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Association between self-reported quality of life and demographic and condition-specific variables in a large sample of patients with spina bifida

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Background: Research on quality of life (QOL) among individuals with spina bifida (SB) demonstrates mixed findings regarding the association between reported QOL and demographic and condition-specific factors. Small sample sizes and variation in participant characteristics could be contributing to the range of previous findings. We investigated associations between self-reported QOL and demographic and condition-specific variables in a large sample using the National Spina Bifida Patient Registry (NSBPR).
Methods: NSBPR participants were invited to report on QOL using a single-item prompt (i.e., "In general, would you say your quality of life is: …": Excellent, Very Good, Good, Fair, Poor; note "Fair" and "Poor" were combined during analysis). Participants were provided with a definition of QOL. Chi-square tests were performed to examine the associations between QOL and sociodemographic and condition-specific factors.
Results: Data were obtained from 890 NSBPR participants (50.8% female, 74.3% non-Hispanic White, 81.5% myelomeningocele), sample size varied by analysis due to missing data. QOL ratings varied by age group (8-12y [n=245], 13-17y [n=215], 18+y [n=430]). Among those aged 8–12 years, 4.1% reported Fair/Poor and 31.4% reported Excellent, compared with 13.5% and 21.6% in those 18 years or older, respectively ($p < 0.0001$). Very good or Excellent QOL was reported in 64.4% of those who had private insurance, compared to 55.7% of participants with non-private insurance ($p = 0.0293$). QOL was not associated with race, ethnicity, SB type, level of lesion, lifetime number of shunts, or ambulation status.
Conclusions: While consideration of QOL is important for all with SB, findings highlight the particular significance of examining QOL for adults and those with public insurance as a larger percentage of those patients reported poorer QOL. The large sample size of this study addresses a limitation of previous QOL research in SB.

The feasibility of obtaining pain, pain interference, quality of life (QOL) and health-related quality of life (HRQOL) data in National Spina Bifida Patient Registry clinics (NSBPR)

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Background: Pain, Pain Interference, Quality of Life (QOL), and Health Related Quality of Life

(HRQOL) are important concepts to measure over time in individuals with spina bifida (SB). Through a pilot project we aimed to assess the feasibility of collecting QOL data as part of the National Spina Bifida Patient Registry (NSBPR).

Methods: Concepts were assessed with self-reported measures in a 6-month pilot study at 12 NSBPR sites. During multidisciplinary SB clinic visits, data on three core concepts were collected using single items; Pain (0-10), Pain Interference with school, work, play or self-care (Never to Almost Always), and QOL (Poor to Excellent), while 10-15 HRQOL items (from 3 previously validated age & SB-specific scales) were collected. Clinical or research team members provided feedback regarding their experience collecting data on standardized forms. Frequencies of their responses are reported.

Results: Feasibility data were reported on 538 individuals approached either in the 3-item core arm (n=207) or the core + SB-specific HRQOL instrument arm (n=331). Data were collected from 89% of participants overall, 91% in the core and 87% in the core + HRQOL arms. Participation differed by age with child participation being the lowest (84%; n=150) followed by adolescent (88%; n=126) and adult (94%; 202). Reasons for non-participation were few but included cognitive limitations/did not understand questions (higher in children/adolescents), parent or patient refusal, or timing issues. Although initially 59% of children in the core arm and 64% in core+HRQOL arm had to have the questions read, data collectors indicated that when read to them most children were able to answer the questions. In addition, a few children needed the questions restated or clarified to understand them but were then able to answer the questions.

Conclusions: Collecting QOL and HRQOL data was feasible for most of the NSBPR participants. However, items needed to be read to 50-60% of the children, suggesting collecting the data from this population may require additional staff time, especially for the HRQOL instrument.

Pain and pain interference among people with spina bifida: Association with quality of life

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Background: People with spina bifida (SB) are at risk of experiencing pain due to effects of aging and orthopedic, neurosurgical, and other sequelae. This study aimed to evaluate the association between self-reported pain, pain interference, and quality of life (QOL) among patients in the National Spina Bifida Patient Registry.

Methods: Patients from 12 multidisciplinary clinics reported pain level (11-point Likert-type scale, higher scores = more pain), pain interference ("How often does pain interfere with activities?": five options from Never to Almost Always), and QOL ("In general, would you say your quality of life is: …": Excellent, Very Good, Good, Fair, Poor). Chi-square tests were performed to examine the association between pain/pain interference and demographic and condition-specific factors. Person correlations were used to test association between pain, pain interference, and QOL.

Results: Data were obtained from 895 patients (51.1% female, 90% non-Hispanic White, 81.3% myelomeningocele); 846 reported on pain and 701 reported on pain interference. Higher pain ratings were more likely for older patients (age groups= 8-12, 13-17, 18+ years; $p < 0.0001$), females ($p=0.0089$), non-Hispanic or Latino patients ($p = 0.0007$), those with sacral level lesions ($p < 0.0001$), and a higher lifetime number of shunts ($p = 0.0066$). Higher pain interference was reported for patients who are older ($p = 0.0092$), females ($p = 0.0073$), of Asian race ($p = 0.0497$), and with non-private insurance ($p = 0.0015$), non-myelomeningocele ($p = 0.0306$), sacral level lesions ($p = 0.0001$), higher lifetime number of shunts ($p = 0.0165$), and those who are community ambulators ($p = 0.0148$). Both pain and pain interference negatively correlated with QOL ($r = -0.25$ and -0.31, respectively; both $p < 0.0001$).

Conclusions: Examining pain and pain interference among people with SB is important, and findings suggest sub-populations at higher risk. Results also suggest efforts to improve pain/pain interference may impact QOL.

Mobile health systems to support self-management in spina bifida: Developing a dashboard for integration of mhealth with the electronic health record (EHR) system

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Background: The *Guidelines for the Care of People with Spina Bifida* recommend using mobile health (mHealth) systems to support self-management. The Interactive Mobile Health and Rehabilitation System 2.0 (iMHere) is an mHealth system comprised of a smartphone app and web-based portal. Research has shown the system to be feasible to implement, usable, and accessible for people with spina bifida, caregivers, and clinicians. This study aimed to develop an integration of mHealth with an Electronic Health Record (EHR) system through a care dashboard. The dashboard is intended for clinicians to prescribe mHealth as a digital intervention and to view integrated EHR data with data from patients' use of the app to support self-management.
Methods: A pilot project was carried out to develop a digital dashboard that displays integrated data from EpicCare EHR system and the iMHere 2.0 mHealth System.
Results: iMHere 2.0 can be digitally prescribed to patients using EpicCare. The patient receives an alert to download the app. The patient can use the app for tracking medical problems and medications, managing self-care routines for bowel and bladder care, and accessing educational material. Patient data are summarized on a dashboard that is accessible to the clinician within EpicCare, and utilization metrics can be used to track implementation.
Conclusions: Integration of mHealth systems like iMHere 2.0 into the electronic health record can allow clinicians access to data needed for building and supporting patients' self-management skills.

Adolescent/Young Adult Self-Management and Independence Self-Report questionnaire (AMIS-II-SR): Preliminary psychometrics

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Background: The purpose of this study was to examine preliminary psychometrics of the Adolescent/Young Adult Self-Management and Independence Self-Report Questionnaire (AMIS-II-SR).
Methods: Adolescents and adults (N = 133; 14 to 38 years old) with spina bifida (SB) completed the AMIS-II-SR. One-hundred fifteen (86.5%) had myelomeningocele. About half were female (48.1%) and Hispanic/Latino (45.1%); 40.6% were White, 12% were Black. Descriptive analyses and reliability were assessed; a confirmatory factor analysis is planned after completing data collection at a third site.
Results: Item-to-total correlations support the AMIS-II Total scale (r = .41 to .79) and two subscales, Condition (r = .51 to .73) and Independent Living (r = .49 to .87); internal consistency reliability was high (α = .91 to .96). The mean AMIS total score was 4.11 (SD = 1.63); response pattern ranges from 1 to 7 where higher scores represent greater self-management performance. Participants scored higher on the Condition (M = 4.67, SD = 1.55) than Independent Living (M = 3.62, SD = 1.84) subscale ($p < .001$). Age, race/ethnicity, and SB type were associated with the total self-management score (all $p < .05$). Regarding item level performance, the means ranged from 2.59 to 5.44. The averages for four items were below 3.0 indicating participants needed help paying for supplies/medications, handling insurance, generating income, and deciding when to go grocery shopping. Conversely, the averages for seven items were above 5.0 indicating more independence in taking medications, self-catheterization, maintaining assistive devices, and social

communication. Five item pairs (all $r > .80$) were strongly correlated (e.g., paying for supplies/medications, arranging delivery/pick up).
Conclusions: This study supports using the AMIS-II-SR for adolescents and emerging adults. Respondents were slightly more independent in their total self-management than published psychometric evidence of the interview version. Likewise, their condition scores were consistently higher than independent living scores.

Developmental study of the Japanese version of the quality of life assessment in spina bifida for adults: Cross-cultural validation in pilot study

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Background: The quality of life assessment in spina bifida (QUALAS) is a disease-specific HRQOL scale with three versions, namely, for Children, Teenagers, and Adults. Japanese versions of the QUALAS for children (QUALAS-C-J) and teenagers (QUALAS-T-J) have already been developed; however, a Japanese version for adults has not. The purpose of this study was to develop a Japanese version of the adults instrument (QUALAS-A-J) and to verify the face and cross-cultural validity in accordance with Japanese culture
Methods: Two urologists translated the QUALAS-A into Japanese (ver. 1), and the developmental team received a consensus integrated version (ver. 2). A pilot study was conducted in September 2021, and 17 adult patients with spina bifida were recruited from one hospital to complete the QUALAS-A-J and provide feedback (ver. 2). Questionnaires were mailed to the participants' homes, and after being completed, feedback was provided online. One respondent was excluded because of their intellectual developmental stage.
Results: Sixteen participants were 11 women, and 5 were men, ages 18-35 (median 28), with <5 min response time on the QUALAS-A-J. Nine of the 15 items were expressed as acceptable in ver. 2. Regarding questions content relating to sexuality, participants indicated that abstract expressions may be too vague in meaning while others were embarrassed by concrete expressions. In fact, 19% of participants chose "no answer". We also received feedback on whether 'health problems' were perceived as 'spina bifida' or 'disability'. These expressions were modified to created ver.3.
Conclusions: The QUALAS-A-J was sufficiently validated to ensure that the response time was short and that the wording was appropriate for the Japanese population.

Exploration of the relationships between different domains of health-related quality of life in children, teens, and adults with spina bifida

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Background: The quality of life assessment in spina bifida (QUALAS) – a validated health-related quality of life (HRQoL) instrument for individuals with spina bifida (SB) – was recently designed to more accurately capture HRQoL in SB. Few studies have been published utilizing QUALAS and have primarily focused on how bowel & bladder functioning affect overall quality of life (QoL). There is a need for additional research utilizing QUALAS to explore how bowel and bladder related QoL is correlated with other aspects of QoL including self-esteem, independence, and sexuality.
Methods: Participants in the national spina bifida patient registry in a single healthcare system were administered the child, teen, or adult QUALAS as appropriate based on their age. Analyses were completed exploring the correlation between the different domains of the QUALAS.
Results: A total of 43 children ages 8-12 years (22 female, 21 male), 43 teens ages 13-17 years (19 female, 24 male), and 88 adults ages 18 years or greater (40 female, 48 male), were included in the study. Male children demonstrated a stronger positive correlation between the esteem/independence domain and the bowel/bladder domain than female children. Male teenagers similarly showed a stronger positive correlation than females between the family/inde-

pendence domain and the bowel/bladder domain. Lastly, adult men showed a stronger positive correlation than women between the esteem/sexuality domain and the bowel/bladder domain.
Conclusions: There is a positive correlation between how bothered an individual is by bowel & bladder dysfunction and measures of esteem & independence in children, teens, and adults with SB as measured by the QUALAS. This correlation appears more robust in males than females, but additional studies with larger sample sizes will be required to determine if these differences are statistically significant.

Neurogenic bowel dysfunction scores in a large cohort of pediatric patients with spina bifida

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Background: Most Children with spina bifida (SB) experience neurogenic bowel dysfunction (NBoD) that requires a bowel management program. Despite good bowel management, they may have soiling which impacts their quality of life. The neurogenic bowel dysfunction score (NBoDS) is a validated questionnaire used to monitor patients with NBoD. A score >8.5 indicates NBoD. Our aim is t*o* describe NBoD in pediatric patients with SB using the NBoDS.
Methods: We retrospectively reviewed patients aged 2-18 seen in our pediatric Spina Bifida Multidisciplinary Clinic who completed the NBoDS at a visit from September 1, 2017 – March 31, 2022. Only patients whose problem list in the EMR contained at least one of the following diagnoses based on ICD-10 codes were included in analysis: myelomeningocele, spina bifida, tethered cord, lipomeningocele, neurogenic bowel, or neurogenic bladder. From the EMR we extracted demographics and NBoDS data (responses to each question and overall scores) for each patient from the first visit that they completed the NBoDS.
Results: Six hundred and ninety-nine patients (50.4% male; 49.6% female) completed the NBoDS, 39.8% were ages 2-5 years (NBoDS = 14.21), 36.2% were ages 6-11 years (NBoDS = 14.67), and 24% were ages 12-18 years (NBoDS = 13.32). Most patients identified as non-Hispanic White (55.7%), followed by Hispanic or Latino (17%), non-Hispanic Black (9.6%), Asian (5.7%), and Other (12%). The average NBoDS score across all patients was 14.16 (SD 6.8).
Conclusions: In this large cohort of children and adolescents with SB, we found that the majority have neurogenic bowel dysfunction when assessed with a validated questionnaire. The NBoDS is a useful tool to help in assessment of NBoD symptoms, facilitation of conversations between clinicians and families about bowel management, evaluation of the bowel management program, and recommendations for improved bowel function.

Quality of life studies among people living with spina bifida and neurogenic bowel: A literature review

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Background: Neurogenic bowel dysfunction (NBD) has major impacts among individuals living with spina bifida (SB). There are significantly higher odds of continence among individuals aged ≥ 12 years, female, non-Hispanic white, and those with private insurance; in adulthood bowel continence is significantly associated with employment. Yet, despite the measured impact of NBD, few studies have elucidated the effect of NBD on quality of life (QOL). Furthermore, since NBD is often managed by multiple specialties, little consensus exists for its management algorithm. As a first step, we set out to identify the tools used in the study of QOL and NBD.
Methods: A systematic review was conducted utilizing search terms "spina bifida" AND "neurogenic bowel", from the PubMed database. Inclusion criteria allowed studies assessing quality of life (QOL) using formal QOL tools. Exclusion criteria exempted articles that were not related to QOL and/or assessed QOL without a formal tool.
Results: Seventy-two articles were identified from 1979-2022. Inclusion criteria was met by 11 articles, representing 13 differing QOL instruments. The *Neurogenic Bowel Dysfunction* score was used

most commonly – five studies (45%). Two studies (18%) used both the *St Marks Fecal Incontinence* score and *Cleveland Clinic Constipation Scoring System*. The *SF-36 Questionnaire* was used in two different studies. The remainder of articles (9%) used other tools including the *Fecal Incontinence Quality of Life Assessment*, *Adolescent Fecal Incontinence and Constipation Symptom Index*, *Parkin QOL*, *Modified Barthel's Activity of Daily Living Index* score, *PIN Q*, *Visual Analog* score, *CHQ-PF50* and *PEDS QL4.0*.

Conclusions: There is wide divergence in QOL tools used to study NBD in SB. Given the weight of NBD across the lifespan and the known associations with sociodemographic variables, there is a greater need for QOL to be explored. However, to date no specific scale has emerged as a best tool to be utilized for future multicenter studies.

Supporting independence in bladder and bowel management in children through use of social stories

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Background: Occupational therapists strive to promote the greatest level of independence in self-care tasks. One tool that can be used with children is called a "social story". This visual learning tool can help explain a new experience, an upcoming transition, or understanding of a new concept. Children often learn best with visuals and a story that can be told repeatedly in child-friendly language, to make a new task less scary. A social story was developed for children with Spina Bifida to support their understanding and participation in daily Clean Intermittent Catheterization (CIC), and use of a cone enema with the goal of fostering independence in bladder and bowel management.

Methods: Three variations of social stories were developed with child-friendly language and familiar cartoon images: CIC for Females; CIC for Males; and Learning to Use a Cone Enema. Images and content were reviewed with other disciplines within the institution for consistency. Drafts of each story were reviewed with families before production to gather feedback.

Results: Approximately 150 copies of the social stories were given to families in clinic in the past year. Patients as early as age 3 were provided with the cone enema social story if the medical team had identified the plan to start a bowel enema program. Patients between the ages of 5-9 were provided with the CIC social stories, depending on several factors including family readiness, cognition, fine motor coordination, and positioning needs.

Conclusions: Occupational Therapy emphasizes the importance of independence with bladder and bowel routines. A social story aims to foster a child's participation in these routines at an early age, in order to gain confidence and improve likelihood of long-term success and independence with this vital self-care task.

The relationship between health-related quality of life and bladder and bowel management in adults with spina bifida

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Background: This study aimed to determine the actual health-related quality of life (HRQOL) of adult patients with spinal bifida (SB) and the factors associated with HRQOL.

Methods: The survey was distributed to SB patients aged ≥18 years who were able to complete a self-administered instrument sent by mail to patient and family associations and in person at spina bifida-related outpatient clinics in two different regions in Japan. The survey started in March 2022, and of the 167 currently distributed surveys, 133 valid responses were analyzed by August 2022. The HRQOL instrument used for patients with SB was the World Health Organization Quality of Life Scale (WHO-QOL-26), and related factors included items that had been shown to be significant in previous studies and items related to bladder and bowel management. Statistical analyses were conducted using univariate (correlation coefficient, t-test) and multivariate (multiple regression analysis) methods.

Results: Respondents were 51.9% female, with a mean age of 31.3 ± 10.5 SD (range 18-69). Of the respondents, 60.9% were community ambulators, 36.8% had a shunt, 62.4% were employed, and 18.1% had a partner. A total of 81.2% and 72.9% of

the participants had clean intermittent catheterisation (CIC) and bowel management, respectively. Factors associated with WHOQOL-26 were sex, age, employment status, incontinence, independence in bladder management, and confidence in bowel management, depending on each domain of HRQOL.
Conclusions: Factors associated with bladder and bowel management of patients with SB were found to be influenced by various aspects of HRQOL.

Trajectories of self-management and independence in youth with spina bifida: Socioeconomic and condition-related predictors of growth

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Background: This study examines the contextual predictors of self-management trajectories in adolescents and young adults (AYA) with spina bifida (SB).
Methods: Participants completed the Adolescent/Young Adult Self-Management and Independence Scale (AMIS-II) interview across 4 time points. Socioeconomic status (SES), shunt status, lesion level, and executive functioning were assessed at baseline. Growth in total self-management and its subscales (condition and independent living) was estimated using linear mixed effects models.
Results: This study included 99 respondents (18 to 27 years old). About half (52.5%) were female and White; 15.2% were Black, and about one-third Hispanic/Latino. Eighty-seven AYAs had myelomeningocele and 81 had a shunt. The lesion level was 31.3% sacral, 48.5% lumbar, and 18.2% thoracic. Growth in self-management was not moderated by participants' contextual factors (all interaction $p > .05$). The following factors predict the intercept at age 18 for total self-management. Higher SES predicted a higher self-management score ($b = 0.03$, $SE = .01$; $p < .001$). Participants with a shunt or a shunt revision scored on average about 1 point lower than those without a shunt ($b = -0.90$, $SE = 0.32$; $p = .01$). Similarly, participants with a thoracic lesion scored lower when compared to those with lumbar ($b = -1.22$, $SE = 0.34$) and sacral lesions ($b = -1.20$, $SE = 0.36$; both $p = .001$). Better executive function reported by parents/teachers predicted higher self-management scores (Metacognitive: $b = -0.03$, $SE = 0.01$; Behavioral Regulation: $b = -0.04$, $SE = 0.01$; both $p < .05$). Findings were consistent across total and subscales.
Conclusions: This study identifies contextual predictors of self-management. Youth without a shunt, with a lower lesion level, better executive function, and higher SES start young adulthood more independent in self-management and remain higher over time. On average, participants demonstrated the same rate of growth in self-management behaviors.

"My bowel and me" a booklet for school-age children with spina bifida who require bowel management

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Background: Many children with spina bifida (SB) depend on a regular bowel management mostly with the ultimate goal to achieve social continence. Due to the many different intervention options and the complexity of the topic, age-appropriate information is crucial and should be available for every patient at any age. However, much information is mainly designed for the patients' parents or for adults with SB. A suitable source of information is lacking and prevents age-appropriate instruction and thereof long-term adherence. School-age children with SB should be able to learn more about their condition and understand the interventions involved. Therefore, the goal of these project was to create a booklet for school-age children with SB requiring bowel management. Moreover, caregivers will be able to use the booklet to provide structured instruction.
Methods: A practice development project based on a literature review and collaboration with an interdisciplinary group, consisting of a pedagogical and medical specialist as well as the nurse practitioner SB and a specialized continence nurse, was conducted. A comprehensive literature search was carried out using CINAHL and PubMed to identify the chal-

lenges and issues that bowel management presents to children and their families. Based on these results, the interdisciplinary group developed the contents of the booklet.

Results: An evidence-based booklet was created to meet the needs of school-age children with SB and a regular bowel management. The booklet contains child-friendly information, practical examples of living with bowel management and lovingly illustrated by fantasy creatures.

Conclusions: Age-appropriate patient information and education can have a positive impact on the treatment, its course and thus the quality of care of patients. Through the age-appropriate information, patients are empowered and have more control over their situation. Moreover, nurses and caregivers are alert and enabled to respond more specifically to school-age children with SB and their needs.

Use of the PedsQL and CarerQoL in young children with spina bifida

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Background: Much of the focus on urologic Quality of Life (QOL) in the Spina Bifida (SB) population has focused on fecal and urinary continence in older children and adolescents. However, much less is known regarding how urologic care impacts QOL of younger children and their families. The aim of this project is to assess proxy QOL and caregiver burden over the first 5 years of life in children and parents with SB utilizing validated measures from the pediatric population (PedsQL™, CarerQoL). We hypothesized that parent reported QOL and caregiver burden would be correlated in this population and that use of these validated instruments could provide value to care teams in identifying families with high caregiver burden and impaired QOL.

Methods: The PedsQL™ and the CarerQoL surveys were completed by enrolled parent(s) at outpatient visits (3 months, 6 months, 1 year). Descriptive statistics were used in analysis for surveys completed at 3 months (n=8) and 6 months (n=5).

Results: At 3 months, both parent-reported QOL and caregiver burden were rated at levels comparable to healthy infants (88.5, 100). By 6 months of age, median QoL and caregiver burden decreased (79.5, 75) to levels associated with children with chronic illness.

Conclusions: Parents may find more challenges with caregiver burden in young children with SB at 6 months. Results from the PedsQLTM and CarerQoL may provide specific areas of anticipatory guidance for this population of children and assist care teams in identifying families with high caregiver burden and decreased QOL.