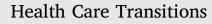
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# Gynecological care needs for young women with spina bifida

Ellen Fremion<sup>a,\*</sup>, Rachel Madey<sup>b</sup>, Elizabeth Harper<sup>c</sup>, Kristen A. Staggers<sup>d</sup>, K. Jordan Kemere<sup>e</sup>, John Berens<sup>f</sup>, Tara Harris<sup>g</sup>

<sup>a</sup> Transition Medicine Clinic, Department of Medicine, Baylor College of Medicine, One Baylor Plaza MS902, Houston, TX 77030, USA

<sup>b</sup> Internal Medicine and Pediatrics Residency, Baylor College of Medicine, One Baylor Plaza MS620, Houston, TX 77030, USA

<sup>c</sup> Surgery Residency, Baylor College of Medicine, One Baylor Plaza MS390, Houston, TX 77030, USA

<sup>d</sup> Institute for Clinical and Translational Research, Baylor College of Medicine, One Baylor Plaza MS450, Houston, TX 77030, USA

e Transition Medicine Clinic, Department of Medicine, Baylor College of Medicine, One Baylor Plaza MS902, Houston, TX 77030, USA

<sup>f</sup> Transition Medicine Clinic, Department of Medicine, Baylor College of Medicine, One Baylor Plaza MS902, Houston, TX 77030, USA

<sup>8</sup> Department of Obstetrics and Gynecology, Baylor College of Medicine, One Baylor Plaza MS902, Houston, TX 77030, USA

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# 1. Introduction

Women with spina bifida (SB) have unique and often under-met reproductive health care needs.<sup>1</sup> Known gynecological concerns include pelvic organ prolapse, precocious puberty, uterine/vaginal anatomical anomalies, and high-risk pregnancies.<sup>1–4</sup> Clinicians must also consider that women with SB may have unique needs regarding sexual function and contraception options, adaptive considerations for menstrual self-management, and nuanced questions about sexuality and reproduction.<sup>1,5,6</sup> Moreover, individuals with disabilities are at higher risk for sexual dysfunction due to both medical and psychological etiologies and sexual abuse.<sup>7</sup> However, women with SB and those with other disabilities often face barriers to adequate reproductive care such as difficulty accessing accommodating facilities for exams, inadequate reproductive education, provider biases, lack of provider knowledge about their reproductive care needs, and lack of education and preparation for pregnancy and healthy intimate relationships.<sup>5,8–10</sup> Further study of reproductive healthcare disparities, specifically deficits in meeting national guideline based preventive measures can better inform the development of interventions aimed at closing these gaps in reproductive care.

The Women's Health section in the Spina Bifida Association's 2018 Guidelines for the Care of People with SB offers guidance on reproductive health management, but acknowledges evidence limitations in reproductive education, sexual function, and menses/menopause care.<sup>11</sup> For women with SB aged 18 and above, these guidelines encourage the following routine preventive gynecological care including age-appropriate cervical cancer screening and mammograms, sexual health care and education. In addition, the United States Preventative Services Task Force (USPSTF) gives age-specific general reproductive health screenings for all women. The 2018 recommendations pertinent to women aged 18-40 include: screening for human immunodeficiency virus (HIV) beginning at age 15 and completing the human papillomavirus (HPV) vaccine series starting at age 11 per the Center for Disease Control guidelines. For women aged 12-29 years, routine cervical cancer screening is recommended every 3 years with cervical cytology alone. For women aged 30-65 years, screening is recommended every 3 years with cervical cytology alone, every 5 years for high-risk human papillomavirus (hrHPV) testing alone, or every 5 years with hrHPV testing in combination with cytology (cotesting).<sup>12</sup> These SB-specific and general guidelines offer recommendations that

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Abbreviations: SB, spina bifida; HIV, human immunodeficiency virus; HPV, human papillomavirus; hrHPV, high-risk human papillomavirus; USPSTF, United States Preventative Services Task Force; EHR, electronic healthcare record; IDD, intellectual and developmental disabilities

<sup>\*</sup> Corresponding author at: Transition Medicine Clinic, Department Internal Medicine, Baylor College of Medicine, One Baylor Plaza (BCM 902), Houston, TX 77030, USA.

E-mail addresses: Ellen.fremion@bcm.edu (E. Fremion), Rachel.Madey@bcm.edu (R. Madey), Elizabeth.Harper@bcm.edu (E. Harper),

kandrews@bcm.edu (K.A. Staggers), Kathryn.Kemere@bcm.edu (K.J. Kemere), John.Berens@bcm.edu (J. Berens), Tara.Harris@bcm.edu (T. Harris).

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should be routinely implemented in clinics caring for adolescent and adult women with SB.

This cross-sectional study sought to add to the limited body of knowledge about gynecological care needs of young women with SB transferring to adult care by (1) describing demographic and clinical characteristics, gynecological concerns, and exam findings in young adult women with SB establishing gynecological care and (2) evaluating the frequency at which they had received USPSTF recommended reproductive health screenings.<sup>13</sup> This study will inform future research areas and further development of SB gynecological care and transition to adult care guidelines.

# 2. Methods

The STROBE checklist was used to guide this cross-sectional study.<sup>14</sup> After receiving approval from the Baylor College of Medicine Institutional Review Board, investigators reviewed electronic healthcare record (EHR) records of women with SB who had established gynecological care in a single clinic between June 1, 2018 and May 31, 2020.<sup>15</sup>

# 2.1. Clinic setting

The Baylor Transition Medicine Clinic is a primary care medical home clinic for adults who have intellectual and developmental disabilities (IDD) including SB.<sup>15</sup> The clinic not only "transitions" patients graduating from the pediatric hospital system to the adult system, but then continues as the primary care medical home for these patients for the entire lifespan. The clinic also accepts adults with IDD who prefer to see a primary care provider experienced in IDD care. Women with IDD from this primary clinic are referred to a gynecologist imbedded in the clinic for well woman care (e.g. reproductive health screenings, education, and exams) and gynecological health management (menses management, reproductive health planning, and sexual function questions). The gynecologist has a specific interest in caring for women with IDD. To better accommodate this patient population's needs, the clinic provides longer visit times to counsel and educate patients, a wheelchair-accessible environment, and access to a larger women's hospital system for procedures and further gynecological subspecialty care if needed. The gynecologist routinely asks about menstruation patterns, sexual history, and reproductive health screenings during visits. If patients can give consent for pelvic examinations and cervical cancer screening, these exams are completed during the visit. If the patient is not able to complete the exam or give consent, the risks and benefits of a pelvic exam under anesthesia are discussed with the patient and her medical decision-makers and, if desired, the exams are scheduled at the women's hospital.

# 2.2. Population

Eligible patients were identified from EHR searches using the inclusion and exclusion criteria. Inclusion criteria were the diagnosis of SB or related spinal dysraphism (i.e. myelomeningocele or non-myelomeningocele lesions: lipomyelomeningocele or caudal regression/sacral agenesis) as listed on the EHR problem list, and having at least one visit with the gynecologist. Women with SB seen in the primary care clinic who had not established care with the clinic gynecologist were excluded in order to have the most complete data.

# 2.3. Measures

Demographic and clinical data were collected from visit notes and the problem list at the time of the first gynecology visit and entered in a standardized form in the institution's RedCap database.<sup>16,17</sup> The EHR problem list is standardly used by the clinic providers to update the patients' conditions and care plan. EHR records were also typically available from patients' previous pediatric visits in the affiliated children's hospital system. All RedCap entries were verified by an additional author.

Demographic variables collected were age at the time of establishing care, race/ethnicity, and primary insurance (private or public, i.e., Medicare or Medicaid). SB-specific clinical variables included: level of the SB lesion according to the Hoffer functional ambulation scale,<sup>18</sup> community ambulation status, and presence of a ventricular shunt, as these variables are often used describe SB condition severity.<sup>19,20</sup>

Gynecological care variables collected were the patient-reported reason for establishing care (per chief complaint in the EHR); gynecological history as documented by the gynecologist performing the interview: menstrual patterns, contraception management, age of menarche, number of previous pregnancies, history of reported sexual activity, history of reported sexually transmitted infections; and pelvic exam findings if the exam was performed at the first visit. Regarding menstrual patterns, *primary amenorrhea* was defined as the absence of menarche by age 15 and thereafter. *Secondary amenorrhea* was defined as the absence of menses for more than three months in girls or women who previously had regular menstrual cycles or six months in girls or women who had irregular menses. *Induced* was used to distinguish a menstrual pattern due to medical or device management. *Irregular menses* was defined as length of cycle  $\leq 21$  or  $\geq 35$  days, and *regular menses* was defined as frequency every 21–35 days.<sup>21</sup>

The included USPSTF-recommended screenings were having previously started the HPV vaccine series (at least one vaccine), having at least one previous HIV screening, and having had previous cervical cancer (high-risk HPV testing alone or cytology) for women over 21 at the time of the visit. These guideline measures were selected as they are recommended for all young adult women, and thus, our study population was expected to have received them.<sup>13</sup> If there was no documented history of receiving HPV vaccination, HIV lab test, or cervical cancer screening in a clinic visit or on a lab test in the EHR record, it was recorded as not completed.

# 2.4. Data analysis

Patient characteristics were summarized by median with minimum and maximum value, or frequency with percent. Independent logistic regression was used to test the associations between patient characteristics and reproductive health screening variables (i.e., completed HIV screening, at least one HPV vaccine, and cervical cancer screening for those aged 21 and above prior to the visit). Variables found to be significant were included in a multiple logistic regression. A significance level of 0.05 was used for all analyses.

# 3. Results

# 3.1. Patient characteristics and exam findings

Sixty women with SB established with the gynecology clinic between June 1, 2018 and May 31, 2020. The sample represents 68 % of all the women with SB established with the primary care clinic. Demographic and SB-related clinical characteristics are described in Table 1. The median age for establishing care was 24 (range 19–46). Gynecological history variables, including the reason for establishing with a gynecologist, are listed in Table 2. All patients were offered a pelvic exam as part of their first visit, and forty-four (73 %) women gave consent to undergo a pelvic examination, Table 3. Of the two women who had Mullerian abnormalities, one had sacral agenesis and Mayer-Rokitansky-Kuster-Hasuer syndrome, and the other had lumbar myelomeningocele and uterus didelphys with a bifid cervix.

# 3.2. USPSTF screening outcomes

The frequency of meeting USPSTF guidelines were as follows: only 23.3 % (n = 14) had a previous HIV screening, 43.3 % (n = 26) had

#### Table 1

Demographic and clinical characteristics.

Number of patients established	60	
Age of establishing care	24 years (range 19-46)	
Characteristic	N (%)	
Race/Ethnicity	8 (13.3)	
African American	19 (31.6)	
Caucasian	33 (55)	
Latina		
Primary insurance	18 (30)	
Private	42 (70)	
Public (Medicare/Medicaid)		
Spina Bifida Type	59 (98)	
Myelomeningocele	1 (2)	
Caudal Regression/Sacral Agenesis		
Level of SB lesion	24 (40)	
Thoracic/High lumbar	24 (40)	
Mid lumbar/Low lumbar	12 (20)	
Sacral		
Uses a wheelchair in the community	35 (58.3)	
Ventricular shunt present	45 (75)	

### Table 2

Gynecological history.

Characteristic	N (%)	
Reason for establishing care ( $N = 60$ )	31 (51.7)	
Well-woman visit	21 (35)	
Menstruation concerns	3 (5)	
Vaginal discharge	4 (6.7)	
Preconception counseling	1 (1.7)	
Obstetrical care	3 (5)	
Sexual function concerns	3 (5)	
Pelvic floor symptoms (e.g., pain or bulging)	14 (23.3)	
Other		
Age of menarche (N $=$ 55)	12 years	
	(range 8–17)	
Menstrual history (N = 59)	34 (57.6)	
Regular, spontaneous	2 (3.4)	
Regular, induced	2 (3.3)	
Primary amenorrhea	3 (5.1)	
Secondary amenorrhea, spontaneous	6 (10.2)	
Secondary amenorrhea, induced	11 (18.6)	
Irregular, spontaneous	1 (1.7)	
Irregular, induced		
Dysmenorrhea present? ( $N = 46$ )	32 (69.6)	
Not present	9 (19.6)	
Present, tolerable with or without mild	2 (4.3)	
intervention (NSAIDs, heating pads, etc.)	3 (6.5)	
Present, interferes with quality of life		
Present, unknown severity		
Contraceptive management ( $N = 60$ )	9 (15)	
Combined OCPs	1 (1.7)	
Progesterone only	1 (1.5)	
Medroxyprogesterone injection	3 (5.0)	
Hormonal intrauterine device	1 (1.7)	
Etonogestrel implant	6 (10)	
Male condoms	4 (6.7)	
Hysterectomy	36 (60)	
None		
Sexual activity history (N = 59)	15 (25.4)	
Current partner	6 (10.6)	
History of sexual activity	38 (64.4)	
Never sexually active		
Previous pregnancies (N = 60)	56 (93.3)	
0	3 (5)	
2	1 (1.7)	
3		
Positive history of a sexually transmitted	2 (9.1)	
infection?		

begun the HPV vaccine series, and 26.7 % (n = 16) of women aged 21 and above had previous cervical cancer screening. In independent regression analysis for HIV screening, only age at the time of establishing

Table 3Pelvic exam findings.

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Characteristics Number completing pelvic exam	<b>N (%)</b> N total = 44
Exam findings	19 (43.2)
Normal	8 (18.2)
Pelvic organ prolapse (at the hymen or beyond)	2 (4.5)
Mullerian abnormalities	1 (2.3)
Anorectal malformations	3 (6.8)
Labia hypertrophy	8 (18.2)
Elongated cervix	2 (4.5)
Skin irritation	5 (11.4)
Difficulty to palpate adnexa/uterus due to post- surgical changes	

care was associated with prior HIV screening (p = 0.021, Table 4). The odds of having HIV screening increased 3.97 times (95 % CI: 1.23, 12.86) for every 10-year increase in the age at which they established care. For HPV vaccination, the patient's age at the time of establishing care was the only factor associated with previously starting the HPV vaccine series (p = 0.005) with older age being associated with a lower chance of having started the HPV vaccine series (Table 5). For every 10-year increase in age, the odds of initiating the HPV vaccine series was 0.09 (95 % CI: 0.02, 0.49). Finally, both age and sexual activity history were significantly correlated with having had cervical cancer screening (p = 0.029 and p = 0.014, respectively, Table 6). However, in multiple logistic regression with age and sexual history as variables, only sexual history remained significant. The adjusted odds of having had cervical cancer screening were 6.81 times (95 % CI: 1.47, 31.64) higher for women with a positive sexual history.

# 4. Discussion

This study describes the characteristics and associations with completing USPTS age-based reproductive health screening recommendations of sixty women with SB who established care with a gynecologist affiliated with a medical home for adults with IDD. While the most common reason for establishing gynecological care was for a wellwoman visit (n = 31, 51.7 %), almost half of the women had other gynecological questions or concerns related to menstruation, reproductive counseling/care, and pelvic floor health. These gynecological care concerns highlight the importance of taking a complete gynecological history during preventive care visits for adolescent and young women with SB and referring for appropriate gynecological consultation.

# 4.1. Demographic characteristics

More than half of the women in this study were Latina/Hispanic (n = 33, 55 %), and the majority had public insurance (n = 42, 70 %). These findings are representative of the sociodemographic composition of the SB population nationally: the prevalence of babies born with SB to Latina/Hispanic mothers is higher than any other race/ ethnicity group (3.80 per 10,000 for Latinas/Hispanics vs. 3.09 per 1000 for Whites and 2.73 per 1000 for African Americans).<sup>22</sup> As with all women, cultural and family values and considerations should be included in sexual and reproductive health visits for this population. Additionally, in studies of adults with SB in the United States, 54.9–70.7 % had public insurance.<sup>23,24</sup> As insurance plays a significant role in determining access to care, it is important to discuss insurance planning, services covered, and in-network providers for preventive sexual health care as well as obstetrical or gynecological subspecialty care needed as women with SB transition to and continue in the adult health care setting.

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### Table 4

Independent logistic regressions for HIV screening prior to adult visit.

Characteristic Age established care (per 10-year increase)	N 60	Odds ratio	95 % Confidence Interval		p-value
			1.23	12.86	0.021
Race	60				0.959
African American	Reference	1.00			
White, non-Latina/Hispanic		0.80	0.12	5.59	0.822
Latina/Hispanic		0.96	0.16	5.74	0.964
Private insurance	60	0.56	0.14	2.33	0.428
Level of lesion	60				0.057
Thoracic/ high lumbar	Reference	1.00			
Mid/ low lumbar		0.54	0.11	2.58	0.443
Sacral		3.80	0.85	17.04	0.081
Community ambulatory	60	1.56	0.47	5.18	0.472
Current or previous sexual activity	59	3.28	0.95	11.33	0.060

# Table 5

Independent logistic regressions for at least starting HPV vaccine series.

Characteristic Age established care (per 10-year increase)	N 60	Odds ratio	95 % Confidence Interval		p-value
			0.02	0.49	0.005
Race	60				0.359
African American	Reference	1.00			
White, non-Latina/Hispanic		0.77	0.14	4.33	0.766
Latina/Hispanic		1.77	0.36	8.65	0.480
Private insurance	60	0.77	0.25	2.37	0.650
Level of lesion	60				0.198
Thoracic/ high lumbar	Reference	1.00			
Mid/ low lumbar		2.87	0.87	9.45	0.083
Sacral		2.43	0.58	10.19	0.225
Community ambulatory	60	2.44	0.85	7.00	0.097
Current or previous sexual activity	59	2.56	0.86	7.65	0.092

# Table 6

Independent logistic regressions for cervical cancer screening prior to adult visit if over 21 years old.

Characteristic	N 43	Odds ratio	95 % Confidence Interval		p-value
Age established care (per 10-year increase)			1.19	28.07	0.029
Race	43				0.788
African American	Reference	1.00			
White, non-Latina/Hispanic		0.67	0.07	6.11	0.720
Latina/Hispanic		0.50	0.06	4.23	0.525
Private insurance	43	1.30	0.33	5.08	0.707
Level of lesion	43				0.493
Thoracic/ high lumbar	Reference	1.00			
Mid/ low lumbar		1.19	0.29	4.90	0.809
Sacral		2.86	0.50	16.36	0.238
Community ambulatory	43	2.22	0.60	8.24	0.232
Current or previous sexual activity	42	9.17	2.11	39.85	0.003

## 4.2. Gynecological health characteristics

Like the general population, the median age of menarche in this study was twelve (range 8–17).<sup>25</sup> The age of menarche in this group was higher than expected given that central precocious puberty related to hydrocephalus has been documented in several studies of girls with SB.<sup>1</sup> Furman et al. found that in 25 adolescent girls with SB, the average age of menarche was 10.25 (SD 1.68, range 7-14.5), which was significantly lower than patients' mothers or siblings.<sup>26</sup> Given the potential for precocious puberty in this population, the Spina Bifida Association's Women's Health Guidelines recommend educating families on the possibility of precocious puberty in early childhood, monitoring for signs and progression of puberty beginning at age six and referring to pediatric endocrinology for concerns about abnormal pubertal development.<sup>11</sup> For young adult women who have had precocious puberty due to multiple etiologies, there is not consensus about the long-term sequala of this condition or its treatment. However, for those who received treatment with Gonadotropin-releasing hormone analogs, long term outcomes of body-mass index, bone mineral density, and

reproductive function are generally reassuring.<sup>27</sup> The average age of menarche, prevalence of precocious puberty in the SB population, and sequala needs further study.

While most women in this study had regular menses, 27 % had spontaneously irregular menses or amenorrhea compared to approximately 9 % of women (aged 29–46) in the general population.<sup>28</sup> There are no studies specifically evaluating menstruation differences in SB or the impact of menses on quality of life, self-management, urinary tract infections, or hygiene management for women with SB. However, a retrospective study of 262 adolescents and young women with developmental disabilities (including three with SB) who had menstrual complaints determined that those with amenorrhea or light regular periods were more likely to be satisfied with their menses management than patients with heavy or irregular bleeding, and that satisfaction rates were similar amongst the various types of menses management (i.e., oral medication, depo, implant, or intrauterine device).<sup>29</sup> These findings emphasize the importance of regularly discussing menstrual care and patient-centered management options based on risks for adverse effects with hormonal therapies, dosing/adherence concerns, and

potential benefits. Additionally, further study of menses concerns and management considerations specifically for women with SB is needed.

# 4.3. Pelvic exam findings

While most women in our study had normal pelvic exam findings, POP and elongated cervix were the most common atypical findings. Women with SB have a known increased risk for POP at young ages and frequently with nulliparity.<sup>2,30</sup> Lifelong decreased pelvic muscular tone as well as congenital pelvic anatomy differences from the underlying spinal dysraphism likely contribute to this finding.<sup>1</sup> In a few small studies of women with SB, POP symptoms were similar to those in the general population, i.e., vaginal bulge or dyspareunia, and the apical or cervical compartment was the most common leading compartment.<sup>2,30,31</sup> In the general population, POP is associated elongated cervix, and the degree of POP correlates with cervical length.<sup>32,33</sup> In a single-center study of women with congenital genitourinary abnormalities including those with SB, elongated cervix was noted in four of the six patients and had implications for surgical correction.<sup>31</sup> The prognosis of POP, POP treatment, and the impact on bowel/bladder management, sexual function, pregnancy, and quality of life in women with SB needs to be further studied.

# 4.4. Factors associated with meeting USPTSF reproductive health screening guidelines

The second aim of this study was to determine the frequency and factors associated with completing of reproductive health screenings recommended for young adult women. The USPSTF gives a grade A recommendation that all individuals aged 15-65 are screened at least once for HIV.<sup>34</sup> In our study, only 23.3 % had met the recommendation and older age was the only factor associated with having had a previous HIV test (OR 3.97 per 10-year increase in age (95 % CI: 1.23, 12.86)). In comparison, the 2017 Kaiser Women's Health Survey, a nationally representative survey of women, found that 49 % of women in the United States aged 18-64 reported having had an HIV test.<sup>35</sup> The lower frequency of HIV screenings and the age difference in screening in our population may reflect pediatric versus adult care practices in HIV screening, but could also indicate a presumption that women with SB may have a decreased risk HIV compared to the general population (i.e. lower rates of sexual activity) leading to lower rates of screening. In our study, 35.6 % of young women reported being sexually active compared to other studies in which 47-68 % of similar-age women with SB (mean ages 20-29) reported being sexually active.<sup>36-38</sup> A recent study evaluating solo and partnered sexual behavior in 345 adults with SB reported that 70 % of respondents had participated in at least one type of sexual behavior in their lifetime emphasizing the importance of routine sexual health screenings, discussion, and education.<sup>39</sup> Nevertheless, the percentage of women in this study who reported having been sexually active was higher than the percentage who had HIV testing (23.3 %) emphasizing the need to improve routine HIV screening. In addition to sexual transmission risks for HIV, individuals with SB often have multiple surgeries during childhood and may have received blood products posing further potential HIV risk and further promoting the importance of universal HIV screening in adults with SB.40

While the Advisory Committee on Immunization Practices recommends that HPV vaccine series be initiated at 11–12 years with catch-up vaccination for females through age 26, less than half of the women in our study had started the series (43.3 %).<sup>41</sup> In the general population, HPV vaccinations are much higher. Of the adolescents aged 13–17 years surveyed in the National Immunization Survey–Teen, 71.5 % in 2019 and 75.1 % in 2020 had completed at least one dose of the HPV vaccine series.<sup>42</sup> Reasons for this difference in HPV vaccination rates are not clear from this study, and both HPV vaccination rates and potential reasons for hesitancy in the SB population need to be further explored. However, in the general population, reasons for hesitancy include vaccine safety, early age of HPV vaccine initiation, and misinformation about HPV screening and vaccination as well as messaging that the HPV vaccine will increase rates of sexual activity in adolescents. In a study to better understand HPV vaccine promotion in a cohort of insured females between 2006 and 2009, Hirth et al. found that gynecologists were more likely to administer HPV vaccines than pediatric primary care providers and that younger patients, aged 9–18, were less likely to have completed the vaccine series than those older than 19.<sup>43</sup> In contrast, patients in this study who established gynecology care at an older age were significantly less likely to have started the HPV vaccine series (10-year increase in age: adj OR 0.09, 95 % CI: 0.02, 0.49). Our finding that younger patients were more likely to have started the HPV series may indicate a trend towards more HPV vaccine promotion in general practice over time in our local community.

Regarding USPSTF cervical cancer screening recommendations, only 26.7 % (n = 16) of women aged 21 and above in the study cohort had previous cervical cancer screening compared to 69.4 % of women aged 21–30 in the general population with private insurance in a study from 2014.<sup>44</sup> While there are no previous studies specifically evaluating rates of cervical cancer screening in SB, several studies have found that women with disabilities in general are less likely to be up to date on cervical cancer screening.<sup>45–47</sup> Barriers to cervical cancer screening for women with disabilities include lack of health insurance coverage, lack of a regular physician who is knowledgeable and welcoming to someone with disabilities, the need for adaptive facilities, transportation, or positioning accommodations, stereotypes or misconceptions about the care that women with disabilities need, and the woman's previous negative experiences with screenings or beliefs about screenings.<sup>48,49</sup> Having facilities to accommodate women with disabilities and training staff to assist with transfers to ensure safety may facilitate completing cancer screenings in this population.49

# 4.5. Limitations

There are several limitations for this study. First, this was a study of patients establishing within a single gynecology clinic designed to meet the needs of women with IDD, limiting the generalizability of these findings. Additionally, only women who had established care with the gynecologist were included in this study as specific gynecological history was available in notes from these visits. As these women may have sought out gynecological care, this population may have had more gynecological concerns prompting them to seek care and may have been more likely to have had previous preventive care than the population who had did not establish gynecological care. Nevertheless, the gynecological care needs identified can add to the very limited data on this topic and may be used as background for further study. Additionally, for those whose reproductive health screening was unknown, data were recorded as not having been completed, and thus the data may have underestimated the number of patients who received the recommended screenings. Finally, breast cancer screening and menopause symptom data were not included due to the cohort's young age (median age 24). As the SB Association's Women's Health Guidelines suggest, further study is needed to evaluate breast cancer screening and the menopausal needs of women with SB.

# 5. Conclusions

Almost half of the women in this study presented with gynecological concerns, highlighting the need to promote accessible gynecology care for women with SB. To provide patient-centered care for adolescent and adult women with SB, clinicians need to be aware of their potential menstrual concerns, common pelvic exam findings, and considerations for hormonal therapy management. Women with SB should be presented with the same opportunities for reproductive health screening and prevention, and further efforts may be necessary to overcome the barriers that may have led to the lower rates of adherence. HIV screening and HPV vaccination are recommended for adolescent age groups and therefore should be included in adolescent care prior to transition as well. Further studies are needed to identify ways to improve preventive gynecological care for women with SB and promote access to gynecological care throughout healthcare transition.

## **Funding/Financial Statement**

Internal funding only was used for the data collection and preparation of this manuscript.

# **Ethical Statement**

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

# CRediT authorship contribution statement

Ellen Fremion: Conceptualization, Oversight, Manuscript Preparation. Rachel Madey: Conceptualization, Data collection, Manuscript Review. Elizabeth Harper: Conceptualization, Data collection, Manuscript Review. Kristen A Staggers: Data Review, Statistical Analysis. K Jordan Kemere: Data review, Manuscript Review. John Berens: Data review, Manuscript Review. Tara Harris: Data review, Manuscript Review.

# Data availability

The data that has been used is confidential.

# **Declaration of Competing Interest**

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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