42	−5.41–0.55	.110	−3.36	−6.63 to −0.08	.044	−2.93	−5.88 to 0.01	.051
Yes									
Physical function score	−0.15	−0.34–0.03	.102	−0.16	−0.36–0.03	.113	−0.15	−0.33–0.03	.102
Neurogenic bladder symptom score	0.30	0.17–0.43	<.001	0.36	0.22–0.49	<.001	0.32	0.20–0.45	<.001

Table 4.

Multiple linear regression model for social isolation

Participant characteristic	Social isolation		
	B	95% CI	P-value
Age (years)	−0.12	−0.20 – −0.03	0.006
Gender			
Male		-	
Female			
Race			
White		-	
Non-white			
Household education			
Less than college		-	
College/post-graduate			
Household income			
<$20,000			
$20,000 – $49,999		-	
$50,000 – $99,999			
$100,000			
Insurance			
None		-	
Public or dual			
Private only			
Prior surgeries for urologic condition			
No			
Yes	−3.31	−5.71 – −0.91	0.007
VP shunt			
No		-	
Yes			
Physical function score		-	
Neurogenic bladder symptom score	0.14	0.03 – 0.25	0.010
Composite depression/anxiety score	0.50	0.38 – 0.61	<0.001