Published in final edited form as:

Disabil Rehabil. 2020 October ; 42(20): 2910–2916. doi:10.1080/09638288.2019.1575483.

Health Behaviors and Disordered Eating in Adolescents and Young Adults with Spina Bifida: Results from a National Survey

Colleen Stiles-Shields^a, Grayson N. Holmbeck^a

^aDepartment of Psychology, Loyola University Chicago, Chicago, IL, USA

Abstract

Purpose: Youth with disabilities are at higher risk for obesity, disordered eating, and poor body image, but are often excluded from research on these domains. The current study is the first to characterize health behaviors, body mass index, and disordered eating cognitions and behaviors in a national sample of adolescent and young adult males and females with spina bifida.

Methods: Participants were recruited nationally through the support of a national spina bifida-related organization to complete an anonymous survey assessing health behaviors and disordered eating.

Results: Participants were primarily Caucasian, had myelomeningocele, and were between 15–24 years of age. Body mass indices ranged from underweight to Class Three obesity. Health behaviors (e.g., healthy food consumption, physical activity) were often subthreshold compared to Centers for Disease Control recommendations made to the general public. Both male and female respondents endorsed higher purging and restricting behaviors than norms established with typically-developing college aged peers.

Conclusions: Findings revealed that there are few sex-based differences. Additionally, the need for thorough assessment of disordered eating behaviors in this population is warranted, including those with a lower body mass index who might be overlooked for assessment of unhealthy attempts to lose or maintain their weight.

Keywords

spina bifida; disordered eating; body image; health behaviors; disability

Introduction

Disordered eating and poor body image are common and create a significant public health burden due to their association with multiple psychological and health vulnerabilities (e.g., depression, obesity) [1–3]. Assessment and treatment research in this area is primarily focused on typically-developing (TD), young adult females [4, 5]. However, compared to their TD peers, adolescents and young adults with disabilities have demonstrated disordered

Correspondence regarding this manuscript can be sent to Colleen Stiles-Shields, Ph.D., Department of Psychology, Loyola University Chicago, Chicago, IL 60611. Telephone: 1-773-508-8902. Fax: 1-773-508-8713. estilesshields@luc.edu.

Declaration of Interest

The authors report no conflicts of interest.

eating behaviors [6] and are at increased risk for obesity (odds ratio of 1.89) [7] and poor body image [8–10]. Further, this risk extends to both male and female adolescents and young adults with disabilities. A call for attending to the body image experience of people with disabilities has been made [9].

Spina bifida (SB), a chronic health condition resulting from a neural tube defect during early pregnancy [11], stands as a potential lens through which to examine the experience of disordered eating and body image in adolescents and young adults with disabilities. Indeed, SB is the most common congenital birth defect affecting the central nervous system, occurring in about 1,500 births annually [12]. Further, because of its unique symptom profile, the care and management of SB overlap with such management across three other groups, namely, those with chronic illnesses (e.g., lifetime care for bladder and bowel problems, ongoing monitoring and care of skin irritations), physical disabilities (e.g., leg weakness or paralysis, orthopedic abnormalities, use of ambulatory aids), and intellectual disabilities (e.g., lower IQ than general population, difficulties with social skills and independent functioning) [13, 14].

Adolescents and young adults with SB have been identified as being disproportionately impacted by obesity [15–17]. While health providers often recommend weight loss for youth with SB, guidance on actual implementation is provided inconsistently [18]. Implementation is also difficult in SB due to frequent condition-related complications (e.g., recovery from surgery reducing mobility, thereby increasing weight) [19]. A disconnect therefore exists, such that there is little information and effective support for adolescents and young adults with SB in addressing obesity. This disconnect between recommendations to reduce weight and lack of effective guidance on how to do so has been identified as a partial explanation for heightened risk of disordered eating and poor body image in people with SB. Indeed, multiple cases of young adults with SB with eating disorders attributed their disordered eating behaviors to attempts for self-improvement through weight loss [6]. Youth with SB have also been found to evaluate their bodies less positively than peers [8, 10], experience slenderness as a form of achievement or success [6], and identify losing weight as a means to reduce negative comments and be less physically burdensome when seeking ambulation assistance [9]. Further, in a sample of young adult women with SB or rheumatoid arthritis who were administered a validated eating disorders questionnaire, more than 20% scored at or above the clinical cut point on at least one subscale, and 8% met criteria for an eating disorder (compared to .5–2% in the general population) [20]. However, national prevalence rates for disordered eating and poor body image are unknown in adolescents and young adults with SB. Targeting this gap in the literature is critical, as such a characterization is needed to eventually inform Centers for Disease Control (CDC) recommendations for people with SB and youth with disabilities more generally.

The primary aim of the current study was to be the first to characterize health behaviors, body mass index (BMI), and disordered eating cognitions and behaviors in adolescents and young adults with SB with a national sample. Additionally, this characterization was targeted towards both males and females, an important extension of previous research that has examined disordered eating variables only in females [20]. Indeed, there is no evidence to suggest that disordered eating and body image concerns impact only females [21, 22].

Consistent with prior health and obesity research in samples with SB, it was hypothesized that the sample would report health behaviors below the minimum recommendations made by the CDC [23–25], BMIs in the overweight range [15–17], and higher disordered eating and body image difficulties than norms for the general population [20]. A secondary aim was to explore demographic/medical characteristics and desire to change weight status (e.g., gain, lose weight) in association with disordered eating and poor body image in adolescents and young adults with SB. It was hypothesized that those reporting a desire to lose weight and those with more severe SB characteristics would endorse higher disordered eating and body image concerns.

Methods

Participants

Participants were recruited nationally through the support of the Spina Bifida Association, a national health organization supporting education, advocacy, and research to improve the lives of individuals with SB. The Spina Bifida Association advertised the study link on their Facebook and Chapter pages. Participants were eligible for inclusion if they: 1) had SB, 2) were between 15 and 25 years of age, and 3) were able to answer the survey questions without assistance from others (to ensure privacy and honesty in responses, and to exclude lower functioning adolescents and young adults with SB). The first 150 participants were compensated for their time and participation with a \$10 Amazon Gift Code.

Procedure

In compliance with the University Institutional Review Board, participants were consented via digital waiver of documented consent before participating. Specifically, those interested in participating were provided a link connecting them to a detailed digital version of the study consent form. Subjects agreed to participate in the study by checking a “yes” box. However, to ensure that minors (i.e., <18 years of age) had parental permission to complete the survey, two more boxes appeared after a participant checked the “yes” box: 1) a box with the instructions, “If you are under 18 years of age: Please have your parent or legal guardian sign their name in the box below to serve as written parental permission for you to participate in this survey.”; and 2) a check box with the instructions, “If you are 18 years of age or older: Please click the “yes” box below to indicate that you are 18 years of age or older and do not require parental permission to complete this survey.” Without the completion of these sections, participants were unable to proceed to the survey. Following the digital waiver of documented consent page, participants then anonymously completed the assessment. The survey was anonymous to promote the likelihood of honest responses. Upon completion of the survey, a debriefing page detailing resources from the National Eating Disorders Association was presented (should participants experience any distress due to answering the assessment questions). Finally, to maintain the anonymity of the assessment responses, participants were provided a link to initiate a different survey that enabled them to provide contact information for compensation.

Measures

Self-report assessments were administered and managed via the secure online survey platform Opinio (<http://www.objectplanet.com/opinio>), licensed and administered by Loyola University Chicago. Opinio meets all criteria of the Institutional Review Board online survey software checklist, including: record of informed consent with time stamp, secure transmission and encryption, database security, server security, backups, and masking of respondent IP address.

Demographics and Medical Characteristics—Participants were asked to report the following information: age, sex, race/ethnicity, education/employment status, and SB characteristics, including type, shunt status and type, and shunt revision history.

Eating Pathology Symptoms Inventory—The Eating Pathology Symptoms Inventory (EPSI) is a 45-item self-report measure assessing the frequency of disordered eating beliefs and behaviors over the previous four weeks [4, 26]. Respondents were instructed to indicate their responses across a five-point likert scale (i.e., 0 = Never to 4 = Often). The EPSI has 8 subscales: body dissatisfaction, binge eating, cognitive restraint, excessive exercise, restricting, purging, muscle building, and negative attitudes toward obesity. The EPSI has demonstrated satisfactory internal consistency (α s = .84-.89) and reliability (r = .73) and was selected for its development and validation with “special populations” (e.g., men, those with obesity, etc.) [4]. The EPSI demonstrated acceptable internal consistency for all subscales in the current sample (α s = .71), with the exception of cognitive restraint (α = .58). The cognitive restraint subscale was therefore removed from subsequent analyses.

The Health Questionnaire—The Health Questionnaire is a modified version of the CDC’s Youth Risk Behavior Survey [27], including 17 of the original 87 items. Items used for this study address self-report of weight, height, desire to change weight, diet, food, and exercise questions appropriate for youth with spina bifida, based on their inclusion in longitudinal research of youth with SB [28]. Responses on the Health Questionnaire were used to calculate BMI based upon self-reported height and weight ($\text{weight (lb)} / [\text{height (in)}]^2 \times 703$) (29).

Data Analysis

Bivariate Pearson correlations were used to explore relationships between disordered eating (i.e., EPSI subscales: body dissatisfaction, binge eating, excessive exercise, restricting, purging, and negative attitudes toward obesity, and muscle building) and continuous demographic characteristics (e.g., age). Given non-normal distributions of some demographic variables (i.e., higher prevalence of males, Caucasians, and individuals with meningocele and a shunt) Mann-Whitney *U*-tests were used to examine the relationships between these dichotomized demographic variables (i.e., sex, race [Caucasian vs. Minority], SB type [Myelomeningocele vs. Other], shunt status) and disordered eating (EPSI subscales) and BMI. Through the use of previously reported means, standard deviations, and sample sizes [26], exploratory *t*-tests were used to compare EPSI norms for TD college aged men and women to the current sample. Finally, analyses of variance were used to explore relationships between: 1) reported attempts to change weight status (i.e., lose, gain,

maintain, or make no change) and disordered eating, and 2) reported attempts to change weight status and BMI.

Results

Sample Characteristics

Participants were recruited in late May 2018. Two hundred and seven participants completed consent for the survey. Following the removal of those who were ineligible or had more than 80% missing data in survey responses, 167 participants were included in the current study. More than half of the sample was male (60.5%) and Caucasian (73.7%), and most often had myelomeningocele (the most severe type of SB; 56.9%) and a shunt (76.0%). The sample ranged in age from 15 to 24 (*Mean Age* = 20.06 ± 1.91). Table 1 displays the sample characteristics.

Body Mass Index

The BMI of participants ranged from 15.3 (underweight) to 48.8 (Class 3 or “severe” obesity) [30], with the average BMI falling within the healthy weight range (*Mean BMI* = 24.87 ± 6.15; *Median BMI* = 22.89). There was no evidence to suggest differences in BMI based on sex, race, or shunt status (*ps* > .05). However, those with myelomeningocele had significantly higher BMIs than those with other types of SB (*U* = 2629, *p* = .02). The majority of the sample indicated that they were currently attempting to lose weight (41.3%) or to maintain weight (38.3%). There was no evidence to suggest a relationship between current weight change attempts and BMI (*p* = .4).

Health Behaviors

Table 2 displays the frequency of responses across queried health behaviors. The majority of the sample reported health behaviors below the minimum frequency of behaviors consistent with the CDC recommendations. For dietary behaviors, the CDC recommends a daily minimum intake of two fruits/100% juice servings, two and a half servings of vegetables, and three servings of milk/dairy (24). However, the most commonly reported frequency of these intakes was four to six times per week for fruit (29.9%), vegetable (29.3%), 100% fruit juice (25.7%), and milk (29.9%) consumption. For physical activity, teens under 18 are recommended to get at least 60 minutes of physical activity daily and adults 18 and older are recommended to get at least 150 minutes of physical activity weekly (including aerobic, muscle strengthening, and bone strengthening activities) [24]. The majority of the sample reported engaging in strenuous physical activity for at least 30 minutes (24.0%) and strength exercises (32.3%) three days per week, and non-strenuous physical activity for at least 30 minutes four days per week (31.1%). The sample therefore reported achieving the goal of variety in physical activity but fell short of the recommended weekly duration of physical activity. About half of the sample reported engaging in sedentary screen time (e.g., tv watching, playing video games) for two hours per day (49.7%), which falls in line with the CDC recommendation that 15–18 year olds get no more than one to two hours of screen time daily [25]. With regards to sleep, the CDC recommends that teens get eight to 10 hours of sleep nightly, whereas adults are recommended to get seven hours or more [23]. The

majority of the sample reported getting six to seven hours of sleep per night (40.7%), with difficulty falling asleep (56.3%) and staying asleep (47.3%) occurring moderately often.

Disordered Eating Characteristics

Table 3 displays the EPSI subscales for the current sample by sex, compared with previously reported norms for TD college aged men and women (ages 18–25) [26]. There was no evidence of sex differences in EPSI subscales for the sample with SB, with the exception of males having more negative attitudes toward obesity than females ($U = 2450$, $p = .01$). Exploratory t -tests indicated significant differences between TD norms for the EPSI subscales compared with the EPSI means in the SB sample. Specifically, males with SB had higher body dissatisfaction ($p < .001$), purging ($p < .001$), and restricting ($p < .001$), whereas their TD male peers had higher binge eating ($p = .02$), excessive exercise ($p < .001$), and negative attitudes toward obesity ($p < .001$). For females, the sample of adolescents and young adults with SB endorsed higher purging and restricting ($ps < .001$), whereas TD female peers reported higher body dissatisfaction, binge eating, excessive exercise, and negative attitudes toward obesity ($ps < .001$). There was no evidence to suggest differences for males or females for muscle building ($ps > .05$).

Associations with Demographic Characteristics—Bivariate Pearson correlations indicated that age was negatively correlated with every subscale of disordered eating ($ps < .001$), meaning that younger respondents had higher responses on the EPSI. BMI was also negatively correlated with each of the disordered eating subscales ($ps < .05$), meaning that those with lower BMIs (e.g., underweight or healthy range) had higher EPSI responses. Caucasian participants endorsed higher body dissatisfaction ($U = 1980$, $p = .008$), binge eating ($U = 2044$, $p = .02$), restricting ($U = 2141$, $p = .04$), and muscle building ($U = 2062$, $p = .02$) than participants identifying with other racial identities. Participants with myelomeningocele endorsed significantly lower excessive exercise than those with other forms of SB ($U = 2201$, $p < .01$). However, there was no evidence to suggest differences in any other EPSI subscales by SB type ($ps > .05$). Those with a shunt endorsed significantly higher body dissatisfaction ($U = 1607$, $p = .001$), binge eating ($U = 943$, $p < .001$), purging ($U = 1290$, $p < .001$), restricting ($U = 1394$, $p < .001$), negative attitudes towards obesity ($U = 941$, $p < .001$), and muscle building ($U = 1073$, $p < .001$) than those without a shunt.

Associations with Attempts to Change Weight Status—Analyses of variance exploring the relationship among current weight change attempts with EPSI subscales indicated significant differences for body dissatisfaction ($p < .001$), purging ($p = .02$), and restricting ($p = .03$). Bonferroni post hoc comparisons indicated that participants who reported actively trying to lose weight had significantly higher body dissatisfaction than all other weight change attempt groups ($ps < .001$). Additionally, those attempting to lose weight had higher purging scores than those making no attempt to change their weight ($p = .03$) and higher restricting scores than those attempting to maintain their weight ($p = .02$).

Discussion

The current study aimed to characterize multiple health and disordered eating cognitions and behaviors in a national sample of male and female adolescents and young adults with SB. The sample, primarily Caucasian, with myelomeningocele and a shunt, reported a high degree of variability on BMI, the mean for which was at the high end of the healthy range. Consistent with the hypotheses, they reported less healthy food consumption and activity than recommended for the general population [23–25]. No sex differences emerged for the disordered eating and body image variables, with the exception of males endorsing more negative attitudes toward obesity. Partially consistent with the hypothesis that youth with SB would have higher disordered eating cognitions and behaviors compared to TD norms, males with SB had higher body dissatisfaction, purging, and restricting, while females with SB had higher purging and restricting. Having a lower BMI and being younger in age were associated with higher disordered eating and body image problems. Caucasian participants endorsed higher body dissatisfaction, binge eating, restricting, and muscle building behaviors, though we are cautious to overinterpret these findings given that the majority of the sample was Caucasian. Consistent with the hypotheses that SB characteristics would impact endorsement of disordered eating factors, having a shunt was associated with having higher disordered eating and body image problems in most domains. However, having myelomeningocele (the most severe form of SB) was not associated with higher disordered eating, but was associated with a higher BMI. Finally, the majority of the sample described themselves as trying to lose or maintain their current weight. Those trying to lose weight were more likely to have higher rates of body dissatisfaction, purging, and restricting.

Body Mass Index and Health Behaviors

It was anticipated that respondents would be in the overweight to obese categories in terms of their BMI. However, respondents reported a highly varied BMI profile, with the average falling at the high end of the healthy range for the general population [30]. There was no evidence to suggest sex differences for BMI, but those with myelomeningocele had higher BMIs than those with other forms of SB. Nevertheless, we are cautious to overinterpret the BMI findings in the current sample for three primary reasons. First, multiple issues of validity have been identified when attempting to obtain accurate height and weight measurements in individuals with disabilities [31], and the current study relied on self-report, as opposed to physician-report, of these measurements. Second, BMI cut points for obesity are based on TD populations, and therefore are likely to underestimate body fat in individuals with SB (due to differences in body composition and fat distribution) [15, 31, 32]. Finally, given the nature of how the sample was recruited and assessed, the current sample may be particularly health conscious and/or high functioning (only 56.9% of the sample has myelomeningocele), increasing the likelihood that their self-report may not be fully representative of all adolescents and young adults with SB.

The health behaviors of adolescents and young adults with SB were primarily below minimum CDC recommendations for teens and adults. As anticipated, most of the sample did not report recently eating the recommended amounts of fruits, vegetables, and milk. While not assessed, it is assumed that less healthy foods may be eaten more frequently,

reducing the consumption of healthier options. Indeed, this would be consistent with previous parental reports of difficulties in getting youth with SB to eat foods with lower caloric densities or to consume smaller portions [19]. Conversely, nearly half of the sample reported having two hours of screen time during the week, which is in line with CDC recommendations. It is possible this self-reported endorsement is an underestimate. However, if accurate, this is a promising finding that counters previous parental reports that limiting youth with SB to this amount of screen time would likely be unsuccessful [19]. Screen time has been noted as being at odds with physical activity, such that potential screen-based social opportunities (e.g., connecting with peers over the Internet) may replace exercise time for youth with SB [15]. Yet, the current sample of adolescents and young adults with SB also reported engagement with multiple forms of exercise for multiple days each week, activities that are often identified as having multiple barriers for youth with disabilities [19]. While it seems unlikely they are achieving the recommended 60 minutes of activity daily for youth and 150–300 minutes per week for adults, the majority endorsed frequent activity. Finally, with respect to sleep, the sample mean was just below the recommended minimum for sleep duration, and roughly half of participants reported having issues falling and staying asleep. This is consistent with previously identified sleep difficulties in youth with SB compared to TD peers [33]. Taken together, further assessment of barriers to appropriately facilitate increased healthy eating, activity, and improved sleep is needed for adolescents and young adults with SB.

Disordered Eating

It was anticipated that adolescents and young adults with SB would endorse disordered eating cognitions, given previous findings highlighting poor body image [8–10]. Males with SB, not females, endorsed significantly higher body dissatisfaction than the TD norms. Adolescents and young adults with SB of both sexes demonstrated areas of resiliency, reporting significantly lower binge eating, excessive exercise, and negative attitudes towards obesity than their TD peers. However, the areas of greatest concern that emerged for those with SB compared to TD norms were specific disordered eating behaviors. Indeed, both males and females with SB endorsed significantly higher purging and restricting behaviors compared to TD norms. Purging and restricting were also associated with a reported desire to lose weight and having a shunt; moreover and counterintuitively, being younger in age and having a lower BMI were associated with greater disordered eating cognitions and behaviors overall. Therefore, those at highest risk for disordered eating behaviors were adolescents with shunts and those wanting to lose weight, despite already being in the underweight-to-healthy BMI range. These findings highlight the dangers of the previously described disconnect between recommendations to reduce weight in adolescents and young adults with SB and the lack of effective guidance on how to do so.

Disordered eating has been described as prevalent in females with disabilities [20] as a means to self-improvement, success, and increased mobility [6, 9]. The current study highlights that this problematic view of disordered eating behaviors likely extends to males with SB as well. Purging and restriction are associated with serious medical complications in TD populations [34], which would be expected to be exacerbated in populations with a premorbid chronic medical condition. Further, if these behaviors are viewed by adolescents

and young adults with SB as a means to lose weight and potentially achieve better health, they are less likely to endorse these behaviors as problematic to family or health professionals. Additionally, as those at higher risk may already be in an underweight to healthy BMI range, they may not be screened for unhealthy weight loss practices. This lack of reporting and assessment would decrease the likelihood that these behaviors will be identified or treated.

Limitations and Conclusions

The current findings should be considered in light of specific limitations. First, the sample was recruited online through a condition-specific, national resource group (the Spina Bifida Association). The survey was described as “a brief, anonymous online survey to better understand what kinds of health behaviors you do (like how often you exercise or eat fruits, vegetables, or sweets) and how you feel about your body.” The discussion of the current findings should therefore be considered in light of a sample of adolescents and young adults that is: 1) connected to resources (the Spina Bifida Association), 2) engages with the Internet independently, and may therefore represent a higher functioning subset of youth with SB, and 3) may be particularly health-conscious, as they responded to the survey with interest. Second, the nature of the consent process (see Procedure section) may have limited the number of respondents under the age of 18. Indeed, the majority of the sample was comprised of young adults. Further, the sample was primarily Caucasian. Future research would benefit from greater diversity in age and racial/ethnic participation, as well as other demographics (e.g., SES). Third, the current study was limited in its assessment of SB characteristics (i.e., lesion level and ambulation status) and body size (i.e., limited to BMI). Alternative means of determining shape and size (e.g., waist, shoulder, hip measurements) would also improve the characterization of body size in the context of health behaviors in future work. Finally, given the nature of the online survey methodology, the validity of responses is also worth questioning. However, the anonymity of the survey was intended to increase the likelihood of honest responses and the data appeared psychometrically sound. The anonymity also limited the possibility of employing a targeted intervention based on survey responses (e.g., the option for participants to send their data to their primary care providers or a local nutritionist), which might be considered for future studies of this nature. Limitations notwithstanding, this national sample was also the first of its kind to be queried about health and disordered eating across both sexes.

The current study highlighted multiple strengths and vulnerabilities for adolescents and young adults with SB. Positively, respondents reported an average BMI in the healthy range, screen time within the recommended guidelines for the general population, and engagement with various forms of physical activity. However, many of the CDC-recommended minimums for healthy food consumption and physical activity duration were not met. The findings importantly note that much of the health and body image experience of youth with SB is consistent across the sexes. Most critically, disordered eating behaviors, such as purging and restricting, are endorsed at higher rates than in the general population. This highlights the need for a thorough assessment of such behaviors for adolescents and young adults with SB, including those with lower BMIs who might not be considered “at risk” for unhealthy attempts to lose or maintain their weight. Collectively, the current study provides

critical insights into the health behaviors and disordered eating cognitions and behaviors of adolescents and young adults with SB. This work should be further refined through continued assessment, including multi-method and multi-informant methodologies, to improve prevention and intervention services for youth with SB, and more broadly, adolescents and young adults with disabilities.

Acknowledgements

This research was supported in part by grants from the National Institute of Nursing Research and the Office of Behavioral and Social Sciences Research (R01 NR016235), National Institute of Child Health and Human Development (R01 HD048629), and the March of Dimes Birth Defects Foundation (12-FY13–271). This research was also supported by a Research Support Grant from Loyola University Chicago. The authors thank the Spina Bifida Association (SBA), without whom this research would not have been possible.

References

1. Goldschmidt AB, Wall M, Choo TH, Becker C, Neumark-Sztainer D. Shared risk factors for mood-, eating-, and weight-related health outcomes. *Health Psychology*. 2016;35(3):245–52. Epub 2015/12/21. doi: 10.1037/hea0000283. PubMed PMID: ; [PubMed: 26690639]
2. Austin SB. A public health approach to eating disorders prevention: It's time for public health professionals to take a seat at the table. *BMC Public Health*. 2012;12:854 Epub 2012/10/09. doi: 10.1186/1471-2458-12-854. PubMed PMID: ; [PubMed: 23043459]
3. Neumark-Sztainer D, Wall MM, Larson N, Story M, Fulkerson JA, Eisenberg ME, et al. Secular trends in weight status and weight-related attitudes and behaviors in adolescents from 1999 to 2010. *Preventive Medicine*. 2012;54(1):77–81. Epub 2011/10/15. doi: 10.1016/j.ypmed.2011.10.003. PubMed PMID: ; [PubMed: 22024221]
4. Forbush KT, Wildes JE, Pollack LO, Dunbar D, Luo J, Patterson K, et al. Development and validation of the Eating Pathology Symptoms Inventory (EPSI). *Psychol Assess*. 2013;25(3):859–78. Epub 2013/07/01. doi: 10.1037/a0032639. PubMed PMID: . [PubMed: 23815116]
5. Kazdin AE, Fitzsimmons-Craft EE, Wilfley DE. Addressing critical gaps in the treatment of eating disorders. *International Journal of Eating Disorders*. 2017;50(3):170–89. Epub 2017/01/19. doi: 10.1002/eat.22670. PubMed PMID: . [PubMed: 28102908]
6. Silber TJ, Shaer C, Atkins D. Eating disorders in adolescents and young women with spina bifida. *Int J Eat Disord*. 1999;25(4):457–61. PubMed PMID: . [PubMed: 10202657]
7. Segal M, Eliasziw M, Phillips S, Bandini L, Curtin C, Kral TV, et al. Intellectual disability is associated with increased risk for obesity in a nationally representative sample of U.S. children. *Disability and Health Journal*. 2016;9(3):392–8. Epub 2015/12/17. doi: 10.1016/j.dhjo.2015.12.003. PubMed PMID: ; [PubMed: 26785808]
8. Taleporos G, McCabe MP. The relationship between the severity and duration of physical disability and body esteem. *Psychology & Health*. 2005;20(5):637–50.
9. Cicmil N, Eli K. Body image among eating disorder patients with disabilities: a review of published case studies. *Body Image*. 2014;11(3):266–74. Epub 2014/05/06. doi: 10.1016/j.bodyim.2014.04.001. PubMed PMID: . [PubMed: 24958662]
10. Pinquart M. Body image of children and adolescents with chronic illness: a meta-analytic comparison with healthy peers. *Body Image*. 2013;10(2):141–8. Epub 2012/12/07. doi: 10.1016/j.bodyim.2012.10.008. PubMed PMID: . [PubMed: 23219705]
11. Copp AJ, Adzick NS, Chitty LS, Fletcher JM, Holmbeck GN, Shaw GM. Spina bifida. *Nature Reviews Disease Primers*. 2015;1:15007 Epub 2015/04/30. doi: 10.1038/nrdp.2015.7. PubMed PMID: ; [PubMed: 27189655]
12. Parker SE, Mai CT, Canfield MA, Rickard R, Wang Y, Meyer RE, et al. Updated National Birth Prevalence estimates for selected birth defects in the United States, 2004–2006. *Birth Defects Res A Clin Mol Teratol*. 2010;88(12):1008–16. Epub 2010/09/28. doi: 10.1002/bdra.20735. PubMed PMID: . [PubMed: 20878909]

13. Holmbeck GN, Devine KA. Psychosocial and family functioning in spina bifida. *Developmental Disabilities Research*. 2010;16(1):40–6. doi: 10.1002/ddrr.90. PubMed PMID: ; [PubMed: 20419770]
14. Stiles-Shields C, Crowe AN, Driscoll CFB, Ohanian DM, Stern A, Wartman E, et al. A systematic review of behavioral intervention technologies for youth with chronic health conditions and physical and intellectual disabilities: Implications for adolescents and young adults with spina bifida. *Journal of Pediatric Psychology*. Under Review.
15. Polfuss M, Bandini LG, Sawin KJ. Obesity Prevention for Individuals with Spina Bifida. *Curr Obes Rep*. 2017;6(2):116–26. doi: 10.1007/s13679-017-0254-y. PubMed PMID: . [PubMed: 28455677]
16. Agopian AJ, Canfield MA, Olney RS, Lupo PJ, Ramadhani T, Mitchell LE, et al. Spina bifida subtypes and sub-phenotypes by maternal race/ethnicity in the National Birth Defects Prevention Study. *Am J Med Genet A*. 2012;158A(1):109–15. Epub 2011/12/02. doi: 10.1002/ajmg.a.34383. PubMed PMID: . [PubMed: 22140002]
17. Dosa NP, Foley JT, Eckrich M, Woodall-Ruff D, Liptak GS. Obesity across the lifespan among persons with spina bifida. *Disability & Rehabilitation*. 2009;31(11):914–20. doi: 10.1080/09638280802356476. PubMed PMID: . [PubMed: 19037774]
18. Liu JS, Dong C, Vo AX, Dickmeyer LJ, Leung CL, Huang RA, et al. Obesity and anthropometry in spina bifida: What is the best measure. *J Spinal Cord Med*. 2016;1–8. Epub 2016/08/23. doi: 10.1080/10790268.2016.1195071. PubMed PMID: . [PubMed: 27551923]
19. Bush RA, Pérez A, Connelly CD, Jorquera E, Leveque NL, Chiang GJ. Community-academic partnership: Identifying patient perceptions related to obesity in a spina bifida population. *Journal of Participatory Medicine*. 2016;8:e6.
20. Gross SM, Ireys HT, Kinsman SL. Young women with physical disabilities: risk factors for symptoms of eating disorders. *J Dev Behav Pediatr*. 2000;21(2):87–96. PubMed PMID: . [PubMed: 10791476]
21. Le Grange D, O'Connor M, Hughes EK, Macdonald J, Little K, Olsson CA. Developmental antecedents of abnormal eating attitudes and behaviors in adolescence. *Int J Eat Disord*. 2014;47(7):813–24. Epub 2014/07/21. doi: 10.1002/eat.22331. PubMed PMID: . [PubMed: 25046731]
22. Loth KA, MacLehose R, Bucchianeri M, Crow S, Neumark-Sztainer D. Predictors of dieting and disordered eating behaviors from adolescence to young adulthood. *J Adolesc Health*. 2014;55(5):705–12. Epub 2014/06/09. doi: 10.1016/j.jadohealth.2014.04.016. PubMed PMID: ; [PubMed: 24925491]
23. Centers for Disease Control and Prevention. How much sleep do I need? Atlanta, GA: 2017.
24. U.S. Department of Health and Human Services and U.S. Department of Agriculture. 2015–2020 Dietary Guidelines for Americans. 2015.
25. Centers for Disease Control and Prevention. Screen time vs. lean time 2017 Available from: https://www.cdc.gov/nccdphp/dch/images/infographics/getmoving_15-18.png.
26. Forbush KT, Wildes JE, Hunt TK. Gender norms, psychometric properties, and validity for the Eating Pathology Symptoms Inventory. *International Journal of Eating Disorders*. 2014;47(1):85–91. Epub 2013/09/02. doi: 10.1002/eat.22180. PubMed PMID: . [PubMed: 23996154]
27. Kolbe LJ, Kann L, Collins JL. Overview of the Youth Risk Behavior Surveillance System. *Public Health Rep*. 1993;108 Suppl 1:2–10. PubMed PMID: ; [PubMed: 8210269]
28. Murray CB, Holmbeck GN, Ros AM, Flores DM, Mir SA, Varni JW. A longitudinal examination of health-related quality of life in children and adolescents with spina bifida. *Journal of Pediatric Psychology*. 2015;40(4):419–30. doi: 10.1093/jpepsy/jsu098. PubMed PMID: ; [PubMed: 25434043]
29. Centers for Disease Control and Prevention. Calculating BMI using the English system Atlanta, GA2014 [cited 2018]. Available from: https://www.cdc.gov/nccdphp/dnpao/growthcharts/training/bmiage/page5_2.html.
30. Centers for Disease Control and Prevention. Defining adult overweight and obesity: Adult Body Mass Index (BMI) 2016 [cited 2018]. Available from: <https://www.cdc.gov/obesity/adult/defining.html>.

31. Liusuwan RA, Widman LM, Abresch RT, Styne DM, McDonald CM. Body composition and resting energy expenditure in patients aged 11 to 21 years with spinal cord dysfunction compared to controls: comparisons and relationships among the groups. *J Spinal Cord Med.* 2007;30 Suppl 1:S105–11. PubMed PMID: ; [PubMed: 17874695]
32. Mita K, Akataki K, Itoh K, Ono Y, Ishida N, Oki T. Assessment of obesity of children with spina bifida. *Dev Med Child Neurol.* 1993;35(4):305–11. PubMed PMID: . [PubMed: 8335145]
33. Murray CB, Palermo TM, Holmbeck GN. A Multimethod, Case-Controlled Study of Sleep-Wake Disturbances in Adolescents With Spina Bifida. *Journal of Pediatric Psychology.* 2018;43(6):601–12. doi: 10.1093/jpepsy/jsx150. PubMed PMID: ; [PubMed: 29272431]
34. Dickstein LP, Franco KN, Rome ES, Auron M. Recognizing, managing medical consequences of eating disorders in primary care. *Cleveland Clinic Journal of Medicine.* 2014;81(4):255–63. doi: 10.3949/ccjm.81a.12132. PubMed PMID: . [PubMed: 24692444]

Implications for Rehabilitation

- Adolescents and young adults with spina bifida are often advised to lose weight without clear guidelines on how to do so, putting them at risk for disordered eating
- Professionals should expect variable body mass indices in this population, with some health behaviors falling short of recommendations made for the general public by the Centers for Disease Control
- Professionals should fully assess disordered eating behaviors in youth with disabilities, even when at a healthy weight

Table 1.Survey Respondent Demographic and Medical Characteristics ($n = 167$).

	<i>n</i> (%)
Age, <i>M</i> (SD; range)	20.06 (1.91; 15–24)
Sex	
Male	101 (60.5%)
Female	64 (38.3%)
Race/Ethnicity	
African American	13 (7.8%)
Asian	5 (3.0%)
Caucasian	123 (73.7%)
Hispanic	25 (15.0%)
Other	1 (.6%)
Employment Status	
Employed, Full Time	30 (18.0%)
Employed, Part Time	17 (10.2%)
Disability from Work	5 (3.0%)
Full Time Student	97 (58.1%)
Unemployed	16 (9.6%)
Volunteer	1 (.6%)
SB Type	
Myelomeningocele	95 (56.9%)
Other	71 (42.6%)
Meningocele	35 (21%)
Lipomeningocele	13 (7.8%)
Lipomyelomeningocele	3 (1.8%)
Lipoma	20 (12%)
Shunt Present	127 (76.0%)
With Revision History	65 (44.8%)
BMI, <i>M</i> (SD; range)	24.87 (6.15; 15.28–48.80)
Current Weight Change Attempts	
Gain	13 (7.8%)
Lose	69 (41.3%)
Maintain	64 (38.3%)
No Attempts to Change	21 (12.6%)

Note. M = mean; SD = standard deviation; SB = spina bifida; BMI = body mass index.

Table 2.

Health Behavior Frequencies Frequency of Daily Healthy Food Intake and Screen Time

	No times	1–3 in past 7 days	4–6 times in past 7 days	Once per day	Twice per day	3 times per day	4+ times per day
100% fruit juice	0%	25.1%	25.7%	20.4%	7.8%	15.6%	1.8%
Fruit	1.8%	19.2%	29.9%	26.3%	17.4%	3%	1.8%
Vegetables	0%	18.6%	29.3%	16.8%	25.7%	3%	3.6%
Milk	0%	25.7%	29.9%	26.9%	7.8%	0%	2.4%
	None	< 1 hour	1 hour	2 hours	3 hours	4 hours	5+ hours
Screen time	3.6%	10.8%	19.2%	49.7%	13.8%	2.4%	.6%

Frequency of Physical Activity

	0 Days	1 Day	2 Days	3 Days	4 Days	5 Days	6 Days	7 Days
30 minutes of strenuous exercise	7.8%	9.6%	21%	24%	17.4%	18.6%	0%	1.8%
30 minutes of non-strenuous exercise	6%	7.2%	29.3%	19.2%	31.1%	3.6%	1.2%	1.8%
Strength exercises	9.6%	10.2%	26.3%	32.3%	15%	5.4%	0%	1.2%

Sleep Quality

	<5 hours	5–6 hours	6–7 hours	8–9 hours	10+ hours
Average sleep duration	3.6%	27.5%	40.7%	25.1%	2.4%
	Not at all	Very little	Moderately often	Very often	Almost Always
Trouble falling asleep	7.8%	28.1%	56.3%	6.6%	1.2%
Trouble staying asleep	7.2%	39.5%	47.3%	4.8%	1.2%

Note. Frequencies reported from adapted version of the Youth Risk Behavior Surveillance System, as reported in "Overview of the Youth Risk Behavior Surveillance System," by L. J. Kolbe, L. Kann, J. L. Collins, 1993, *Public Health Reports*, 108(Suppl 1), 2–10.

Table 3.

Eating Pathology Symptoms Inventory Subscales Comparing Adolescents and Young Adults with Spina Bifida and Typically Developing College Students ^a, M(SD)

	Males			Females		
	AYA-SB ^b	TD College Sample ^c	<i>t</i> value	AYA-SB ^d	TD College Sample ^e	<i>t</i> value
Body Dissatisfaction	16.56 (6.72)	13.40 (5.73)	4.91 **	15.91 (5.90)	20.68 (6.89)	5.34 **
Binge Eating	17.28 (7.39)	18.71 (5.34)	2.29 *	16.78 (7.55)	19.21 (5.45)	3.26 **
Purging	11.40 (6.25)	6.39 (1.71)	15.37 **	10.64 (5.93)	6.86 (2.13)	10.63 **
Restricting	15.19 (5.73)	10.29 (4.09)	10.20 **	14.39 (5.14)	11.44 (4.53)	4.90 **
Excessive Exercise	10.56 (3.34)	13.10 (5.27)	4.66 **	10.70 (3.54)	11.90 (.90)	6.66 **
Negative Attitudes Toward Obesity	11.03 (4.95)	15.18 (4.69)	8.04 **	9.84 (4.55)	14.48 (4.65)	7.62 **
Muscle Building	10.60 (4.55)	9.75 (4.12)	1.86	9.97 (5.72)	11.90 (5.07)	1.28

Note. M = mean; SD = standard deviation; AYA-SB = adolescents and young adults with spina bifida; TD = typically developing. Cognitive restraint subscale not included due to low reliability for AYA-SB sample. No significant differences between AYA-SB male and female participants, with the exception of males having more negative attitudes toward obesity than females ($p = .01$); TD female college students scored significantly higher than their male counterparts on body dissatisfaction, binge eating, purging, and restricting ($ps < .05$).

* $p < .05$.

** $p < .001$.

^a Data reported in "Gender Norms, Psychometric Properties, and Validity for the Eating Pathology Symptoms Inventory," by K. T. Forbush, J. E. Wildes, T. K. Hunt, 2014, *International Journal of Eating Disorders*, 47(1), 85–91.

^b $n = 101$.

^c $n = 502$.

^d $n = 64$.

^e $n = 625$.