



Perceived barriers transitioning to adult healthcare among adults with spina bifida

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ABSTRACT

Background: This study examined perceived barriers to transitioning to adult healthcare among a sample of young adults with spina bifida (SB) and the degree to which these perceived barriers have impeded the transition process, and assessed relationships between these self-reported barriers and demographic and medical variables. **Methods:** In a large national survey conducted in 2019, young adults with SB between the ages of 18 and 30 years old ($N = 326$) completed a questionnaire on perceived barriers to transition, which yielded scores representing the proportion of barriers experienced and the degree of interference of these barriers. Participants included both individuals who reported that they already transitioned to adult healthcare and those who did not.

Results: Participants endorsed a high number of barriers, with an average of 13 ($SD = 7.39$) of the 21 assessed barriers occurring for participants. Barriers were reported to be significantly interfering ($M = 2.38$, $SD = 0.54$, range: 1–4). Higher proportions of barriers were experienced by individuals who returned to a pediatric provider after transitioning, males, employed or students, and with sacral lesion levels. Higher interference scores were reported by individuals who returned to a pediatric provider after transitioning, as well as by individuals who identified as White, and who had a shunt.

Conclusion: Implications for transition programs and support are discussed.

1. Introduction

Spina bifida (SB) is the most common congenital birth defect affecting the central nervous system.¹ It is the result of an incomplete closure of the neural tube during the early stages of pregnancy, which leaves exposed neural tissue to degenerate in utero.¹ SB is associated with physical, intellectual, and health impairments that vary according to the lesion level on the spine, with higher spinal lesions typically involving more severe complications than lower spinal lesions. In order from highest to lowest lesion level, lesions may be categorized as thoracic, lumbar, or sacral.¹ To manage associated impairments and comorbidities, SB frequently requires multidisciplinary medical care. Physically, depending on the level of the lesion, SB is associated with limited mobility and the need for assistive devices such as crutches, braces, or wheelchairs. Typically, urological and gastroenterological complications may require catheterization or bowel programs.¹ Neurologically, shunts are often used to prevent hydrocephalus in individuals with SB. And cognitively, SB is associated with lower intelligence

quotient (IQ) scores and executive functioning deficits.² Additionally, SB places individuals at greater risk for difficulties with mental health³ and peer relationships.⁴

Fortunately, with medical advancements, the life expectancy of SB is increasing, with an estimated 85% of children with SB now surviving to adulthood.^{5,6} Thus, more individuals with SB are requiring adult-based healthcare and needing to make the transition from pediatric to adult healthcare. This transition involves shifting from pediatric, parent-involved health services to adult, individual-oriented healthcare.⁷ It is essential that this transition be successful since a lack of continuous, coordinated care among individuals with SB is associated with increased morbidity.⁸

However, this transition is often incomplete or unsuccessful, leaving individuals with SB at greater risk for medical decompensation and poor health. Nearly two decades of national child health surveys and community and state studies reveal that most youth with special healthcare needs do not receive adequate support in making this transition.⁹ The national Spina Bifida Association (SBA) has published guidelines

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recommending that the transition process begin early and be a consistent checkpoint throughout development,¹⁰ but it is clear that we are not meeting this standard. A survey of nearly three dozen SB clinics showed very little consistency in transitional care programs and evaluation techniques.¹¹ In recognition of how critical this transition process is to the health and wellbeing of individuals, the National Institute of Child Health and Human Development's (NICHD) 2020 Strategic Plan emphasized improving the transition to adult healthcare, especially among those with chronic conditions.¹²

A theoretical model of transition to adult healthcare among youth with SB, proposed by Holmbeck et al.,¹³ implicates various factors in determining a successful transition to adult healthcare. According to this model, barriers to transition moderate both the relationship between self-management and transition readiness, as well as the relationship between transition readiness and the successful transition to adult healthcare. More specifically, barriers to transition will likely decrease the likelihood of any transition or render a transition less likely to be successful (e.g., discontinuing care after the transition, returning to pediatric care after transitioning). According to this model, barriers are also at play in moderating the relationship between predictors of self-management (demographic, condition-specific, individual-, family-, and peer-level), as well as the relationship between self-management and adherence, and self-management and health complications. Although these barriers are critical in determining a successful transition to adult healthcare, we know very little about the most frequently experienced barriers, the degree to which these barriers interfere with care for youth with SB, or other factors that may exacerbate these barriers.

Hettel and colleagues¹⁴ examined barriers to transition among 27 adults with SB who had not been seen for at least 18 months at their adult myelomeningocele clinic.¹⁴ Twenty of the participants reported experiencing at least one barrier. The most common barriers were patient factors (e.g., not having any problems so not needing to go, forgetting to go). However, the authors speculated that perhaps the measure did not capture all possible barriers, because all participants had not been treated in clinic for 18 months and yet, nearly a quarter of the sample did not report any barriers. Authors hypothesized that there may be additional reasons these participants had not received care.¹⁴

To address SB-specific transition to adult healthcare, a small number of United States-based intervention programs have been evaluated in recent years (with other programs evaluated in Australia, Canada, and the United Kingdom; see Holmbeck et al.¹³ for further review). One such program is *Movin' On Up*, which assigns healthcare transition (HCT) nursing specialists to patients, and includes interdisciplinary HCT plans, an interdisciplinary HCT team, direct HCT services provided in a weekly SB clinic, and phone follow-ups with patients and providers.¹⁵ Another program is the Spina Bifida Transition Project (SBTP), which involves a pretransition orientation visit with a nurse at a children's hospital, a summary of health problems and treatment, a tour of the adult care setting, transfer of medical records, and transition visits to adult clinics.¹⁶ Many transition and transition readiness programs share the common feature of giving a lead role to nurses in facilitating the patient's transition process. Nurses have long-term relationships and frequent contact with their patients; they have expertise in coordinating care and experience and familiarity with many of the features considered necessary in transition programs: educating patients and their families, providing support, monitoring readiness, and promoting important skills related to self-care and self-managements.¹⁷

To maximize the effectiveness of new and existing transition readiness and planning programs for youth with SB, we must better understand the lived experiences of individuals with SB regarding the transition to adult healthcare and the barriers individuals face when making this transition. Of course, the identity marker of SB does not exist independently of other identity markers. Recognizing the role of intersectionality, individuals with SB may experience a multitude of systemic challenges as they transition to the medical system, including

racism,^{18,19} sexism,²⁰ and classism.¹⁸ Thus, it is also critical to examine the impact of these experiences on barriers to transition.

Previous studies with this sample revealed that three quarters of young adults with SB reported transitioning to adult healthcare but one-third reported returning to a pediatric provider following this transition.²¹ Further research is needed to characterize barriers to this transition, so that clinicians may develop interventions that can adequately address these barriers and facilitate the transition process.

Marginalized youth experience more barriers when trying to access and engage with healthcare systems and services. A systematic review conducted by Robards and colleagues²² highlighted that marginalized youth – defined as youth who are homeless, living in rural areas, of refugee background, gender and/or sexuality diverse, indigenous, low income, young offenders, or living with a disability – experience additional barriers to accessing, engaging with, and navigating their healthcare, beyond what all young people experience. These barriers involve ability to recognize and understand health issues, service knowledge and attitudes toward help seeking, structural barriers, professionals' knowledge, skills and attitudes, service environments and structures, ability to navigate the health system, youth participation, and technology opportunities. Moreover, research supports the compounding effects of intersectionality such that youth who belong to multiple marginalized groups tend to report even more barriers to accessing care.²³ Individuals with SB are already exposed to discrimination and bias due to marginalization of disability groups.²⁴

The current study first aims to identify perceived barriers to the transition to adult healthcare among young adults with SB, as well as the degree to which the identified barriers impeded the transition process. Second, this study aims to examine the impact of various aspects of one's identity (gender, race, education, employment) and SB condition (type, shunt status, and lesion level) on the number of barriers experienced and their degree of interference. Based on research by Robards and colleagues,^{22,23} we hypothesized that additional identity markers, that are also often further burdened by discrimination, may increase the likelihood of experiencing barriers to transition. Thus, we hypothesized that female gender (experience of sexism), minoritized race and ethnicity (experience of racism), lower levels of education and unemployment (classism), and more severe forms of SB, including presence of a shunt and higher lesion level (greater experience of ableism, "stereotyping, prejudice, discrimination, and social oppression toward people with disabilities")²⁴ would be associated with a greater number of barriers experienced, as well as greater interference of those barriers in the transition process.

2. Methods

2.1. Participants

Participants in this study were part of a larger national survey of young adults with SB. They were recruited nationally and completed study procedures in November and December 2019 through the support of the Spina Bifida Association (SBA), a national voluntary health organization, supporting education, advocacy, and research to improve the lives of individuals with SB. SBA advertised the survey study on their website and social media pages. Participants were eligible for inclusion if they: 1) had SB, 2) were between 18 and 30 years old, 3) were able to read and write in English, and 4) were able to answer survey questions independently without assistance from others (to promote privacy and honesty and to exclude lower functioning young adults with SB).

2.2. Procedure

This study was approved by the university's Institutional Review Board. Participants completed a digital waiver of documented consent before participating. Specifically, interested participants were provided a link to a detailed digital version of the study consent form. They agreed

to participate in the study by checking a “yes” box; participants were only able to continue to the survey if they completed this section. Participants then anonymously completed the surveys. To maintain the anonymity of their responses, participants were then provided with a separate link to initiate a different survey, in which they provided an email address to receive compensation. Compensation included a \$10 Amazon e-gift card.

2.3. Measures

Self-report questionnaires were administered via Qualtrics, a secure online survey platform licensed and administered by Loyola University Chicago.

2.3.1. Demographics and medical characteristics

Participants provided the following information: age, gender (male/female/other; female gender representing experience of sexism), race/ethnicity (White, African American/Black, Hispanic/Latine, Asian, Other; minoritized races representing experience of racism), education status (dichotomized into college educated vs. not college educated; with lower education representing experiences of classism), employment status (employed and student vs. unemployed, on disability for work, or volunteer; with unemployed, on disability, or volunteer representing experiences of classism) and SB characteristics, including type of SB, shunt status, shunt revision history, and lesion level (with more severe forms of SB representing greater exposure to discrimination on the basis of ableism).

2.3.2. Perceived transition status

Perceived transition status was assessed with two self-report questions. First, participants indicated whether they had transitioned to adult healthcare (yes/no). Second, participants reported on whether or not they had returned to a pediatric provider since transitioning by responding to the following question: “After you transitioned to adult health care services, have you ever needed to go back to see any type of pediatric doctor?” (yes/no). Only participants who reported that they had transitioned to adult healthcare answered the question regarding returning to a pediatric provider after transitioning.

2.3.3. Barriers to adult health care transition questionnaire

The Barriers to Adult Health Care Transition Questionnaire is a 21-item self-report questionnaire that was designed for this study. Potential barriers are assessed for: 1) whether a barrier has ever occurred for the respondent, and 2) how much it would “get in the way” of transitioning to adult healthcare, regardless of whether or not the participant responded “yes” or “no” to the first part of the question (rated across a 4-point Likert-scale, i.e., “None” to “It would make it impossible”). The assessed barriers were derived from the transition literature^{25–30} and from expert input (i.e., single session focus group with interdisciplinary researchers involved in longitudinal research of youth with spina bifida and their families at Loyola University Chicago). The measure can be found in Appendix A. Both the frequency of experienced barriers ($\alpha = 0.957$) and the interference of barriers ($\alpha = 0.950$) demonstrated excellent internal consistency reliability in this sample.

2.4. Data analytic plan

To account for any potential non-normality in the data, Mann-Whitney *U*-tests were used to compare differences in mean number of barriers and interference of perceived barriers across several categorical demographic and medical variables. Pearson *r* correlations were used to examine the association between continuous demographic variables and proportion of barriers and interference scores.

Descriptive statistics were conducted to examine the frequencies of experienced barriers to transitioning to adult healthcare, as well as the degree to which these identified barriers impeded progress during the

transition process. A proportion of barriers score was computed by dividing the number of barriers endorsed with a “yes” by the total number of barrier items answered. An interference score was computed by computing the mean score of all completed interference items. To examine differences in mean rates of endorsement of barriers, paired sample *t*-tests were conducted in the following way: the item with the highest mean score was compared to the item with the next highest mean score. Subsequent *t*-tests were conducted in order of descending mean item scores, such that once a significant *p*-value was yielded, that item was used for comparison with items with lower mean scores.

3. Results

3.1. Sample characteristics

Four hundred and seventy participants completed consent for the survey. Following the removal of participants with incomplete (e.g., those who had completed less than 60% of the survey, $n = 121$, >85% of removed cases) or inaccurate data entry (e.g., didn’t answer what type of SB they had, $n = 7$; took the survey in less than 5 min, $n = 16$ [see Stiles-Shields et al.²¹ for complete list of exclusion details]), 326 participants were included in the current study. Table 1 displays the sample characteristics. There were complete data ($N = 326$) on all demographic

Table 1
Demographic and medical characteristics of survey participants.

Characteristic	N (%)
Age, M (SD; range)	23.44 (2.92; 18–30)
Sex	
Male	230 (70.6%)
Female	96 (29.4%)
Race/ethnicity	
African American	8 (2.5%)
Asian	1 (0.3%)
Caucasian	310 (95.1%)
Hispanic/Latine	7 (2.1%)
Highest level of education	
Some grade school	1 (0.3%)
Grade school	5 (1.5%)
Some high school	19 (5.8%)
High school	37 (11.3%)
Some college	133 (40.8%)
College	121 (37.1%)
Graduate or professional courses	10 (3.1%)
Employment status	
Employed, full time	120 (36.8%)
Employed, part time	37 (11.3%)
Disability from work	37 (11.3%)
Student	96 (29.4%)
Unemployed	34 (10.4%)
Volunteer	2 (0.6%)
SB Type	
Myelomeningocele	173 (53.1%)
Meningocele	67 (20.6%)
Lipomeningocele	57 (17.5%)
Lipomyelomeningocele	14 (4.3%)
Lipoma	15 (4.6%)
Shunt present	213 (65.3%)
With revision history	164 (50.3%)
Lesion Level	
Sacral	100 (30.7%)
Lumbar	196 (60.1%)
Thoracic	30 (9.2%)
Perceived Transition Status	
Yes, transitioned to adult healthcare	249 (76.4%)
Returned to pediatric provider* ($n = 249$)	
Yes, needed to return to a pediatric provider	114 (45.8%)
No, did not need to return to a pediatric provider	132 (53.0%)
Missing	3 (1.2%)

M: mean; SD: standard deviation; SB: spina bifida.

*Participants only completed this question if they endorsed that they had transitioned to adult healthcare.

Table 2Frequencies of responses to the barriers to transition questionnaire for individuals who have not transitioned ($n = 77$).

Barrier	Is/Was This True for You?		How Much Would This Get in the Way of You Transitioning to Adult Health Care?			
	Yes	No	None	A Little Bit	A Lot	It would Make it Impossible
My pediatric doctor said s/he does not want me to change to adult doctors yet	76.6% (59)	23.4% (18)	10.4% (8)	35.1% (27)	48.1% (37)	6.5% (5)
No one has talked to me about how to transition to adult health care providers	61.0% (47)	39.0% (30)	11.7% (9)	37.7% (29)	41.6% (32)	9.1% (7)
Adult providers do not know enough about Spina Bifida	64.9% (50)	35.1% (27)	7.8% (6)	44.2% (34)	42.9% (33)	5.2% (4)
I can't find adult health care providers near my house	63.6% (49)	36.4% (28)	6.5% (5)	42.9% (33)	41.6% (32)	9.1% (7)
I don't know how to find adult health care providers	64.5% (49)	35.5% (27)	5.2% (4)	40.3% (31)	42.9% (33)	11.7% (9)
I don't know what kind of health care I need or the types of doctors I need to see	63.6% (49)	36.4% (28)	6.5% (5)	48.1% (37)	40.3% (31)	5.2% (4)
My parent(s) don't want me to make medical decisions without his/her/their input and are worried that adult providers won't include him/her/them in these important decisions	68.8% (53)	31.2% (24)	7.8% (6)	35.1% (27)	48.1% (37)	9.1% (7)
I don't want to stop seeing my pediatric providers because I like them so much	68.8% (53)	31.2% (24)	6.6% (5)	38.2% (29)	44.7% (34)	10.5% (8)
I don't like going to a hospital for adults	49.4% (38)	50.6% (39)	7.8% (6)	41.6% (32)	42.9% (33)	7.8% (6)
I don't know what my insurance covers	58.4% (45)	41.6% (32)	10.4% (8)	44.2% (34)	37.7% (29)	7.8% (6)
A health crisis came up so I kept being treated by my pediatric providers	58.4% (45)	41.6% (32)	9.2% (7)	50.0% (38)	35.5% (27)	5.3% (4)
I don't know how to make an appointment with someone new	66.2% (51)	33.8% (26)	10.4% (8)	44.2% (34)	40.3% (31)	5.2% (4)
I had a bad experience with an adult doctor and don't want to try another	51.9% (40)	48.1% (37)	9.1% (7)	42.9% (33)	42.9% (33)	5.2% (4)
I am no longer on my parents' insurance	57.1% (44)	42.9% (33)	10.4% (8)	46.8% (36)	37.7% (29)	5.2% (4)
My insurance doesn't cover the care I need and I can't afford to pay out of my own pocket	61.0% (47)	37.7% (29)	10.4% (8)	42.9% (33)	40.3% (31)	6.5% (5)
I don't think I need to transition to an adult provider	67.5% (52)	32.5% (25)	11.7% (9)	37.7% (29)	46.8% (36)	3.9% (3)
I only know how to go to the ER/urgent care when I need to see a doctor	64.9% (50)	35.1% (27)	13.0% (10)	35.1% (27)	45.5% (35)	6.5% (5)
My doctors tried to make me transition to adult health care provider but I do not feel ready	59.7% (46)	40.3% (31)	10.7% (8)	40.0% (30)	45.3% (34)	4.0% (3)
It makes me feel worried to think of not seeing my pediatric providers anymore because they feel like family	64.9% (50)	35.1% (27)	6.5% (5)	54.5% (42)	33.8% (26)	5.2% (4)
I have too many other things going on in my life (for example: a new living situation or problems with my family) to worry about changing to adult health care providers	66.2% (51)	33.8% (26)	5.3% (4)	46.1% (35)	38.2% (29)	10.5% (8)
My family does not want to transition to adult health care because our cultural beliefs match best with pediatric care where the whole family is involved	59.7% (46)	40.3% (31)	6.5% (5)	49.4% (38)	33.8% (26)	10.4% (8)

and background variables, as well as transition status. Across the sample of 326 participants, there were 8 missing data points for the variable of experienced barriers, and 16 missing data points for the degree of barrier interference variable; thus, these participants were excluded from analyses including those variables. The majority of the sample was male (70.6%) and White (95.1%). Participants most often had myelomeningocele (the most severe type of SB; 53.1%), a shunt (65.3%), and a lumbar lesion level (60.1%). The mean age of participants was 23.44 years ($SD = 2.93$; range: 18–30).

3.2. Transition status

Of the 326 participants, 76.4% ($n = 249$) endorsed that they had transitioned to adult healthcare. Of these 249 participants, 45.8% reported that after transitioning to adult healthcare, they needed to return to a pediatric provider at some point.

3.3. Barriers to transition

Of the full sample of transitioned and not transitioned individuals, approximately one third ($n = 106$, 32.5%) endorsed all 21 barriers as relevant to them. Of these participants, only 21.6% ($n = 23$) had not

transitioned to adult healthcare. Alternatively, only 4.6% ($n = 15$) reported that they experienced none of the 21 barriers. Of these participants, most (86.67%, $n = 13$) had transitioned to adult healthcare. Subsequent results will be separated by transition status (transitioned vs. not transitioned groups).

Table 2 displays item-level descriptive information for the 21 barriers on the questionnaire among all participants who self-reported not transitioning ($n = 77$). Among participants who had not yet transitioned to adult healthcare, they endorsed experiencing, on average, approximately 13 barriers to transitioning from pediatric to adult healthcare ($SD = 7.10$, range: 0–21). The endorsement rate of specific barriers ranged from 76.6% ($n = 59$; “My pediatric doctor said s/he does not want me to change to adult doctors yet”) to 49.4% ($n = 38$; “I don't like going to a hospital for adults”). The most endorsed barrier did not statistically differ in mean proportion from the next 5 highest rated barriers. The top-rated barriers involved issues related to provider resistance to transition, parent hesitancy, affinity for their current pediatric providers, not knowing how to make appointments, not seeing a need to transition, and being busy.

Table 3 displays item-level descriptive information for the 21 barriers on the questionnaire among all participants who reported that they had transitioned from pediatric to adult healthcare ($n = 211$). Among

Table 3
Frequencies of responses to the barriers to transition questionnaire for individuals who have transitioned (*n* = 249).

Barrier	Is/Was This True for You?		How Much Would This Get in the Way of You Transitioning to Adult Health Care?			
	Yes	No	None	A Little Bit	A Lot	It would Make it Impossible
My pediatric doctor said s/he does not want me to change to adult doctors yet	61.0% (152)	39.0% (97)	14.5% (36)	34.1% (85)	49.0% (122)	2.4% (6)
No one has talked to me about how to transition to adult health care providers	65.5% (163)	34.5% (86)	12.9% (32)	45.0% (112)	36.5% (91)	5.6% (14)
Adult providers do not know enough about Spina Bifida	64.5% (160)	35.5% (88)	12.9% (32)	39.8% (99)	42.6% (106)	4.8% (12)
I can't find adult health care providers near my house	61.0% (152)	39.0% (97)	13.7% (34)	42.7% (106)	38.7% (96)	4.8% (12)
I don't know how to find adult health care providers	65.1% (162)	34.9% (87)	13.7% (34)	36.1% (90)	45.4% (113)	4.8% (12)
I don't know what kind of health care I need or the types of doctors I need to see	62.5% (155)	37.5% (93)	11.7% (29)	43.1% (107)	41.9% (104)	3.2% (8)
My parent(s) don't want me to make medical decisions without his/her/their input and are worried that adult providers won't include him/her/them in these important decisions	70.7% (176)	29.3% (73)	12.9% (32)	40.2% (100)	41.0% (102)	6.0% (15)
I don't want to stop seeing my pediatric providers because I like them so much	68.3% (170)	31.7% (79)	14.9% (37)	41.4% (103)	40.2% (100)	3.6% (9)
I don't like going to a hospital for adults	60.6% (151)	39.4% (98)	18.1% (45)	36.5% (91)	40.6% (101)	4.8% (12)
I don't know what my insurance covers	68.7% (171)	31.3% (78)	13.7% (34)	37.1% (92)	45.6% (113)	3.6% (9)
A health crisis came up so I kept being treated by my pediatric providers	62.7% (156)	37.3% (93)	15.7% (39)	35.5% (88)	44.8% (111)	4.0% (10)
I don't know how to make an appointment with someone new	67.7% (168)	32.3% (80)	14.5% (36)	37.8% (94)	44.2% (110)	3.6% (9)
I had a bad experience with an adult doctor and don't want to try another	57.4% (143)	42.6% (106)	17.7% (44)	39.8% (99)	39.8% (99)	2.8% (7)
I am no longer on my parents' insurance	64.3% (160)	35.7% (89)	18.5% (46)	35.3% (88)	41.8% (104)	4.4% (11)
My insurance doesn't cover the care I need and I can't afford to pay out of my own pocket	65.9% (164)	34.1% (85)	12.0% (30)	40.2% (100)	42.6% (106)	5.2% (13)
I don't think I need to transition to an adult provider	60.6% (151)	39.4% (98)	14.9% (37)	42.3% (105)	39.9% (99)	2.8% (7)
I only know how to go to the ER/urgent care when I need to see a doctor	68.7% (171)	31.3% (78)	12.1% (30)	42.3% (105)	41.9% (104)	3.6% (9)
My doctors tried to make me transition to adult health care provider but I do not feel ready	59.8% (147)	40.2% (99)	14.5% (36)	43.1% (107)	39.5% (98)	2.8% (7)
It makes me feel worried to think of not seeing my pediatric providers anymore because they feel like family	67.1% (167)	32.9% (82)	17.8% (44)	38.5% (95)	40.1% (99)	3.6% (9)
I have too many other things going on in my life (for example: a new living situation or problems with my family) to worry about changing to adult health care providers	71.1% (177)	28.9% (72)	10.9% (27)	47.4% (117)	38.5% (95)	3.2% (8)
My family does not want to transition to adult health care because our cultural beliefs match best with pediatric care where the whole family is involved	60.2% (150)	39.8% (99)	15.7% (39)	43.0% (107)	37.8% (94)	3.6% (9)

participants who reported that they had transitioned to adult healthcare, they endorsed experiencing, on average, approximately 13 barriers to transitioning from pediatric to adult healthcare (*SD* = 7.49, range: 0–21). The endorsement rate of specific barriers ranged from 71.1% (*n* = 177; “I have too many other things going on in my life to worry about changing to adult health care providers”) to 57.4% (*n* = 143; “I had a bad experience with an adult doctor and don’t want to try another”). The most endorsed barrier did not statistically differ in mean proportion from the next 8 highest rated barriers. The top-rated barriers involved issues related to being busy, parent hesitancy, lack of knowledge or skills (e.g., how to see a doctor outside of ER, how to make an appointment), lack of information about insurance, affinity for their current pediatric providers, financial limitations, and lack of conversation around transition.

Participants also reported varying degrees to which these barriers interfered with the transition process, with a mean rating of 2.47 (*SD* = 0.51, range: 1 – 4) among those that had not yet transitioned and a mean rating of 2.35 (*SD* = 0.55, range: 1 – 4) among those that had transitioned. Nearly half (48% in the non-transitioned group and 44.87% in the transitioned group) of barriers were rated as interfering either “A lot” or “It would make it impossible” (i.e., scores of 3 or 4). Neither the mean interference ratings nor the proportion of barriers rated as highly

interfering statistically differed by transition status (mean rating: *F*(324) = 0.370, *p* = .54; proportion rating highly interfering *F*(324) = 0.18, *p* = .67).

3.4. Relationship of barriers to transition, demographic, and medical variables

Table 4 displays differences in 1) the proportion of barriers experienced and 2) the mean interference scores, according to categorical variables, for the non-transitioned group. The proportion of barriers varied significantly by SB Type. Individuals with myelomeningocele (*n* = 32) experienced significantly more barriers to the transition to adult healthcare than did individuals with other types of SB (*n* = 45) (*U* = 441.5, *z* = −2.93, *p* = .003). Additionally, gender differences trended towards significant. Males tended to experience a significantly higher proportion of barriers than did females (*U* = 437.5, *z* = −1.92, *p* = .05). There were no significant differences in proportion of barriers experienced based on race/ethnicity, education, employment, shunt status, or lesion level.

The mean level of interference of these barriers varied significantly by experience of systemic racism. Unexpectedly, interference scores were significantly lower for individuals who had experienced systemic

racism (i.e., non-White individuals) ($U = 66.5$; $z = -2.79$; $p = .005$). The only continuous variable examined was age, which was not correlated with the proportion of barriers experienced ($r = .08$, $p = .50$) or interference ratings ($r = .04$, $p = .76$).

Table 5 displays differences in 1) the proportion of barriers experienced and 2) the mean interference scores, according to categorical variables, for the transitioned group. The proportion of barriers varied significantly by education status, employment status, and lesion level. In terms of education, those who had received a college education or higher reported more barriers than did those who did not attend or complete college ($U = 5916.0$, $z = 2.49$, $p = .01$). Employment status was also related to the experience of more barriers, such that those who were employed or a student (vs. unemployed, on disability for work, or volunteer) reported experiencing a greater proportion of barriers than those who were not employed ($U = 6805.0$, $z = 3.19$, $p = .001$). There were also significant differences in the proportion of barriers by lesion level ($H = 7.27$, $p = .03$). Individuals with a sacral lesion level endorsed a higher proportion of barriers than those with a lumbar level ($z = 2.63$, $p = .03$). Other differences between lesion level were non-significant. There were no significant differences in proportion of barriers experienced based on gender, race, SB type, or shunt status.

The mean level of interference of these barriers varied significantly by SB type and shunt status. First, the mean level of interference of barriers was higher for individuals with myelomeningocele versus other types of SB ($U = 8760.0$, $z = 2.04$, $p = .04$). Additionally, the mean level of interference of barriers was higher among individuals who reported having a shunt than among those who reported not having a shunt ($U = 5079.00$, $z = 4.14$, $p < .001$). The only continuous variable examined was age, which was not correlated with the proportion of barriers experienced ($r = -.11$, $p = .09$) or interference ratings ($r = -.05$, $p = .44$). There were no significant differences in mean level of interference of barriers based on gender, race/ethnicity, education, employment, or lesion level.

4. Discussion

This national survey study examined perceived barriers to adult healthcare transition among a large sample of young adults with spina bifida. Results uncovered a high rate of endorsement of barriers, with an average of 13 distinct barriers for both individuals who had not yet transitioned and for those who reported that they had transitioned. A small percentage of this full sample (<5%) of both transitioned and non-transitioned individuals reported experiencing no barriers at all. Of this group, the majority reported that they had transitioned. Thus, regardless of transition status and success, most of the young adults with SB seemed to experience many barriers to the transition process. These barriers were often perceived to be substantially interfering with the transition process. We can be encouraged by the fact that even when individuals experience barriers to transitioning, they seem to overcome these barriers and can still successfully transition, as evidenced by the large number of individuals who reported that they had transitioned in this sample. We can also be hopeful about the pattern of differences between the more frequently perceived barriers and less frequently perceived barriers. As the more frequently perceived barriers were largely based on beliefs, biases, and lack of information, they may be more amenable to intervention, education, and support, than less frequently experienced barriers, which would require interventions that repair experiential learning (e.g., bad experiences with providers).

Understanding the types of barriers individuals with SB experience will provide support for the approaches of currently existing transition readiness and planning programs and allow for the development and refinement of future programs tailored to the needs of youth with SB. Programs can then proactively reduce the presence or impact of these barriers. For example, the barrier with one of the highest ratings among the non-transitioned group was “My parent(s) don’t want me to make medical decisions without his/her/their input and are worried that adult

providers won’t include him/her/them in these important decisions.” A transition program that would proactively target such a barrier would benefit from addressing concerns regarding continued caregiver involvement as the young adult transitions to adult care and would work collaboratively with the family system to create a plan for modified parent involvement. Similarly, transition programs could aim to target skill and knowledge areas, such as searching for adult providers, speaking to insurance companies, and making appointments, to combat barriers related to deficits in these domains. Current SB-specific transition programs (i.e., Movin’ On Up¹⁵ and the Spina Bifida Transition Project)¹⁶ have nursing specialists provide education, engage the family system, and participate in care coordination to bridge gaps in care. These findings can support the need for and expansion of these programs to be available to more youth with SB.

These findings also provide useful information regarding who is more likely to experience barriers to transition and who finds these barriers more interfering. Answering these “who” questions can help identify young adults with SB who are currently most in need of transition support. Characteristics that were associated with higher rates of perceived barriers included: having a higher education level, being employed or a student, having Myelomeningocele (vs. other types of SB), having a sacral (vs. lumbar) lesion level (i.e., lesion level that is associated with lower severity than lumbar). Characteristics that were associated with greater interference of these barriers included White race, having Myelomeningocele (vs. other types of SB), and presence of a shunt.

While some of these findings are consistent with our hypotheses (e.g., presence of a shunt indicating greater condition severity and a proxy for possible increased experience of ableism), other findings were surprising or seemingly counterintuitive. In terms of factors associated with higher rates of perceived barriers, we did not expect that being employed or a student would be associated with more perceived barriers than not being employed (i.e., unemployed, on disability for work, or volunteer). However, it is possible that lack of employment and fewer work/school-related obligations could make practical matters associated with transitioning to adult healthcare, such as scheduling and attending medical appointments, easier. Indeed, there is evidence to suggest that students with SB (as opposed to those with other employment statuses) more frequently need to return to pediatric care,²¹ suggesting possible difficulty making a complete transition to adult healthcare. It is also possible that adults with more severe forms of SB, who are also less likely to be employed full-time, have received more assistance from providers and caregivers to facilitate the transition to adult healthcare. Thus, they may not experience as many barriers as individuals with less severe forms of SB who are granted more autonomy and less assistance. In other words, it is possible that less severe forms of SB “slip through the cracks,” so to speak, in terms of receiving support in the transition process. As such, individuals with lower lesion levels, which are generally associated with lesser SB severity, may actually experience more barriers to transitioning to adult healthcare than do individuals with more severe SB who have been followed more closely by a medical team.

Alternatively, it is possible that the perception of barriers is related to a diminished ability to assume autonomy and tackle the medical responsibility inherent in adult healthcare. Females are more than 2.5 times more likely to assume medical responsibility earlier in development than males³¹ and, consistent with this finding, the current study found a trend towards statistical significance ($p = .05$) for males in the non-transitioned group to experience more barriers to transition. This gender disparity may be a reflection of delays in medical responsibility among males, leading them to struggle with the many practical and emotional hurdles of transitioning.

Should future studies replicate these findings regarding risks for experiencing barriers to transition, it is possible that a pattern may emerge in which some youth with SB are neglected and left behind in transition planning, discussions, and preparation. Transition programs

Table 4Relationship of barriers to transition, demographic and medical variables among individuals who have not transitioned to adult healthcare ($n = 77$).

Categorical Variables, n	Proportion of Barriers					Interference of Perceived Barriers				
	<i>Mdn</i>	<i>M</i> (<i>SD</i>),	Mann Whitney <i>U</i> Test	<i>z</i>	<i>p</i> -value	<i>Mdn</i>	<i>M</i> (<i>SD</i>),	Mann Whitney <i>U</i> Test	<i>z</i>	<i>p</i> -value
Sex										
Male, $n = 55$.67	.67 (.32)	437.5	-1.92	.05	2.42	2.49 (.51)	556.5	-.55	.58
Female, $n = 22$.45	.50 (.35)				2.41	2.42 (.52)			
Race										
White, $n = 71$.67	.63 (.35)	191.5	-.42	.68	2.48	2.51 (.51)	66.5	-2.79	.005
Non-white, $n = 6$.60	.63 (.16)				1.95	2.01 (.23)			
Education										
College or higher, $n = 63$.67	.64 (.35)	494.5	.72	.47	2.43	2.47 (.55)	429.0	-.16	.87
Did not attend or complete college, $n = 14$.60	.59 (.32)				2.48	2.44 (.29)			
Employed										
Employed or student, $n = 59$.67	.64 (.33)	564.5	.41	.68	2.43	2.46 (.52)	489.0	-.51	.61
Not employed, $n = 18$.62	.60 (.37)				2.58	2.49 (.51)			
SB Type										
Myelomeningocele, $n = 32$.95	.76 (.30)	441.5	-2.93	.003	2.57	2.54 (.58)	608.5	-1.15	.25
Other ^a , $n = 45$.57	.53 (.34)				2.43	2.42 (.46)			
Shunt										
Yes, $n = 61$.71	.66 (.35)	352.0	-1.74	.08	2.48	2.50 (.55)	398.0	-1.13	.26
No, $n = 16$.57	.51 (.26)				2.43	2.33 (.31)			
Lesion Level ^b										
Sacral, $n = 30$.71	.69 (.30)	1.09		.58	2.36	2.40 (.50)	1.92		.38
Lumbar, $n = 39$.57	.57 (.36)				2.62	2.54 (.52)			
Thoracic, $n = 8$.81	.67 (.38)				2.29	2.40 (.51)			

Note. *Mdn* = median; *M* = mean; *SD* = standard deviation; SB = spina bifida.

^aOther types of SB include meningocele, lipomeningocele, lipomyelomeningocele, or lipoma.

^bFor lesion level, the Kruskal-Wallis Test was used and reported here to compare distributions across $k = 3$ levels of lesion level.

^cPairwise comparisons revealed that sacral lesion level was associated with significantly greater proportion of barriers than lumbar lesion level, $p = .02$.

Table 5Relationship of barriers to transition, demographic and medical variables among individuals who have transitioned to adult healthcare ($n = 249$).

Categorical Variables, n	Proportion of Barriers					Interference of Perceived Barriers				
	<i>Mdn</i>	<i>M</i> (<i>SD</i>),	Mann Whitney <i>U</i> Test	<i>z</i>	<i>P</i> -value	<i>Mdn</i>	<i>M</i> (<i>SD</i>)	Mann Whitney <i>U</i> Test	<i>z</i>	<i>P</i> -value
Sex										
Male, $n = 175$.76	.67 (.34)	5692.0	-1.54	.12	2.43	2.37 (.54)	6193.0	-.54	.59
Female, $n = 74$.67	.59 (.37)				2.48	2.31 (.60)			
Race										
White, $n = 239$.76	.65 (.36)	1143.0	-.28	.81	2.48	2.36 (.56)	932.5	-1.18	.24
Non-white, $n = 10$.62	.62 (.32)				2.29	2.23 (.36)			
Education										
College or higher, $n = 201$.81	.67 (.36)	5916.0	2.49	.01	2.40	2.37 (.54)	4932.5	.24	.81
Did not attend or complete college, $n = 48$.62	.56 (.32)				2.50	2.28 (.60)			
Employed										
Employed or student, $n = 194$.81	.68 (.35)	6805.0	3.19	.001	2.38	2.34 (.51)	4732.0	-1.28	.20
Not employed, $n = 55$.62	.52 (.36)				2.52	2.39 (.69)			
SB Type										
Myelomeningocele, $n = 141$.71	.62 (.36)	8334.5	1.31	.19	2.38	2.30 (.57)	8760.0	2.04	.04
Other ^a , $n = 108$.85	.67 (.35)				2.52	2.41 (.53)			
Shunt										
Yes, $n = 152$.74	.64 (.36)	7411.0	.07	.94	2.52	2.46 (.55)	5079.00	4.14	< .001
No, $n = 97$.76	.65 (.36)				2.33	2.18 (.50)			
Lesion Level ^b										
Sacral, $n = 70$.90	.73 (.32)	7.27		.03	2.38	2.34 (.58)	1.46		.48
Lumbar, $n = 157$.67	.61 (.36)				2.48	2.34 (.55)			
Thoracic, $n = 22$.52	.57 (.40)				2.52	2.48 (.51)			

Note. *Mdn* = median; *M* = mean; *SD* = standard deviation; SB = spina bifida.

^aOther types of SB include meningocele, lipomeningocele, lipomyelomeningocele, or lipoma.

^bFor lesion level, the Kruskal-Wallis Test was used and reported here to compare distributions across $k = 3$ levels of lesion level.

^cPairwise comparisons revealed that sacral lesion level was associated with significantly greater proportion of barriers than lumbar lesion level, $p = .02$.

should consider a possible bell curve shape to individuals who are most in need of supplemental transition support. Perhaps, young adults with SB who have more medically complex forms of SB that have required frequent medical care or who have for various reasons remained more

dependent on caregivers, do not face as many barriers to transition. These individuals may either be “on the radar” of caregivers and providers in a more overt way or may be unaware of the challenges inherent in transition to adult healthcare since others have been managing their

healthcare decisions for them. Alternatively, we might expect that young adults with SB who are at the farthest end of the bell curve in terms of high functioning and who have fewer medical needs may also face fewer barriers to transition. However, individuals in the middle of the bell curve who may struggle with medical responsibility (males with sacral lesion levels) and face the cognitive, physical, and chronic health complications of SB may struggle with the challenges of transition. It may be that these individuals are overlooked by our medical systems, providers, and caregivers and would benefit from additional transition support to bolster their self-management skills, and thereby enhance their transition readiness. Transition programs such as Movin' On Up¹⁵ and the Spina Bifida Transition Project¹⁶ could prevent these individuals from falling through the cracks of the system by intervening early and tailoring the level of support based on patient need and presence of risk factors. For example, Movin' On Up proposes a timeline where healthcare transition planning is initiated at age 10 years old.¹⁵

Returning to Holmbeck's model of transition,¹³ self-management is a likely starting point and a precursor to the transition to adult healthcare. Specifically, the successful transfer of medical responsibility from caregiver to child may be linked to the successful transition to adult healthcare via transition readiness. There are many potential predictors of self-management, including demographic, condition-specific, individual-, family-, and peer related. Caregiver scaffolding is one such potential predictor and refers to the process by which a caregiver helps their child in acquiring skills and moving towards independence by gradually removing support as the child becomes more responsible.³² In light of the present findings that males, who are less likely to take on medical responsibility than are females at a young age,³¹ also report more barriers, we may consider intervening with caregiver scaffolding to augment support for these young adults as they gain more responsibility through development. This recommendation is aligned with the goals of programs such as Movin' On Up which incorporates caregiver education.¹⁵

These findings should be interpreted in light of several limitations. Transition status was determined with two single questions: asking the respondent whether they had transitioned to adult healthcare and whether they had returned to a pediatric provider since transitioning. Transition to adult healthcare is much more complex than these questions. Multiple informants and multiple sources of data would be helpful in representing this complexity. Data was collected prior to the COVID-19 pandemic; thus, COVID-related impacts on transition barriers were not assessed and are likely important factors to consider in the transition process. The sample demographics were also skewed with regards to gender and race, with a disproportionate number of male and White participants and minimal representation of underrepresented groups (female gender, non-White race, not employed). SB has high prevalence rates in Latino/a/e populations³³; thus, this work should be replicated in a more representative sample. Our gender identity question was limited (male, female, other). More inclusive gender assessments will allow for better understanding of how gender identity may impact barriers. Additional information including co-occurring chronic conditions and geographic access to care would provide helpful information regarding barriers. The Barriers to Transition questionnaire had limitations as well, including the use of double-barreled questions (e.g., "My parent(s) don't want me to make medical decision without his/her/their input and are worried that adult providers won't include him/her/them in these important decisions.") Future research could improve on the list of barriers experienced by taking a human-centered design approach³⁴ and partnering with individuals with SB in the creation of the measure. The barriers measure was administered via an online survey, and participants were not able to ask questions or expand on specific items. Our list of barriers, though developed based on the transition literature and expert input, is not exhaustive and may not be capturing barriers experienced by various intersecting domains of identity (race, gender, socioeconomic status). Additionally, this sample consisted of participants who volunteered to take an online survey (and excluded

individuals who could not read or fill out the survey independently), and therefore the sample is likely skewed in terms of being higher functioning and perhaps even experiencing fewer barriers than the larger population with SB.

Future research should look at barriers in relation to more comprehensive measures of transition, and further develop the barriers questionnaire to examine the factor structure and gain patient input. As part of NICHD's strategic plan to improve the transition to adulthood, there is a call to develop measures that can examine successful transition at the individual, provider, or system level.¹² Thus, it is critical to examine barriers at each of these levels of transition, and from informants at each of these levels. Barriers should also be examined in relation to earlier progress toward self-management, as it is a proposed predictor of transition readiness.¹⁸ Additionally, future research should expand on the study of how intersectionality – the intersection of multiple facets of identity (e.g., race, ethnicity, gender, socioeconomic status, disability status) – impacts barriers to transition. The current findings provide a critical first step in centering the voice of young adults with SB and understanding their perspective on barriers, the potential interference of these barriers, and who is most likely to experience these barriers.

Ethical statement

Institutional Review Board approval was obtained prior to data collection for this study.

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CRediT authorship contribution statement

Grayson N. Holmbeck: Conceptualization, Data curation, Funding acquisition, Methodology, Writing – review & editing. **Raynie S. Leard:** Writing – original draft, Writing – review & editing. **Colleen Stiles-Shields:** Conceptualization, Data curation, Formal analysis, Writing – review & editing. **Tessa K. Kritikos:** Conceptualization, Data curation, Formal analysis, Project administration, Writing – original draft, Writing – review & editing.

Declaration of Competing Interest

We have no conflicts of interests to disclose.

Data availability

The data that has been used is confidential.

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Appendix A. Supporting information

Supplementary data associated with this article can be found in the

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