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Adult Care, Aging & Sexuality

Assessing end of life planning for caregivers of adults with spina bifida

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Background: Neural tube defects (NTDs) are the most common congenital central nervous system anomalies. In the U.S., 100,000 people suffer from the chronic disability engendered in these conditions. Medical complications that occur in adult patients with this condition are the direct result of long-term aberrations of normal neurological, urologic, and musculoskeletal function. The caregiver role not only consists of matters of health but also matters of finance. Special needs trusts (SNTs) enable patients to have access to services that go beyond governmental provisions. An end-of-life assessment in caregivers of chronic diseases remains largely unknown. Our hypothesis was that most families will not have a living will and are unaware of resources that they can take advantage of.

Methods: The study consisted of survey distribution to 86 consented caregivers of patients at University of Alabama at Birmingham Adult Spina Bifida Clinic. The survey consisted of patient and caregiver demographic background, patient functional status including activities of daily living (ADL) and mobility, and assessment on end-of-life plans. Knowledge of supplemental or special needs trusts was evaluated. Our data was then analyzed using descriptive statistics.

Results: Caregivers concern about the patient's future living situation (48%), finances (56%), and medical care (79%) were common. Concern about future living situation was more common when patients required assistance in activities of daily living (ADL) (all $p < 0.02$). Most caregivers did not have a will (71%), had not taken steps to ensure "proper care" for their loved one if they were to pass away (69%), but had spoken to family or friends about their wishes (66%). Most indicated they were familiar with some trust options (73%), that no-one had discussed EOL with them (78%), and they would

benefit from more information (76%). Caregiver education level was related to having a will, having had a discussion regarding EOL planning, and perceived benefit of more information (all $p < 0.01$). Caregiver future concerns were related to perceived benefit of more information (all $p < 0.04$), but not to formal or informal end-of-life planning (all $p > 0.06$). **Conclusions:** Most of our cohort did not have a living will in place. Caregivers of people with spina bifida are largely unaware of supplemental trusts. More information regarding this topic would benefit the majority of our cohort, particularly those who have dependence with ADLs. Healthcare providers can fill this gap by providing End of Life planning education.

Survival and causes of death in adults with spina bifida in Sweden: A population-based case-control study

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Background: Although survival among infants with spina bifida (SB) increased to approximately 75% in the last few decades, the mortality rate for people with SB aged 5-40 years has been reported to be ten times higher than that of the general population. The most common causes of death found in the group are infectious, renal, cardio-pulmonary, and nervous system related. The objective of this study was to analyze the survival rate and causes of death in adults with SB in Sweden compared with a matched control group from the general population.

Methods: The study was population-based and included 11,900 adults born between 1950 and 1997. Three Swedish registers were used to identify all individuals with a diagnosis of SB in Sweden and a matched comparison group without SB. The period analyzed was 1990-2015. International Classification of Diseases codes were used to identify causes of death. Frequencies for each cause were calculated in both groups and compared using a two-proportions test. Finally, survival analysis was conducted in the two populations.

Results: Results showed lower probability of survival for people with SB in all age groups ($p < 0.001$). Survival at 25 years for people with SB was 84.7% compared to 98.4% in the comparison group. The most prevalent causes of death in people with SB were congenital, respiratory, nervous, cardiovascular, genitourinary, and injuries. People with SB had a higher probability of dying from congenital ($p < 0.001$), respiratory ($p = 0.002$), genitourinary ($p < 0.002$), and nervous-related ($p > 0.001$) causes whereas people who did not have SB had a higher probability of injury-related deaths ($p < 0.001$).

Conclusions: Adults with SB in Sweden have a lower survival rate compared to the general population, with the frequency of certain causes of death differing between the two groups. To reduce excess premature mortality, prevention and careful management of potentially dangerous conditions are greatly needed.

Sexual health developmental milestones: Integration of sexual health anticipatory guidance in an outpatient spina bifida clinic - a pilot

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Background: Sexual health development occurs throughout childhood in age-specific stages in all children starting in the first years of life, yet unlike other developmental milestones, there is little information on impacts of delayed or missed sexual health developmental milestones on sexual health in adulthood for people with spina bifida. Routine sexual health monitoring and intervention is lacking for people with spina bifida (SB), despite the increased psychosocial and physical challenges related to their condition that can impact successful milestone progression, including motor and sensory deficits. The Spina Bifida Association (SBA) brings much needed attention to the importance of age-appropriate sexual health anticipatory guidance specific to spina bifida in their Sexual Health and Education Guidelines. Routine anticipatory guidance in a busy multi-disciplinary clinic serving patients with complicated

medical conditions is a veritable challenge and warrants purposeful and methodical clinic integration.

Methods: Primary stakeholders were identified, including spina bifida patients aged up to 25 years old, their caregivers, SB nurses, social worker, psychologists, and SB medical care providers.

SBA Sexual Health and Education guidelines were broken down into age groups. Guidelines within each age group were flushed out to include additional specific developmentally appropriate questions and education points to be integrated into routine visits. These were then divided between clinic providers and nursing to allow manageable sizes of information that could be addressed at any visit throughout duration of

A navigation tool was created to monitor progression and ensure completeness of anticipatory guidance goal within and across age groups.

Results: An organized inter-disciplinary patient care plan was structured to ensure routine integration of the SBA's Sexual Health and Education Guidelines in manageable parts.

Conclusions: Increased anticipatory guidance for children with spina bifida is necessary to help children with spina bifida reach the same sexual developmental milestones as their peers. This requires proactive efforts involving open communication between parent, child, and provider at each stage of sexual development. We describe one framework for integrating routine sexual health monitoring and anticipatory guidance in a busy spina bifida clinic.

The experiences of women with spina bifida with obtaining information about sexuality and access to needed reproductive health care

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Background: Nearly 25 years after passage of the Americans with Disabilities Act (ADA), women with disabilities such as spina bifida still face substantial barriers with regard to sexuality and reproductive health care. At times, they may receive inadequate information about sexuality and reproductive health from clinicians and family members while growing up with spina bifida. Some women with spina bifida report that they are often perceived

as asexual and that their needs for reproductive health care are inadequately met. Inadequate information and clinicians' challenges with addressing the reproductive health care needs of women with spina bifida can affect these women with throughout the life span.

Methods: Using semi-structured telephone interviews with seven women with spina bifida conducted as part of two larger research projects with national samples of women with physical disabilities, we explored women's experiences with sexuality, pregnancy, and reproductive health care. Women were recruited via social media and through community-based organizations.

Results: Women reported a wide range of information and support available to them regarding sexuality and reproductive health while growing up with spina bifida and in obtaining reproductive health care. While some women reported receiving positive support and helpful information regarding sexuality and reproductive health from family and clinicians, others reported inadequate information and unhelpful attitudes toward their sexuality and reproductive health. Additionally, some reported a lack of knowledge and experience among clinicians regarding these topics.

Conclusions: Although some women with spina bifida report positive experiences, others face significant barriers to obtaining information and adequate clinical support regarding sexuality and reproductive health care. Their needs could be met more effectively by increasing their access to information about sexuality and reproductive health throughout the life span and by supporting clinicians' ability to provide quality care through education and a planful, team-based approach to care.

Sexual health and experiences among adult patients with spina bifida: A cross-sectional survey at a tertiary transitional spina bifida center

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Background: Reproductive education in patients with spina bifida (SB) is poorly understood and inadequately addressed. There is an increasing effort within the SB community for improvement. Herein we present our results of a sexual health survey developed by our multidisciplinary SB team on intimacy, sexual knowledge, and intimate partner violence. Our aim is to assess the level of SB patient education regarding sexual and reproductive health within the UAB multidisciplinary SB clinic population.

Methods: A 40-part de-identified survey was designed by the SB multidisciplinary team with input from patients with SB. After IRB approval, the survey was administered to all patients in the UAB multidisciplinary SB clinic from March 2021 to April 2022. Patient knowledge/experiences regarding sexual activity/safe practices, STIs, pregnancy, and contraception were queried. Descriptive analysis was conducted using Excel version 2205.

Results: 64 patients were approached for participation. 12 incomplete surveys were excluded. 55% of males and 38% of females have been/are currently sexually active. Nearly 70% of SB patients understand that they can have sex, although only 40% of women believe women with SB can get pregnant. 20% of males and 13% of females stated they've experienced pain with intercourse related to positioning. Only 25% of males and 31% of females learned about sex from a medical provider. Up to 10% of females reported a history of sexual coercion.

Conclusions: Determining the level of education regarding sexual/reproductive health is a crucial first step in improving the multidisciplinary care that patients with SB need. This study demonstrates that a vast majority of patients with SB live a sexually active lifestyle, yet they continue to have perceived barriers/concerns that are unique to SB. A tailored sex counseling and health care plan for these patients might help address their challenges and minimize unwanted sexual experiences and intimate partner violence.

A peer navigation program for the adult spina bifida population

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Background: *The Guidelines for the Care of People with Spina Bifida* recommend engagement with peers. The Spina Bifida Care Advisory Network (SB-CAN) is a council comprised of adults with spina bifida (SB), caregivers, and clinicians who advise the UPMC Adult Spina Bifida Clinic as part of the Spina Bifida Association's Clinical Care Partner program. SB-CAN members who are adults with SB designed a Peer Navigation Program (PNP). We hypothesize that after 1 year, mentees and mentors will have improvements in all physical and psychosocial outcome measures being collected, and burnout rates of mentors will remain low (median <3/5) on Maslach Burnout Inventory (MBI).

Methods: Mentors undergo a screening and formal training by the PNP coordinator and clinic director and must pass an exam. Mentees are matched to mentors according to the patient's preference per demographics, diagnosis, ambulation status, shunt status, and sexual orientation. Mentees and mentors meet virtually one-on-one biweekly, and in quarterly group meetings. Mentors also meet monthly. Mentees and Mentors complete baseline and annual surveys. Mentees complete the Beck Depression Inventory II, National SB Patient Registry core quality of life measures, and Generalized Self-Efficacy Scale, and rate level of confidence in health-related domains. Mentors complete the MBI. Both groups rate physical health, mental health, and their interference with community activities.

Results: The PNP has recruited 7 mentors: 2 (28%) African American females with non-myelomeningocele, 1 (15%) Asian female with myelomeningocele, 3 (42%) Caucasian females with myelomeningocele and 1 (15%) Caucasian male with myelomeningocele. The PNP has members identifying with the LGBT and disability communities, and lived experience with athletics, nursing, social work, and college. Mentors have been matched to 6 mentees. Data collection is ongoing.

Conclusions: A PNP designed and led by adults with SB has been established. If it is found to have positive impact, it will be scaled to other SB clinics.

A review of emergency department and inpatient admissions of adults with spina bifida followed by a multidisciplinary clinic

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Background: Given the complexity and common complications of Spina Bifida (SB) many patients are encouraged to work with a multidisciplinary (MD) clinic to better address their needs; however, a subset of SB patients are not regularly followed. This project aims to address the difference in frequency and cause for Emergency Department Visits and Inpatient Admissions between these two groups. **Methods:** Using MSO Billing Data, 312 patients with a diagnosis of Spina Bifida were identified and retrospectively followed over a 5-year period (01/01/17-12/31/21). Patients followed by a MD clinic were denoted and an analysis on all ED visits and Inpatient Admissions over the period was performed to establish the chief complaint/admission diagnosis for the visit type.

Results: Of the total 312 Spina Bifida patients, 187 patients were followed by a MD clinic and 125 were not. In the 5-year period, 65 of 187 clinic patients (35%) accounted for 178 inpatient admissions, while 50 of 125 non-clinic patients (40%) accounted for 101 inpatient admissions. Although 69% of all inpatient admits for the MD clinic patients were admitted through the ED, only 40% of non-clinic patients were admitted. The clinic patients were primarily admitted due to infections (37%), shunt procedures (11%), and neurologic complaints (7%), while non-clinic patients were admitted due to infections (26%), neurologic complaints (12%), and pregnancy (9%). A larger percentage of non-clinic patients presented to the ED, 38% vs 23% of clinic patients. MD clinic patients primarily reported urological issues (12%), UTI (11%), and headache (11%) while non-clinic patients reported musculoskeletal pain (20%), ostomy complications (13%), various infections (7%), and headache (3%).

Conclusions: The review shows that MD clinic patients were more likely to be admitted from the ED than non-clinic patients (69% vs 40%). MD clinic patients primarily reported to the ED due to SB complications such as urological /UTI (23%) and shunt related headache (11%) while non-clinic patients primarily came for musculoskeletal complaints (20%) and ostomy complications (13%). Receiving preventative care could account for the more serious medical conditions that led to MD clinic patients seeking ED care and subsequent admission to the hospital. Furthermore, this review shows an oppor-

tunity to collaborate with the ED to increase the number of SB patients who attend the MD clinic and preserve emergency department resources.

Organization of transitional and adult urology care for spina bifida patients in Florida and Puerto Rico

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Background: Organized multispecialty pediatric clinics and medical advances have resulted in significant increases in life expectancy for individuals with spina bifida. In the United States transition and access to adult medical care has been challenging. A network of pediatric and adult urologists in Florida and Puerto Rico were organized to improve and facilitate access to adult urology services.

Methods: Pediatric and adult urologists working in Florida and Puerto Rico were organized to provide transitional care coordination, consultation, and surgical cooperation for spina bifida patients. The total number of pediatric spina bifida patients and those transitioning to adult care were tabulated. Billing data and diagnosis codes used to query the number of patients seen during 2021. Demographic information about the individual urologists and their clinical settings were analyzed.

Results: Approximately 8,000 patients with Spina Bifida reside in Florida with 4,000 being adults. In 2021, a total of 821 unique spina bifida patients were seen across 10 locations in Florida and Puerto Rico for either new or return visits. 788 patients were seen in pediatric clinics and 33 patients were noted to have transitioned to adult urology clinics. Among the urologists providing care, 24 were fellowship-trained pediatric urologists and 23 were adult urologists of whom four were fellowship-trained in reconstructive urology. The clinics included university as well as private and hospital-employed practices.

Conclusions: Statewide organization of pediatric and adult urologists is feasible. To our knowledge, this is among the first reports of a statewide collaborative network designed to help improve transition and access to urology care for adult spina bifida patients. Additional efforts to involve spina bifida patients and maintain this network are ongoing. Additional research is warranted to evaluate the network's effectiveness in providing transitional care to spina bifida patients as they progress to adulthood.

Inpatient and emergency healthcare use of young adults with spina bifida in Los Angeles

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Background: Spina bifida, due to its variable association with herniation of the spinal cord and meninges, can cause minimally to severely disabling effects on mobility and on intellectual, bladder, and bowel functioning. Previous studies demonstrated higher rates of preventable hospitalization for adults with spina bifida compared to those without spina bifida.

Methods: The Los Angeles Data Resource (LADR) is a collaborative project of several major healthcare organizations in the Los Angeles metropolitan region, including UCLA; aggregate de-identified data from UCLA were collected on 362 young adults

with spina bifida from 2006-2022. Information was captured and analyzed regarding demographics and primary diagnoses of emergency visits and hospitalizations.

Results: Of the 362 patients with spina bifida, 206 (56.8%) were female, 277 (76.3%) identified as White/Caucasian, and 148 (40.9%) identified as Hispanic. The patients ranged from 18-34 years old, and 179 (65%) were 21-30 years old. The entire data set included 25,352 encounters, then was filtered to 470 encounters from 121 unique patients based on the presence of a “diagnosis at admission” flag, presumably excluding outpatient encounters, and by only including encounters with a primary diagnosis identified. The most frequently identified primary diagnoses in this final group were calculus in bladder or kidney (24 patients, 35 encounters), neurogenic bladder (21 patients, 33 encounters), urinary tract infection (19 patients, 38 encounters), sepsis or septicemia (13 patients, 23 encounters), abdominal pain (12 patients, 17 encounters), and kidney disease (9 patients, 24 encounters).

Conclusions: The most common primary diagnoses for non-outpatient encounters were predominantly urologic, and not frequently neurosurgical and orthopedic. Analysis was limited by variable specificity of diagnoses, and relied on assuming that the primary diagnosis truly represented the acute issue causing patient presentation. Further analysis of this data set and those from the other collaborating LADR institutions is needed.

Lessons learned from Alabama’s first primary care medical home for patients with medical complexity: What our patients with spina bifida are teaching us

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Background: Adult providers describe barriers in caring for individuals with complex conditions of childhood including lack of training, education and poor communication between pediatric and adult providers. Evidence shows patients with complex medical conditions are vulnerable to poor physical and mental health outcomes during their transition to adulthood, including depression, anxiety, poor follow-up, and declining physical health. In 2020

UAB established a primary care medical home for patients with medical complexity.

Methods: After IRB approval, we reviewed the list of patients with a diagnosis of spina bifida (6.7% of total STEP population). A retrospective chart review revealed demographic data as well as depression (PHQ-9) and anxiety screening (GAD-7), transition readiness assessment (TRAQ), number of specialists, and details of hospital admissions. Descriptive statistics were completed and extensive chart review and investigation was outlined to report problematic emergency department and in-patient admissions data related to two patients with > 90 day hospital admissions.

Results: Results are reported from 20/23 (87%) patients who were scheduled in the STEP clinic. These patients were already followed in the UAB adult spina bifida clinic but had not established with a primary care physician. Three patients no showed the appointment after several attempts. The patients ranged in age from 20.8-37 years with a mean age of 25.93 ± 5.28 . The race and distribution was representative of the entire STEP population with 12/20 white (60%), 5/20 black (25%), 3 other (15%) and 12/20 female (60%). 18% scored severe anxiety and 82% scored mild to minimal but one of those participants was on anxiety medication and one reported self-treating anxiety with marijuana daily. 64% of patients had minimal depression, 36% scored mild-moderate, and no patients scored severe. The mean TRAQ score was $3.82 \pm .91$ on a 5-point scale. Hospital-wide changes were created to improve system knowledge of vulnerable patients and need for caregiver presence, strategic lines of communication were opened between pediatric and adult providers, and emergency planning was done with both the ED and with emergency cards developed for patients.

Conclusions: Patients with spina bifida are often missing a critical component of transition - an adult primary care physician even when there is a well-established spina bifida transition program in place. This can lead to untreated depression and anxiety through the transition period. Admissions and emergency department challenges have also led to important system-wide changes that will impact all patients being transitioned.

Pain and the labor market outcomes of adults with spina bifida in Sweden

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Background: To estimate the association between pain, employment, and earnings for adults with spina bifida (SB) in Sweden.

Methods: A longitudinal cohort study based on data from Swedish population-based administrative registries of 1811 individuals (14,315 person-years) with SB aged 20-64 years. Individual fixed effects regression models were used to analyze the association between pain, employment, and earnings, as

well as potential pathways through which pain might affect labour market outcomes, sickness absenteeism, early retirement, and unemployment benefits.

Results: Pain was associated with adverse labour market outcomes, with varying effect across sex of individuals, corresponding to, a reduction of 5-8% in employment and 3% in earnings. Pain increased the likelihood of both sickness leave and early retirement, but reduced the likelihood of unemployment benefits.

Conclusions: Pain management could potentially be important to improve labour market outcomes for adults with SB, in addition to ease the suffering and improve the quality of life of individuals with CP.