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Resilience and associated characteristics in adults with spina bifida

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Abstract

AIM—To measure resilience and identify associated demographic and clinical factors in individuals with spina bifida.

METHOD—An anonymous survey was distributed via Facebook advertising to individuals with congenital urological conditions. Respondents 18 years or older with spina bifida were included in this study. Resilience was measured with the 10-item Connor-Davidson Resilience Scale. Mean resilience levels in the study population and a US general population sample were compared with Student's *t*-test. Multiple linear regression assessed demographic and clinical factors associated with resilience.

RESULTS—The mean resilience score for participants (n=195; 49 males, 146 females; mean age 40y 2mo [SD 12y 7mo] range 18–74y) was 27.2 (SD 7.5), which differed from a mean of 31.8 (SD 5.4) for a US general population sample (p<0.01). Multiple linear regression demonstrated significant positive associations between resilience and older age (p=0.04), prior urological surgeries (p=0.03), higher household education (p<0.01), and higher physical function (p<0.01).

INTERPRETATION—Resilience in individuals with spina bifida is moderately poor, relative to the general population, and is associated with certain demographic and clinical factors. As a modifiable construct with positive effects on quality of life, psychological well-being, and health-related behaviors, resilience is a promising target for intervention in individuals with spina bifida.

The management and prognosis of spina bifida has changed dramatically over the past 75 years.[1] Notable clinical advances include the introduction of antibiotics, development of shunts for hydrocephalus, and improvements in urinary diversion and renal preservation techniques.[1] As a result, over 80% of individuals born with spina bifida now survive to adulthood.[2] Thus, spina bifida is considered to be a chronic condition.[3]

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Individuals with spina bifida commonly experience multiple physical and psychosocial health issues across the lifespan. Conditions such as hydrocephalus, bladder dysfunction, impaired mobility, and their associated complications may require regular care by oneself or one's caregiver, and frequent interaction with the healthcare system.[3] Additionally, people with spina bifida have high rates of depression, anxiety, and social isolation.[4–6] Given these lifelong physical and psychosocial challenges, resilience may play a powerful role in the unique challenge faced by people with spina bifida to continually adapt to their congenital condition.

Resilience is the process of positive adaptation in the face of adversity. A strengths-based construct that explains how individual and environmental protective factors counteract the adverse effects of risk factors, resilience elucidates how some individuals thrive while others struggle in challenging life circumstances.[7] While the concept of resilience originated from the study of at-risk young people, it has since been applied to populations experiencing varied hardships, including health-related adversities such as cancer, chronic illness, and physical disability.[8–11] It is unclear whether there is generally a positive or negative association of resilience with chronic disease. Studies in individuals with some chronic diseases appear to be more resilient than population norm controls, whereas individuals with other chronic diseases appear to be less resilient. Nevertheless, across diverse populations, higher resilience is associated with improved outcomes, including psychological well-being and quality of life.[8,11] In individuals with chronic diseases specifically, resilience is associated with improved self-care, perception of disease and pain, and adherence to treatment programs.[12] Importantly, as a dynamic process rather than stable character trait, resilience appears to be modifiable.[7] As such, resilience represents a promising target for intervention, which may be particularly salient for individuals with spina bifida.

Factors associated with high or low resilience in a given population are termed protective factors and risk factors respectively. Protective and risk factors can be contextualized within a socio-ecological framework, at the individual, family, community, and society levels. Protective factors have been most studied in children and include emotion regulation, positive self-esteem, prosocial behavior, family cohesion and social support, links with cultural identity, and spirituality.[13,14] In adults, protective factors include personality dimensions such as extraversion and conscientiousness, as well as social support, secure attachment, and task-oriented coping styles.[15,16] Across the lifespan, key risk factors include severity and frequency of exposure to stress, weaker executive function, poor self-efficacy, and low social support.[17] An understanding of the protective and risk factors in a given population, such as individuals with spina bifida, may help to illuminate how resilience is developed and how this process can be encouraged. Additionally, it may aid in identifying those individuals at risk for non-resilient outcomes.

Despite clear theoretical relevance, there is extremely limited research on resilience and protective/risk factors in spina bifida specifically. A prior study of 97 adults with spina bifida in Australia evaluated resilience and found psychological distress to be a risk factor for poorer resilience.[18] In the pediatric literature, a longitudinal study of trajectories of psychosocial adjustment in 68 adolescents with spina bifida demonstrated resilient outcomes in some areas (i.e. level of child engagement in family) relative to their typically developing

peers, but enduring difficulties in other areas (i.e. academic performance, attention, and social development).[19] A nuanced understanding of resilience in individuals with spina bifida will likely require many iterations of investigation as has occurred in other groups. In the present study, we aimed to measure resilience and identify associations with baseline demographic and clinical factors in individuals with spina bifida. We hypothesize that resilience in individuals with spina bifida will be poor, relative to the general population.

METHOD

Survey development and distribution

An anonymous online survey was developed at the University of California, San Francisco and distributed using Facebook advertising to persons with congenital urological conditions from 22nd March 2018 to 30th September 2018. Advertisements were targeted to Facebook users who expressed an interest in or liked pages related to the Spina Bifida Association. In addition, Facebook groups related to other congenital genitourinary conditions were identified (i.e. neurogenic bowel and bladder), and the groups 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 randomly selected to receive an iPad mini. Participant recruitment through Facebook may bias our sample. However, this practice has gained popularity amongst researchers because of 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.[20]

Inclusion criteria

Any individual aged 13 years or older who identified as having a congenital urological condition was eligible to complete the survey. This analysis, however, was restricted to respondents who met the following inclusion criteria: diagnosis of spina bifida, age 18 years or older, primary residence in the USA, and complete survey data available.

Ethical approval and consent

The study received Institutional Review Board approval by the University of California, San Francisco Committee on Human Research (UCSF IRB#17-23699). All participants provided written informed consent.

Variables

The primary outcome, resilience, was measured using the 10-item Connor-Davidson Resilience Scale (CD-RISC 10; www.cd-risc.com). CD-RISC 10 is a self-report measure of an individual's ability to cope with adversity. Participants use a 5-point Likert scale (0–4) to rank 10 items, such as the following: able to adapt to change, can achieve goals despite obstacles, can handle unpleasant feelings. Summed item responses can range from 0 to 40, with high scores indicating greater resilience. While a number of resilience scales exist, CD-RISC 10 is amongst the most widely used, and allows for comparison to various samples, including the US general population. Furthermore, CD-RISC 10 is a user-friendly instrument that has been employed successfully in a prior study of individuals with spina

bifida; it is, however, important to note that the instrument has not yet been validated in this group.[18] CD-RISC 10 demonstrates good psychometric properties in numerous studies (internal consistency: Cronbach's alpha 0.88; convergent validity: r=−0.51 for anxiety and r=−0.57 for depression on the Hospital Anxiety and Depression Scale; test–retest reliability: r=0.89 over a 6-week interval).[21–23] Cronbach's alpha in the present study is 0.91.

The demographic variables hypothesized a priori to be associated with resilience and thus included in our analysis were age, sex, ethnic group, household education, household income, insurance. For the purposes of regression analysis, a number of variables were dichotomized (ethnic group as white vs non-white, household education as lower than college degree vs college or higher, total household income as <$100 000 vs ≥$100 000, and insurance status as private insurance only vs all other [dual, public, or no insurance]). The clinical variables hypothesized a priori to be associated with resilience and thus included in our analysis were prior surgeries for urological conditions, ventriculoperitoneal shunt presence, and physical function. These variables were selected as they are easily provided by participants and suggest the degree to which they are affected by their disease in three key clinical areas (urology, neurology, and physical function). Physical function was measured using the Patient-Reported Outcome Measures Information System (PROMIS) v1.0 Physical Function with Mobility Aid Short Form instrument, which is a self-report measure of physical capabilities, including walking and instrumental activities of daily living (i.e. bathing, toileting, and using utensils). Scores are presented as T-scores, with higher T-scores indicating higher degrees of physical function.[24] The short form is one of many versions derived from the PROMIS physical function item bank. The item bank has moderate to good internal consistency (Cronbach's alpha 0.83–1.0), and correlates well with a similar short form (r=0.96) as well as legacy measures (r=−0.80 with the Health Assessment Questionnaire; r=−0.88 with the 36-Item Short Form Survey).[25] Cronbach's alpha in the present study is 0.82. PROMIS instruments enable measurement of a given construct across participants in a standardized fashion, which may not be possible from review of retrospective medical record data.

Data analysis

Standard descriptive statistics were calculated for each variable. The mean resilience score was compared to that of a US general population sample using a two-sided Student's *t*-test. Bivariate analysis was conducted with two-sided Student's *t*-test, one-way analysis of variance, and Pearson's correlation, as appropriate. Multiple linear regression assessed factors associated with resilience. All independent variables were initially entered into the model, and a backwards elimination approach was employed until all *p*-values were ≤0.2. Results were considered significant at a *p*-value of <0.05. The collinearity of independent variables included in regression analysis was assessed and determined to be minimal. Statistical analysis was performed in Stata 16.0 (Stata Corp., College Station, TX, USA). Figures were generated with IMathAS Boxplot Grapher (https://www.imathas.com/stattools/boxplot.html).

RESULTS

Of the 271 respondents who completed the survey, 21 were excluded because they did not have a diagnosis of spina bifida, 54 were excluded secondary to incomplete data, and one was excluded because of outlying values suspected to be erroneous. The remaining 195 respondents met inclusion criteria for this study.

Participant characteristics can be seen in Table 1. Patients encompassed a wide range of ages (18–74y), with a mean of 40 years 2 months (SD 12y 7mo). The sex distribution was skewed toward females (75%), and the ethical group distribution skewed toward white participants (83%). There was an even distribution of household education between lower than college and college or higher. A wide variety of household income levels were reported. With respect to insurance status, the majority of participants had public or dual coverage (59%), a sizable minority had private coverage (38%), and very few participants lacked insurance entirely (3%). Prior surgeries for a urological condition were reported by 69% of participants, whilst ventriculoperitoneal shunts were reported by 45% of participants. The mean physical function t-score ranged from 21 to 58 with a mean of 39.7 (SD 7.6), which is roughly one SD below the general population mean. The internal consistency of the PROMIS physical function t-score in the study sample was appropriate (Cronbach's alpha=0.82). The mean resilience score was 27.2 (SD 7.5), which differed significantly from a mean score of 31.8 (SD 5.4) for a US general population sample ($t[194]=-8.48$, $p<0.01$).[26] The internal consistency of the CD-RISC 10 resilience score in the study sample was appropriate (Cronbach's alpha=0.91).

The results of bivariate analyses and the multiple linear regression analysis are presented in Table 2. In the bivariate analyses, significant associations were demonstrated between resilience and age, ethnic group, household education, household income, insurance status, prior urological surgeries, and physical function. Multiple linear regression showed significant associations between resilience and older age (B=0.08, 95% confidence interval [CI] 0.00–0.15, $p=0.04$), household education of college degree or higher (B=3.08, 95% CI 1.16–5.00, $p<0.01$), prior surgeries for urological conditions (B=2.35, 95% CI 0.30–4.41, $p=0.03$), and higher physical function scores (B=0.32, 95% CI 0.19–0.45, $p<0.01$). Notably, the final model accounted for 25% of the variance in resilience scores ($R^2=0.25$, $p<0.01$).

DISCUSSION

Our findings show that resilience in individuals with spina bifida is moderately poor relative to the general population. This is illustrated by comparison with general population sample quartile scores for the CD-RISC 10 (25th=29; 50th=32; 75th=36).[26] In our study, 76% of individuals with spina bifida had resilience scores equal to or below the median for a general population sample, and 62% had scores corresponding to the lowest quartile for a general population sample (Fig. 1). Mean resilience scores in our study were similar to, albeit slightly higher than, those of a prior study in individuals with spina bifida in Australia (mean 25.7, SD 8.1).[18] Mean resilience scores in our study were also similar to those of individuals with muscular dystrophy (mean 27.9, SD 7.9), multiple sclerosis (mean 26.8, SD 6.2), and cystic fibrosis (mean 25.7, SD 4.3).[8,27,28] This implies a pattern

of low resilience amongst those with complex, chronic diseases with onset in childhood or early adulthood. Conceivably, this could be due to negative impacts on typical development, psychological stress related to ongoing medical issues or medical trauma, or lack of tangible (financial, social, etc.) resources. In contrast, studies of individuals with acquired spinal cord injury (mean 29.5, SD 7.2) and cancer (mean 29.3, SD 7.0) demonstrate somewhat higher resilience scores, suggesting that an abrupt insult to health (even if life-threating) in a previously resilient individual may be less damaging to resilience than chronic disease processes in adolescents and young adults.[29,30]

We found that certain demographic and clinical characteristics – older age, higher household education, prior urological surgeries, and greater physical function – are significantly associated with higher resilience in individuals with spina bifida. These characteristics may represent protective factors that moderate the relationship between adversity and resilience in this population.

The association between older age and resilience is consistent with findings of other studies, in both the general population and patients with physical disabilities.[8,31] As individuals with spina bifida age, they may accrue experiences, relationships, skills, and resources that allow them to better adapt to or cope with the challenges they encounter. It is also possible that people with spina bifida judge their own resilience relative to the resilience required to adapt to a given situation, and that some of the greatest challenges occur early in life – particularly during the period in which they transition from adolescence to adulthood, and negotiate their ability to function autonomously in society. Finally, it is possible that more resilient individuals simply live to be older.

We found a positive relationship between higher household education and resilience, an association that has also been documented in parents of children with cancer, who may face some similar challenges.[32] Theoretically, higher household education may result in a higher locus of control for individuals or their caregivers – meaning the degree to which people believe that they, as opposed to external forces, have control over events in their lives – which in turn is associated with higher resilience.[9,14] More specifically, more educated families may be better able to navigate complex systems including healthcare and school systems in order to address the specific needs of individuals with spina bifida. Finally, higher household education may be associated with financial or social capital that enhances one's capacity to adapt to challenges.

Our study demonstrated an association between higher physical function and resilience that is consistent with results from studies of adults with physical disabilities, amongst others.[9,33] Higher physical function may allow individuals to more readily and fully participate in multiple domains of life, including school, the workplace, and interpersonal relationships. Additionally, it may provide healthy outlets such as exercise or team sports for coping. Of note, Hayter and Dorstyn examined the association of a related concept, physical independence (as measured by the Craig Handicap Assessment and Reporting Technique), with resilience and found a small correlation that did not achieve statistical significance.[18]

Interestingly, prior surgeries for urological conditions were associated with resilience. One potential interpretation of this finding is that prior surgeries represent a challenging experience that, having been navigated successfully, may promote resilience to further adversity. Another possible interpretation is that urological surgery may enable greater independence or functioning, which is in turn associated with resilience. A final possible interpretation is that resilient individuals are more likely to seek out or be selected for surgery in the first place. Of note, evidence from studies that have examined the role of prior disease experiences, not necessarily surgical, on resilience has been mixed; while most studies demonstrate a relationship between prior health experiences and resilience to new adversity, the direction of this association varies.[10]

These findings advance our understanding of resilience in individuals with spina bifida, which may be important for overcoming lifelong challenges to physical or psychosocial well-being resulting from their congenital condition. Growing evidence suggests that resilience is a modifiable process that can be cultivated and enhanced; a recent meta-analysis of randomized controlled trials found a moderate positive effect of interventions on measures of resilience (standardized mean difference 0.44, 95% CI 0.23–0.64).[7] A wide variety of interventions to improve resilience have been developed, including cognitive behavioral therapy, mindfulness, social support, coaching, and relaxation.[7,11] Interventions utilizing cognitive behavioral therapy (standardized mean difference 0.27, 95% CI 0.05–0.50) or mindfulness (standardized mean difference 0.46, 95% CI 0.10–0.82) appear to be particularly effective at fostering resilience.[7] A systematic review of resilience-promoting interventions in chronic disease groups specifically documented positive effects on quality of life, psychosocial well-being including depression and anxiety, and health-related behaviors such as adherence in some studies.[11] The authors concluded from their review of these studies that ‘increasing resilience is less related with overcoming a chronic disease, but largely concerns helping patients to accept their physical and social situations and comply with therapeutic care, which can ultimately lead to a healthier life’.[11] It follows that resilience is a promising target for intervention to improve outcomes in individuals with spina bifida. Young adults may particularly benefit from resilience-building interventions, given our finding that younger individuals demonstrate lower resilience. There is considerable variation in intervention content, delivery, length, and timing in prior studies, and the optimal protocol for delivering resilience interventions remains uncertain.[7] Additionally, special attention to accessibility will be crucial when designing and studying interventions for individuals with spina bifida.

This study has several limitations. First, the cross-sectional design precludes any conclusions regarding causality. Second, data on specific spina bifida diagnoses (i.e. myelomeningocele, meningocele), which would help contextualize the study’s findings, were not collected. Third, the recruitment of participants via Facebook advertising may bias our sample, as individuals with spina bifida who utilize Facebook may be different than those who do not. With respect to demographic and clinical characteristics, white participants were overrepresented in our study (82.6%) compared to a study from the largest national database of patients with spina bifida (65.5%), as were female participants (74.9% in our study vs 52.4% in the national registry). Further, only 44.6% and 68.7% of our population reported having a ventriculoperitoneal shunt and urological surgery respectively, while data from

the same national registry documented that all spina bifida registry patients older than 25 years had undergone at least one neurological procedure (including but not limited to ventriculoperitoneal shunts) and urological procedure in their lifetime. This suggests that our study may have captured a subset of patients with less severe spina bifida than those in the national registry (which may itself skew toward complex patients, as only patients who attend select specialized spina bifida clinics are enrolled in the national registry).[34] This is a reasonable suggestion, since utilizing Facebook requires a degree of physical and cognitive function that not all individuals with spina bifida possess. However, if we are capturing a subset of patients with relatively mild spina bifida and finding lower resilience score than the US general population, then resilience in individuals with spina bifida generally may be even lower than we report here. There may also be bias introduced by the complex interplay between Facebook use, mental health, and resilience. We cannot know the extent to which this exists in our study. Fourth, this study relies on self-report data, and is thus at risk of response bias. Finally, there are numerous definitions of resilience and no criterion standard for measuring it; as such, it is possible that CD-RISC 10 (though validated and widely used), may not fully capture the complex, multidimensional nature of resilience.[35]

Conclusions

This study contributes to our understanding of resilience in individuals with spina bifida. Importantly, it demonstrates that resilience in individuals with spina bifida is moderately poor relative to the general population. Further, it reveals that certain demographic and clinical characteristics – older age, higher household education, prior urological surgeries, and greater physical function – are significantly associated with higher resilience, and may represent protective factors that moderate the relationship between adversity and outcomes in this population. Further research is needed to better understand protective factors in individuals with spina bifida, including about those factors that have been identified in other populations and may be particularly relevant to some individuals with spina bifida (i.e. executive function, self-efficacy), and/or are potentially modifiable by cognitive behavioural therapy or mindfulness interventions (i.e. social support and engagement, coping styles). Additionally, the optimal content, delivery, timing, and length of resilience-promoting interventions, with particular attention to accessibility, should be explored. Finally, further investigation of resilience in minority groups less represented in this cohort is needed.

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ABBREVIATIONS

CD-RISC 10	10-item Connor-Davidson Resilience Scale
PROMIS	Patient-Reported Outcome Measures Information System

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What this paper adds

- Resilience in individuals with spina bifida is moderately poor.
- Resilience is lower in individuals with spina bifida than the general population.
- Resilience is associated with age, household education, physical function, and urological surgery.

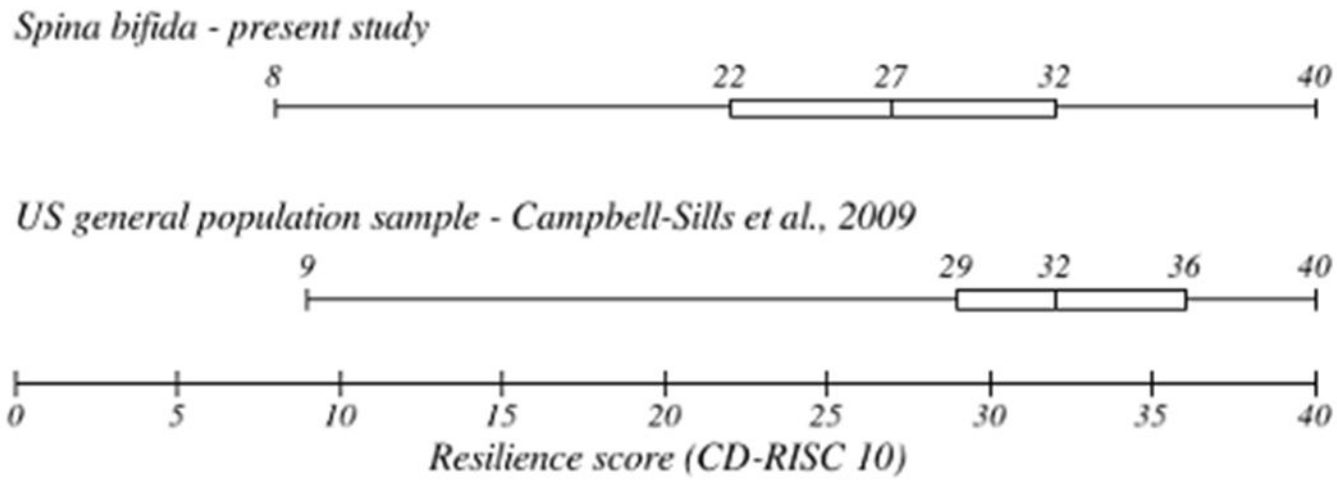

Figure 1:
Resilience scores for study participants in comparison to a US general population sample.[26]
CD-RISC 10, 10-item Connor-Davidson Resilience Scale.

Table 1:

Baseline characteristics for 195 study participants

Participant characteristic	*n* (%)
Age (y:mo), mean (SD)	40:2 (12:7)
Sex	
Male	49 (25.1)
Female	146 (74.9)
Ethnic group	
White	161 (82.6)
Non-white	34 (17.4)
Household education	
Less than college degree	97 (49.7)
College or postgraduate degree	98 (50.3)
Household income	
<$20 000	59 (30.3)
$20 000–$49 999	55 (28.2)
$50 000–$99 999	61 (31.3)
≥$100 000	20 (10.2)
Insurance	
None	6 (3.1)
Public or dual	115 (59.0)
Private only	74 (37.9)
Prior surgeries for urological condition	
No	61 (31.3)
Yes	134 (68.7)
Ventriculoperitoneal shunt	
No	108 (55.4)
Yes	87 (44.6)
Physical function z-score (PROMIS), mean (SD)	39.7 (7.6)
Resilience score (CD-RISC 10), mean (SD)	27.2 (7.5)

PROMIS, Patient-Reported Outcome Measures Information System; CD-RISC 10, 10-item Connor-Davidson Resilience Scale

Table 2:

Association of demographic and clinical characteristics with resilience in bivariate and multiple linear regression analysis

Participant characteristic	Resilience score, mean (SD) or Pearson correlation	Bivariate analysis,[a] *p*	Linear regression		
			Coefficient	95% CI	*p*
Age	0.16	0.02	0.08	0.00–0.15	0.04
Sex					
Male	28.5 (7.7)	0.16		*b*	
Female	26.8 (7.4)				
Ethnic group					
White	26.7 (7.5)	0.04			
Non-white	29.6 (7.3)		1.93	−0.57 to 4.44	0.13
Household education					
Less than college degree	25.1 (7.3)	<0.01			
College or postgraduate degree	29.3 (7.2)		3.08	1.16–5.00	<0.01
Household income					
<$20 000	25.4 (7.6)	0.04		*b*	
$20 000–$49 999	27.0 (7.5)				
$50 000–$99 999	28.2 (7.4)				
≥$100 000	30.3 (6.4)				
Insurance					
None	29.8 (7.0)	0.04		*b*	
Public or dual	26.1 (7.8)				
Private only	28.8 (6.9)				
Prior surgeries for urological condition	24.8 (7.4)	<0.01			
No	28.3 (7.4)		2.35	0.30–4.41	0.03
Yes					
Ventriculoperitoneal shunt					
No	27.6 (7.7)	0.50		*b*	
Yes	26.8 (7.3)				
Physical function score (PROMIS)	0.39	<0.01	0.32	0.19–0.45	<0.01

[a] Two-sided *t*-test, one-way analysis of variance, and Pearson's correlation, as appropriate.

[b] Removed from model. R^2=0.25, F(5,189)=12.6, p<0.01. PROMIS, Patient-Reported Outcome Measures Information System.