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Mental Health & Weight-Related Behaviors

Exploring parental perception of body weight, lesion level and BMI Z-score in children living with spina bifida

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Background: Children living with spina bifida can experience reduced mobility and short stature. Mobility limitations increase with higher spinal lesion level and places children at risk for becoming overweight. Early-stage research of neurotypical preschoolers using the Child Feeding Questionnaire (CFQ) indicates misalignment between parent perception of their child's weight and BMI z-score. Our study investigated trends between parental perceptions of their child's weight and eating patterns, spinal lesion level and BMI z-score for children living with spina bifida.

Methods: The CFQ assesses parental beliefs, attitudes, and practices around child feeding. To reduce participant burden, only the "concern for child weight" subscale from the CFQ was used. CFQ data were collected by interview, over a 6-month period, from parents of children enrolled in a pediatric spina bifida clinic. Lesion level and BMI z-score were obtained from the child's clinic record. Descriptive analysis explored frequency and potential associations between data elements.

Results: Data collected from a sample of 54 children, age 2-17, evenly split by gender, and diagnosed with spina bifida were analyzed. BMI-z score classified 44% (n=24) of the sample as overweight. Within the overweight subsample, less than half the parents perceived their child as overweight and even fewer (29%) were unconcerned about their child becoming overweight. 55% of the sample had a lesion level of mid-lumbar or higher and nearly ¾ of this sample were classified as overweight by BMI z-score.

Conclusions: The prevalence of overweight children in our sample is significantly larger than the 19% reported for typically developing children. Eating can be one of the few activities that children living with spina bifida often have control over and 'can feel normal' about. Parents and providers may

be reluctant to eliminate this source of control and normality with diet restrictions. Healthy lifestyle programs must allow children the ability to maintain this control.

Exploring the complexities of weight management care for youth with spina bifida: A qualitative study with youth and parents

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Background: Spina bifida (SB) is caused by a complex interaction of physiological, environmental, psychosocial and physical factors. Youth with this condition in Canada are more at risk for developing higher weights compared to non-disabled youth. Little is known about how these youth conceptualize their bodyweight and health. This study aimed at (i) exploring how youth with SB and their parents conceptualize bodyweight, health and weight management and (ii) identifying what services and supports youth with SB and their families perceive as appropriate to help them with weight management.

Methods: An interpretive descriptive approach was used to conduct semi-structured, individual interviews with youth with SB and their parents. Youth and families were eligible to participate if they were 10 – 18 years old, had a diagnosis of SB, received care from a children's hospital in Ontario, and had prior discussions about weight with a healthcare provider. Interviews were conducted in-person or virtually, audio-recorded, transcribed verbatim, and analyzed thematically.

Results: Five youth (three girls; two boys; 12–16 years old) with SB and five mothers (40–49 years old) participated. Three themes were identified, including larger bodies are unhealthy bodies, weight management relies on individual actions, and trusting relationships can support weight management care. Youth with SB and their mothers defined health based on bodyweight and size – a bigger body was seen as unhealthy. Weight loss was idealized and excess weight was equated with reduced mobility, which was considered unhealthy. The responsibility of weight management was placed on the child and participants felt they could improve their health through food intake – avoiding ‘bad’ foods and increasing ‘good’ foods. Participants stressed the importance of building trust with healthcare providers and engaging youth with SB directly. Finally, making activities related to weight management fun and practical were desired.

Conclusions: Education and awareness raising is needed so that health is not seen as solely linked to bodyweight. Weight stigma should be addressed through training and education for both families with SB and healthcare providers. Weight management care should be patient-centered with the responsibilities shared between families and healthcare providers to address the complexities of weight and health.

Feasibility of a mobile health app for adolescents & young adults with spina bifida

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Background: The prevalence of obesity in young adults with spina bifida (SB) is 34–64%. The use of mobile technology provides an innovative way to address obesity. The aim of this study is to assess the feasibility of using a mobile app over 3-months for adolescents with SB.

Methods: Patients between 11-21 years of age from the CHLA Spina Bifida Clinic identified as overweight & obese defined by BMI were invited to participate. The program consisted of monthly group

virtual nutrition sessions & an individualized adaptive exercise plan using PT Pal™ Mobile Health App paired with coaching by an athletic trainer. Outcome measures were changes in BMI & survey responses on the Pediatric Quality of Life Inventory (Peds QL), modified Youth Risk Behavior Survey Questionnaire (YRBS), Mobile App Rating Scale (MARS), & final program evaluation.

Results: 15 participants were enrolled & 10 completed the program. The mean age of participants was 16.2 years. 78% of participants reduced their overall BMI with a mean change of 1.51 (SD ± 2.57). Older participants were more interactive with the app than younger participants. The number of participants using the app declined after the first week. Episodic increases in app use occurred at 4-week & 8-week mark, respectively. 3 of 10 participants would recommend the app. 9 out of 10 participants reported they liked the program overall. Participants believed the program improved their ability to exercise regularly, eat healthier, & feel more self-confident. Post-intervention Peds QL scores showed an increase in psychosocial health. Half of participants reported being active at least one more day per week & 60% reported less sedentary time after completing the program.

Conclusions: A mobile app-based virtual weight loss program with coaching is feasible for young persons with SB. Coaching was highly favored. This information will be useful to build a coach & mobile app virtual program for those with SB.

Weight cycling in pediatric spina bifida: A pilot study

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Background: Weight cycling is a pattern of repetitive weight gain and loss which is associated with negative health outcomes in otherwise healthy individuals. While prior research has focused on preventing obesity in children with spina bifida (SB), little is known regarding weight cycling in SB patients. The goal of this project is to assess if children with SB exhibit weight cycling, and if any common SB symptoms are associated with weight cycling.

Methods: Children with SB ages 12-20 were included in this study if they were seen in SB clinic from 2019 to 2022. Medical record review was performed. Weight percentiles were graphed for each patient using their most recent clinic visit. Patients were then categorized as showing weight cycling if they gained and then lost 5% of their body weight (or if the opposite occurred) once a year. Patients were categorized as rapid weight cycling if they showed cycling patterns more than once a year. Chi-square and binary logistic regression analyses were used to determine associations between SB-related variables and weight outcomes.

Results: Final cohort included 164 children ages 16±2.6 years. The majority patients were underweight (30% in the 1-10 percentile) or overweight (32% in the 90-99 percentile). Weight cycling was present in 49%, and 32% of the total sample showed rapid cycling.

Rapid weight cycling was associated with the presence of psychiatric diagnoses (OR = 2.63, 95% CI [1.3-5.3]; $p=0.01$), gastroparesis (OR = 4.04, 95% CI [1.4-11.5]; $p=0.01$) and chronic headaches (OR = 2.94 95% CL [1.2-7.1]; $p<0.02$).

Conclusions: This study is the first to identify rapid weight cycling among children with spina bifida. Further investigation of this phenomenon is warranted.

Weight status of children participating in the national spina bifida patient registry

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Background: Evidence suggests that individuals with spina bifida (SB) have a higher prevalence of overweight/obesity (OW/OB) than typically developing (TD) peers. However, the prevalence of OW/OB for the different types of SB is unknown. Study objectives were to describe the distribution of weight status categories and determine factors associated with OW/OB in children and adolescents with SB using the National Spina Bifida Patient Registry (NSBPR).

Methods: Demographic, anthropometric, and clinical data collected from 2009 through 2018 were used to describe the prevalence of OW/OB. Generalized estimating equation model (GEE) identified factors associated with OW/OB among individuals with SB.

Results: Participants (n=7215) were aged 2 to 19 years (Mean = 11.1, SE 0.06) and 51.4% female. The majority were Non-Hispanic White (57.2%) followed by Hispanic or Latino (25.1%) and Non-Hispanic Black (7.5%). The myelomeningocele (MMC) subgroup accounted for 76.3%. Most (60.2%) were community ambulators. The overall percentage of OW/OB was 45.2% with 49.2% of MMC and 32.0% of non-myelomeningocele OW/OB.

Following the CDC Obesity Severity Classification System, 19.7% of MMC was in class 1, 6.6% in class 2, and 3.5% in class 3. Univariate analysis of MMC participants demonstrated demographic (age, sex, race/ethnicity, and clinic region) and clinical variables (functional level of lesion, ambulation, and number of shunt surgeries) were associated with OW/OB.

GEE model showed that OW/OB was independently, and significantly, associated with age, sex, race/ethnicity, lesion levels, and geographic location of the clinics.

Conclusions: The demographic and clinical factors associated with OW/OB in children and adolescents with SB furthers our understanding of factors contributing to the higher prevalence of OW/OB in this population and may inform prevention and treatment strategies.

Psychotropic medication use in children with spina bifida

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Background: Neurodevelopmental differences and medical interventions in children with spina bifida (SB) can be associated with behavioral disorders. Children with SB meeting criteria for Attention-Deficit-Hyperactivity Disorder (ADHD) (~30%) respond less robustly to stimulants, likely associated with cerebral variations. Given the limited research, we examined psychotropic use in children with SB followed at an interdisciplinary SB clinic between 2010 and 2021.

Methods: We conducted retrospective review of medical records of children with SB with behavioral diagnoses (e.g., ADHD, anxiety). Children taking psychotropic medication were compared to those not taking psychotropics with respect to sociodemographic, clinical, and treatment variables. A chi-square test was used to compare categorical variables and a Fisher's exact test was utilized. Continuous variables were examined for normality of data distribution and a Mann-Whitney test was executed for comparison to the non-medication group.

Results: 104 of the 149 children with behavioral diagnoses were taking psychotropics (55% stimulants, 29% serotonin reuptake inhibitors [SSRIs]). Subspecialists prescribed 76% of psychotropics and mean age for initiation of short-acting stimulants and SSRIs was 7.47 and 11.9, respectively. There were no differences between medication and non-medication groups for type of SB lesion, presence of Chiari malformation or intracranial shunt, sex, race/ethnicity, or insurance status. Psychotropic use was associated with family history of ADHD (25%; $p=0.0121$). Adjunctive therapies (e.g., psychotropics and psychotherapy) were used by 51% with behavior therapy being associated with non-medication use ($p=0.0001$).

Conclusions: Younger age for initiating stimulants compared to SSRIs may reflect timing of symptom presentation for ADHD vs. mood disorders. Management of mood and attention is largely managed by subspecialists highlighting the need for gaining further competence in this area.

Resilience factors in pediatric spina bifida: Associations with internalizing symptoms and executive functioning skills

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Background: A growing body of literature has indicated that many individuals impacted by spina bifida (SB) are well-adjusted in many ways, despite the multisystemic challenges individuals with SB face. The factors promoting this resilient functioning have not yet been explored in this population. As such, the current study aims to characterize resiliency factors in children, adolescents, and young adults with SB.

Methods: Participants were drawn from clinical cases seen through a multidisciplinary outpatient SB clinic at a children's hospital in 2022. Participants included 17 youth under 21 years old ($M=13.24$, $SD=3.77$) who were diagnosed with SB. Self-reported resilience was measured with the Child and Youth Resilience Measure (CYRM; Ungar & Liebenberg, 2011). Internalizing symptoms were assessed with the age-appropriate version of the parent-report Behavior Assessment System for Children – 3rd Edition (BASC-3; Altmann et al., 2017). Executive functioning skills were assessed using performance-based neuropsychological assessments. We explored associations among demographic variables, markers of disease severity, internalizing symptoms, and executive functioning using Pearson correlations and t-tests. We also compared mean resilience in our sample to a previously published sample of typically developing high school students ($n = 1500$) using a t-test.

Results: Resiliency factors were unrelated to SB disease severity and ethnicity. Older age was associated with less relational resilience ($r = -.49$, $p = .05$). Individual resilience was lower on average for female than male participants [$t(9) = 2.51$, $p=.02$]. Higher individual resilience was associated with lower levels of internalizing symptoms ($r = -.60$, $p = .03$) and higher executive functioning skills ($r = -.70$, $p = .02$). Youth with SB had similar overall resilience

as typically developing high schoolers ($t(512)=1.05, p=.29$).

Conclusions: Overall, youth with SB appear to have similar rates of resiliency as typically developing high school students. Importantly, higher individual resilience in this sample was associated with lower levels of internalizing symptoms. Treatment focused on bolstering resilience may be important in this population.

Body composition and energy expenditure in youth with spina bifida

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Background: Creating and testing interventions to prevent or treat obesity in youth with spina bifida (SB) is compromised by the lack of clinically feasible, valid, and reliable measures of body fat and total energy expenditure (TEE) for youth with SB. The aims of our federally funded study are to:

1. Develop a clinically usable algorithm that accurately models body fat% in youth with SB, considering mobility, sex, and pubertal status.
2. Using Doubly Labeled Water (DLW), calculate TEE and develop an algorithm to predict energy requirements with a best-fit model based on fat-free mass, sex, age, mobility, height and/or weight of the sample, stratified by age and mobility.
3. Evaluate the frequency and duration of physical activity and dietary intake of the sample, using activity and food screeners.

Methods: A multisite prospective cross-sectional study is in progress with a targeted enrollment of 232 youth with myelomeningocele, ages 5-18 (stratified by age and mobility) from four regional pediatric SB programs. Participants undergo four measures of body composition (Waist circumference, skin folds, bioelectrical impedance analysis and DLW) and up to five height measures (stadiometer [if able to stand], arm span, recumbent length, knee height and ulnar length), a ramped protocol and 7 days of wearing an accelerometer. Descriptive analysis, Bland Altman plots, concordance correlation, and regression analysis will be employed.

Results: 30% of participants have enrolled with 50% Female, Mean age = 11.7 years, 32% Hispanic/Latino, and 46% primarily using wheelchairs. Challenges to enrollment include Covid-19, staff turnover, competing priorities within the clinical environment, travel barriers, and decreased incidence of clean intermittent catheterization for potential participants. Modifications have been made to address these challenges.

Conclusions: Unique challenges including Covid-19 impacted site recruitment and necessitated creative solutions. With modified processes, recruitment has intensified and data collection is ongoing.

Exploring the extent and nature of disordered eating in adolescents and young adults with spina bifida and hydrocephalus: An interim analysis

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Background: Young people with spina bifida and/or hydrocephalus (SBH) are at a higher risk of developing eating disorders and disordered eating. However, little is known on their perceived body image concerns and eating patterns, attitudes, and behaviours. As such, the current study aims to explore the nature, extent, type, and frequency of disordered eating behaviours amongst people with SBH. It also aims to understand their perceptions surrounding body image.

Methods: The study comprises a self-report, cross-sectional online survey of young people (aged 12-26) with SBH, across Canada and the United States. The survey asks about disordered eating and eating disorder symptoms and behaviours and their relation to SBH, and includes validated measures of eating behaviours and body esteem. Results from an interim analysis are provided.

Results: Sixteen young people have participated to date. The majority (60%) reported that conversations around their weight with healthcare providers caused them to decrease their food intake. Reasons attributed to decreased food intake included improving bowel/bladder function, self-esteem, and physical transfer-related reasons. Young people reported feeling self-conscious about their body, and that their bodies did not fit within the able-bodied beauty standard. Accordingly, the majority of participants (61%) felt that having SBH affected the way they viewed their body. When compared to a sample of young people without disabilities, participants had greater eating, shape, and weight concerns. They also reported being more likely to engage in emotional eating and externally-induced eating, when compared to a sample attending a paediatric weight loss program.

Conclusions: Recruitment for the current study is ongoing. The interim analysis has shown that disordered eating and eating disorders are a prominent issue in young people with SBH, and should be safely addressed in clinical settings.

Routine suicide screening among pediatric and adult spina bifida patients

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Background: In the last 3 decades, rates of suicide in the United States have increased 33%. According to the CDC, in 2020, suicide was the second leading cause of death among individuals between the ages of 10-14 and 25-34, and the third leading cause of death (after unintentional injuries and homicide) among individuals between the ages of 15-24. Our healthcare organization implemented universal suicide risk screening in all medical patients aged 8 or older, including patients seen in Spina Bifida clinic, in 2017.

Methods: Our organization implemented the use of the “Ask Suicide-Screening Questions” (ASQ) which is validated in pediatric and adult medical patients. It takes less than 20 seconds to administer and is non-proprietary. The ASQ is administered by registered nurses as a part of routine triage. If a patient answers “yes” to any of the questions, appropriate medical staff members are notified, and further suicide safety assessments are performed with disposition determination for each patient who screened positive.

Results: Of 392 eligible visits between July 2019 and August 2022, 274 screenings were completed representing a screening rate of 70%. 251 unique patient completed screening and 118 declined screening. Additional data will report the percentage of Spina Bifida patients who screened positive on the ASQ and compare this data to other medical clinics in our organization.

Conclusions: Universal suicide risk screening represents one step in a global suicide prevention strategy. Our organization demonstrated that these screenings are feasible in the general neurodevelopmental disabilities population and specifically in the Spina Bifida population.

Screening for internalizing symptoms during clinical care: A comparison of scores on the revised children's anxiety and depression scale, parent version in youth with spina bifida, cerebral palsy, and autism spectrum disorder

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Background: Screening for mental health concerns is an essential component of best care practices for youth with spina bifida (SB) due to their increased risk for internalizing symptoms. However, little information is available regarding the use of screening tools for such symptoms in this population. This project examines scores on scales of a free screening tool, the Revised Children's Anxiety and Depression Scale, Parent Version (RCADS-P), among three clinical groups: SB, cerebral palsy (CP), and autism spectrum disorder (ASD).

Methods: We collected data through an online background questionnaire that included the RCADS-P Generalized Anxiety Disorder (GAD) and Depression scales. Primary caregivers completed this questionnaire in preparation for outpatient

neuropsychological/psychological evaluations at one center. We assigned diagnostic groups based on primary caregiver report of medical or developmental conditions.

Results: The sample included 24 youth with SB ($M_{age}=11.0$ years, 58% female), 50 youth with CP ($M_{age}=10.9$ years, 46% female), and 87 youth with ASD ($M_{age}=11.7$ years, 19.5% female). There were no significant differences in mean raw scores on the GAD scale among SB ($M=5.67$), CP ($M=4.73$), or ASD ($M=7.01$) groups, ($F(2, 152)=[2.35]$, $p=0.10$). On the Depression scale, youth with ASD ($M=8.33$) had significantly higher mean raw scores than SB ($M=5.67$) and CP ($M=4.73$) groups, ($F(2, 150)=[7.33]$, $p<0.001$). On the GAD scale, 35% of the SB groups had sex and grade adjusted T -scores in the At-Risk/Elevated range (i.e., $T>59$; $M=54.4$, $SD=15.3$). On the Depression scale, 39% of the SB group had T -scores in the At-Risk/Elevated range ($M=55.5$, $SD=14.7$).

Conclusions: For children with SB, parent ratings resulted in At-Risk/Elevated scores on anxiety (35%) and depression (39%) scales. The RCADS-P may be an appropriate screening tool for anxiety and depression in youth with SB. Future work should examine psychometric properties of the RCADS-P as well as predictive values of RCADS-P scores with clinical diagnoses in youth with SB.