A cross-sectional study of sexual function and fertility status in adults with congenital genitourinary abnormalities in a U.S. tertiary care centre

Hannah McCloskey, MD[1]; Aaron Kaviani, MD[2]; Rashmi Pande, MD[2]; Timothy Boone, MD[2]; Rose Khavari, MD[2]

[1]Baylor College of Medicine, Houston, TX, United States; [2]Houston Methodist Hospital, Houston, TX, United States

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Abstract

Introduction: We aimed to evaluate sexual function, sexual knowledge, and fertility status in adult patients with congenital genitourinary abnormalities (CGUA).

Methods: Adult patients with CGUA who were referred to a single transitional urology clinic between 2014 and 2017 were prospectively recruited to participate in the study. Questionnaires about general demographics, bowel and bladder continence, fertility, and sexuality were gathered. Validated questionnaires, including the Sexual Health Inventory for Men (SHIM) and Brief Index of Sexual Functioning for Women (BISF-W), were also collected.

Results: A total of 167 adults with CGUA were referred to our clinic within the defined time frame. Sixty patients (25 males, 35 females) with a mean age of 25.4 years (range 18–75) met inclusion criteria and responded to questionnaires pertaining to sexuality and fertility. Forty-five (75%) responded to the fertility questionnaire; 26 (58%) had never heard of assisted reproductive technologies, and only one had received prior fertility counselling. Fifty-eight participants (97%) responded to the sexuality questionnaire; 21 (36%) reported a history of sexual activity, with 12 (21%) being currently sexually active. Twenty (34%) wanted to learn more about sexuality and/or fertility. The SHIM response rate was 44%, and only three females (9%) completed the BISF-W in its entirety.

Conclusions: Adults with CGUA desire more sexuality and fertility education, yet they are uncomfortable completing current questionnaires. Our sexuality and fertility questionnaires are too challenging for this patient population to complete despite assistance. Thus, modifications are urgently needed. Additionally, medical providers should discuss sexual and reproductive health with these patients earlier and in more detail.

Introduction

Spinal dysraphism is one of the most common birth defects,[1] with incidence ranging from 3.4–4.0 per 10 000 live births in the U.S.[2] Due to medical advancement, the life expectancy of patients with spinal dysraphism has extended to the point where it is no longer exclusively considered a pediatric disease. As these patients transition into adulthood, they encounter many difficulties. From a urological perspective, bladder/bowel management and preservation of renal function tend to be the primary focus, while problems with sexual or reproductive functioning are less often addressed. However, sexual function and fertility status are important aspects of adult life and have been shown to impact quality of life.[3,4]

Few studies have investigated sexual function in adults with spinal dysraphism or other congenital genitourinary abnormality (CGUA),[5-15] and many of these were published more than a decade ago.[5-10] Five of these studies used validated questionnaires,[9,10,13-15] of which only two included both male and female subjects.[10,14] Given this lack of objective data in the literature, the present study aimed to further examine sexual function in CGUA patients by applying validated questionnaires. Sexual knowledge and fertility status in this patient population was also evaluated.

Methods

Patients who visited a single tertiary transitional urology care clinic at our institution were identified for study participation as part of a prospective cohort database. A cross-sectional study of adult patients with spinal dysraphism or other CGUA referred to the clinic between February 2014 and May 2017 was performed. Approval by the institutional review board was obtained prior to onset.

Questionnaires were administered to patients who consented to study participation. Patients were offered and received assistance in completing questionnaires by research coordinators if they desired. Patients decided if their parents were present or absent during the sexuality/fertility discus-

sions. Patients were excluded from analysis for either poor cognitive ability or poor functional status, defined as an education level of pre-elementary and cumulative self-care score of ≤12, respectively. The self-care score was calculated from participants' self-reported degree of dependence in six domains: feeding, grooming, bathing, dressing upper body, dressing lower body, and toileting. Responses to each of these six domains, which were based on a rating scale from 1 (total assist) to 7 (complete independence), were summed to arrive at the total self-care score (range 6–42). Since the aim of the study was to focus on adult patients, patients under 18 years of age were also excluded from analysis.

Study questionnaires included questions about general demographics, education, health insurance, physical disability, bowel and bladder continence, partnership, fertility status, sexual function, and sexual knowledge. The questionnaires for males also included the Sexual Health Inventory for Men (SHIM), whereas the female questionnaires included the Brief Index of Sexual Functioning for Women (BISF-W), both of which are validated questionnaires to assess sexual function. For ease of reference, the male and female questionnaires are provided in Appendix 1.

The SHIM is a five-item, self-report instrument for screening and diagnosing erectile dysfunction (ED) in clinical practice and research. Reponses to each of the five items are added to give a total SHIM score (range 1–25). ED is classified into five severity grades: no ED (≥22), mild (17–21), mild to moderate (12–16), moderate (8–11) and severe ED (1–7).[16] The SHIM was preferred over the full International Index of Erectile Function (IIEF) because of its brevity and ease of use, especially in this patient population.

The BISF-W is a self-report instrument for assessing female sexual function that was developed for use in clinical trials. The BISF-W is divided into seven dimension scores for each of the important aspects of female sexuality: D1 (thoughts/desire), D2 (arousal), D3 (frequency of sexual activity), D4 (receptivity/initiation), D5 (pleasure/orgasm), D6 (relationship satisfaction), and D7 (problems affecting sexual function).[17]

Ambulatory status was categorized using the Hoffer Classification.[18] Participants with either community or household ambulatory status were considered "ambulators," whereas those with therapeutic and non-ambulatory status were considered "non-ambulators."

Additional data was collected from medical records of patients who filled out questionnaires, including primary diagnosis, surgical history, urodynamic results, and recent renal laboratory values and imaging.

Statistical analysis

Given our small sample size and the likelihood of non-normal data distribution, quantitative values are expressed as the median (range). These values were compared by the Mann-Whitney U-test. Proportions were compared using a Chi-square test or the Fisher's exact test using GraphPad Prism 7.0c software for Mac OS X (GraphPad Software, La Jolla, California, U.S.). The number of observations was considered when choosing the proper statistical test in order to ensure validity of results. $P<0.05$ was considered statistically significant.

Results

Demographics & health status

A total of 167 patients were referred to the transitional urology clinic during the defined time period; 75 patients consented and filled out questionnaires. Of the 75 patients administered questionnaires, 67 (89%) responded to questions pertaining to their sexual function and fertility status. Two patients failed to meet our minimum age requirement and five patients failed to meet our criteria for study participation based on cognitive ability and functional status. Thus, seven patients in total were excluded from analysis. Sixty participants (25 males, 35 females) with a median age of 23 years (range 18–75) remained. Twenty-five percent of participants used assistance from research coordinators to complete the questionnaires. Research coordinators helped by reading and explaining the questionnaires.

Table 1 lists characteristics of male and female patients. There was no difference between genders regarding general demographics, hydrocephalus status (determined by presence or absence of a shunt), extent of physical disability (measured by self-care score and ambulatory status), and degree of urinary incontinence. Our small sample size prevented further comparison of characteristics.

Males

Fertility

Seventeen of the 25 male participants (68%) responded to the fertility questionnaire (Table 2). Fifteen (88%) had a primary diagnosis of myelomeningocele, one (6%) had meningocele, and one (6%) had sacral agenesis. At the time of investigation, most men (82%) were unmarried and none had fathered biological children. None of the men had ever received fertility or conception/contraception counselling and most (65%) had never heard of assisted reproductive technologies (ART).

Sexual function

Twenty-four of the 25 male participants (96%) responded to the sexual function questionnaire completely (Table 2).

Table 1. Sample characteristics of male and female participants

	Males (n=25)	Females (n=35)	p
Age	22 (18–75)	23 (18–42)	0.55 (NS)
Ethnicity (%)			>0.99 (NS)
Hispanic or Latino	11 (48)	15 (47)	
Not Hispanic or Latino	12 (52)	17 (53)	
Race (%)			—
White	19 (83)	26 (81)	
Black	3 (13)	4 (13)	
Asian	1 (4)	1 (3)	
Native American	—	1 (3)	
Employment (%)			0.43 (NS)
Employed	6 (25)	4 (13)	
Unemployed	14 (58)	20 (63)	
Student	4 (17)	8 (25)	
Education level (%)			—
Primary/secondary	10 (56)	15 (54)	
Some college	6 (33)	9 (32)	
College degree	—	3 (11)	
Advanced degree	2 (11)	1 (4)	
Primary diagnosis (%)			—
Myelomeningocele	18 (72)	24 (69)	
Meningocele	1 (4)	—	
Tethered cord	—	1 (3)	
Sacral agenesis	1 (4)	—	
Bladder exstrophy	—	2 (6)	
Cloacal exstrophy	1 (4)	2 (6)	
Other*	4 (16)	6 (17)	
Shunt placement (%)			0.27 (NS)
Yes	19 (76)	21 (60)	
No	6 (24)	14 (40)	
Self-care score (possible range: 6–42)	40 (14–42)	36 (16–42)	0.28 (NS)
Ambulatory status (%)			0.79 (NS)
Ambulator	12 (55)	17 (50)	
Non-ambulator	10 (45)	17 (50)	
Urinary incontinence frequency (%)			0.82 (NS)
>1/day	8 (38)	8 (27)	
<1/day, >1/month	5 (24)	7 (23)	
<1/month (incl. never)	5 (24)	10 (33)	
Cannot assess	3 (14)	5 (17)	

*Other includes cerebral palsy, chromosomal abnormalities, renal agenesis, Hirschsprung's disease, etc. Note: Proportions based on participants who provided a valid answer to that question. NS: not significant.

Seventeen (71%) had myelomeningocele, one (4%) had meningocele, one (4%) had cloacal exstrophy, and five (21%) had other diagnoses. Eleven men (46%) reported a history of sexual activity, with six (25%) being currently sexually active. Most men (71%) expressed desire to become or continue being sexually active and greater than half wanted to learn more about sexuality and/or fertility.

Eleven of the 25 male participants (44%) completed the SHIM questionnaire in its entirety (Table 3). Eight (73%) had myelomeningocele, one (9%) had meningocele, one (9%) had sacral agenesis, and one (9%) had congenital Guillain-Barre syndrome. The median SHIM score was 17 (range 10–24). Of the men with spina bifida (SB), the median SHIM score was 16.5 (range 10–24). There was no significant difference between SHIM scores of men with a history of sexual activity compared to those without. No diagnosis was obviously associated with lower SHIM scores; however, the ability to recognize associations was limited by the small size — the Mann-Whitney U-test is invalid if either group has less than five samples. Similarly, no relationship between the level of the myelomeningocele and SHIM score could be detected due to the small sample size. One would assume a high level of myelomeningocele would be associated with a low SHIM score, but further testing is needed to support this assumption. Four men (16%) partially completed the SHIM questionnaire, so a composite score could not be calculated. The remaining male participants (40%) left the questionnaire blank because they were uncomfortable answering the questions. Research coordinators offered help, but these participants refused to answer personal information regarding sexual function.

Females

Fertility

Twenty-eight of the 35 female participants (80%) responded to the fertility questionnaire (Table 2). Nineteen (68%) had a primary diagnosis of myelomeningocele, two (7%) had cloacal exstrophy, one (4%) had bladder exstrophy, one (4%) had tethered cord syndrome, and five (18%) had other diagnoses. At the time of investigation, most women (89%) were unmarried. The two married women were the only participants who had been pregnant and given birth to children, both via cesarean section. Both women had myelomeningocele.

Almost half of the women had never seen an obstetrics/gynecology specialist. Previously visiting an obstetrics/gynecology specialist was associated with higher rates of birth control use ($p<0.005$). Only one woman reported previously receiving any form of fertility or conception/contraception counselling by a healthcare provider. Most women (54%) had never heard of ART.

Sexual function

Thirty-four of the 35 female participants (97%) responded to the sexual function questionnaire (Table 2). Twenty-four (71%) had myelomeningocele, two (6%) had cloacal exstrophy, two (6%) had bladder exstrophy, one (3%) had tethered cord syndrome, and five (15%) had other diagnoses. Ten women (29%) reported a history of sexual activity, with six (18%) being currently sexually active. Nine (26%) expressed desire to become or continue being sexually active, and seven (21%) wanted to learn more about sexuality and/or fertility.

Table 2. Responses to fertility and sexual function questionnaires

Fertility questionnaire responses in all participants and in the subsets of male and female participants

	Males (n=17)	Females (n=28)
Marital status (%)		
Never married	14 (82)	25 (89)
Married	2 (12)	2 (7)
Divorced	—	—
Widowed	1 (6)	—
Unanswered	—	1 (4)
Previously seen obstetrics/gynecology specialist (%)		
Yes		15 (54)
No		13 (46)
Use form of birth control (%)		
Yes	5 (29)	11 (39)
No	11 (65)	16 (57)
Unanswered	1 (6)	1 (4)
Type of birth control (%)		
Oral contraceptive	—	7 (25)
Intrauterine device (IUD)	—	—
Implant (Implanon)	—	1 (4)
Barrier method (condoms)	5 (29)	—
Other	—	2 (7)
Do not use birth control	11 (65)	16 (57)
Unanswered	1 (6)	2 (7)
Have biological children (%)		
Yes	—	2 (7)
No	17 (100)	26 (93)
Have ever received conception/fertility counselling (%)		
Yes	—	1 (4)
No	17 (100)	24 (86)
Unanswered	—	3 (11)
Have heard of assisted reproductive technology (%)		
Yes	6 (35)	8 (29)
No	11 (65)	15 (54)
Unanswered	—	5 (18)

Sexual function questionnaire responses in all participants and in the subsets of SB, male, and female participants

	All subjects (n=58)	SB subjects (n=42)	Males (n=24)	Females (n=34)	p
History of sexual activity (%)					
Yes	21 (36)	17 (40)	11 (46)	10 (29)	0.27 (NS)
No	37 (64)	25 (60)	13 (54)	24 (71)	
Unanswered	—	—	—	—	
Currently sexually active (%)					
Yes	12 (21)	8 (19)	6 (25)	6 (18)	0.53 (NS)
No	46 (79)	34 (81)	18 (75)	28 (82)	
Unanswered	—		—	—	
Desire to become/ continue being sexually active (%)					
Yes	26 (45)	21 (50)	17 (71)	9 (26)	<0.005
No	27 (47)	18 (43)	6 (25)	21 (62)	
Unanswered	5 (9)	3 (7)	1 (4)	4 (12)	
Desire to learn about sexuality/fertility (%)					
Yes	20 (34)	17 (40)	13 (54)	7 (21)	<0.05
No	26 (45)	16 (38)	8 (33)	18 (53)	
Unanswered	12 (21)	9 (21)	3 (13)	9 (26)	

Twenty-eight of the 35 female participants (80%) responded to the BISF-W questionnaire, but only three (9%) completed it in its entirety despite assistance from research coordinators. Female participants were generally hesitant to respond to the BISF-W and left questions unanswered due to discomfort with question content. Of the three who completed the questionnaire, two had myelomeningocele and one had a chromosomal abnormality. Eight (29%) women reported currently

Table 3. Responses to validated questionnaires: SHIM and BISF-W

SHIM scores and descriptive statistics (median and range) in all men and in the subsets of men with and without a sexual history

	All men (n=11)	With sexual history (n=6)	Without sexual history (n=5)	p
SHIM score (%)				
≥22, No ED	1 (9)	1 (17)	—	
17–21, Mild ED	5 (45)	3 (50)	2 (40)	
12–16, Moderate to mild ED	4 (36)	2 (33)	2 (40)	
8–11, Moderate ED	1 (9)	—	1 (20)	
1–7, Severe ED	—	—	—	
Descriptive statistics				0.14 (NS)
Median	17	17	14	
Range	10–24	15–24	10–18	

Descriptive statistics (median and range) for BISF-W D1, D2, D4, and D5 scores in all women and in the subsets of women with partners and without partners

Dimension	Descriptive statistics	All women	With partners	Without partners	p
D1: Thoughts/desire (n=25)	Median	0	2.5	0	<0.001
Possible score range: 0–12	Range	0–9	1–9	0–6	
D2: Arousal (n=25)	Median	0	4	0	<0.002
Possible score range: 0–8	Range	0–5	0–5	0–4	
D4: Receptivity/initiation (n=24)	Median	0	5	0	<0.001
Possible score range: 0–10	Range	0–10	0–10	—	
D5: Pleasure/orgasm (n=24)	Median	0	4	0	<0.001
Possible score range: 0–8	Range	0–6	0–6	0–1	

BISF-W: Brief Index of Sexual Functioning for Women; ED: erectile dysfunction. SHIM: Sexual Health Inventory for Men.

having a sexual partner, with five (18%) being sexually active in the past month. Twelve women (43%) answered questions pertaining to sexual orientation. A mixture of both heterosexual and homosexual desires and experiences were reported.

The remaining BISF-W questions are divided into the seven dimensions. Of the dimensions, D1: Thoughts/Desire and D2: Arousal had the highest response rate (n=25, 89%). Response rates for D4: Receptivity/Initiation and D5: Pleasure/Orgasm were comparable (n=24, 86%). Descriptive statistics of the D1, D2, D4, and D5 scores are given in Table 3.

The remaining domains (D3: Frequency of Sexual Activity, D6: Relationship Satisfaction, and D7: Problems Affecting Sexual Function) had poor response rates ranging from 18–43%. The nine women (32%) who responded to D3 reported engaging in a mixture of erotic kissing, masturbation alone, and vaginal penetration during the last month. Of the twelve women (43%) who responded to D6, eight (67%) had sexual partners and reported a fairly high level of personal and partner satisfaction with their sexual relationship (median 5, range 3–8, possible score range: 0–8). Of the five women (18%) who responded to D7, one (20%) reported occasional involuntary urination during sexual activity and only one (20%) reported that her health problems influenced her level of sexual activity.

All subjects

Table 4 compares characteristics between participants with and without a history of sexual activity. The median age of participants with a history of sexual activity was significantly greater than those without. No significant difference was found between those with or without a sexual history regarding extent of physical disability, degree of urinary incontinence, and hydrocephalus status. Additionally, no association was found between use of birth control and history of sexual activity.

Table 4. Age, self-care score, ambulatory status, incontinence frequency, hydrocephalus status, and birth control use in participants with versus without sexual history

	With sexual history	Without sexual history	p
Age	28 (19–75)	22 (18–41)	<0.01
Self-care score (possible range: 6–42)	41 (19–42)	34.5 (16–42)	0.06 (NS)
Ambulatory status (%)			
Ambulator	12 (60)	15 (44)	0.40
Non-ambulator	8 (40)	19 (56)	(NS)
Incontinence frequency (%)			
>1/day	5 (25)	10 (33)	0.29
<1/day, >1/month	5 (25)	7 (23)	(NS)
<1/month (including never)	4 (20)	10 (29)	
Cannot assess	6 (30)	3 (10)	
Shunt placement (%)			
Yes	6 (29)	16 (44)	0.27
No	15 (71)	20 (56)	(NS)
Birth control use			
Yes	7 (44)	9 (33)	0.49
No	9 (56)	18 (67)	(NS)

Note: Proportions based on participants who provided a valid answer to that question.

Discussion

This is the third study to use validated questionnaires in the assessment of sexual function in a cohort of male and female patients with spinal dysraphsim, but it is the first study to also include adults with other congenital genitourinary abnormalities. Given the limited amount of objective data, our study aimed to contribute to and expand upon the findings of other studies.[10,14] We also included data regarding sexual knowledge, partnership, and fertility.

Fertility

In our study of adult CGUA patients, most participants were unmarried with no biological children. Almost half of female participants had never been to an obstetrics/gynecology specialist and only one participant in the entire cohort had ever received any fertility or conception/contraception counselling. Despite the increasing popularity and public awareness of ART, the majority (58%) of participants had never heard of it, including in vitro fertilization. These findings show that adults with CGUA generally lack knowledge about reproductive health despite being sexually active.

Sexual function

Of our cohort of adult patients with CGUA, 36% reported a history of sexual activity, with 21% being currently sexually active. These proportions are similar to those observed in SB patients by Lassmann et al.[10] The median age of participants with no sexual history was 22 years. Thus, this patient population is delayed compared to their anatomically normal peers. In a recent national survey, 46% of teenagers aged 15–19 years reported a history of sexual activity[19] and the World Health Organization found the median age of first sexual intercourse to be 17.4 years in the U.S.[20]

As observed by Lassmann et al, sexual activity in our study cohort was unrelated to extent of disability and degree of urinary incontinence.[10] Other studies have reported that the prevalence of hydrocephalus is lower in patients who are sexually actives;[13,21] however, we found no association between sexual activity and hydrocephalus status. This discrepancy in results may be partly explained by our exclusion of patients with high dependence of care and poor cognitive ability, making our study population more functional in comparison.

There was no difference in gender distribution among sexually active patients, in accordance with Lassmann et al.[10] However, males expressed a significantly greater interest in learning about sexuality and/or fertility compared to females. Males were also significantly more interested in becoming sexually active or continuing sexual activity. Given that males have a much stronger libido than females,[22] this disparity in sexual interest and desire is not unusual.

In our study, no male participant had a SHIM score corresponding to ED. The median SHIM score was 17, which indicates mild ED. Lee et al observed the contrary, where most male participants were categorized as having severe ED, and the median SHIM score was 5. Our sample population was similar to that of Lee et al regarding ambulatory and hydrocephalus status. While our response rate for the SHIM questionnaire was poor, it was comparable to that of Lee et al.[14] We observed no association between SHIM score and sexual activity.

Most female participants who responded to the BISF-W questionnaire reported satisfaction in their sexual relationships and denied that their personal health or urinary incontinence interfered with sexual activity. However, the small sample size limits generalizability of results. Like that of the SHIM questionnaire, the BISF-W response rate was poor, with only three women completing it in its entirety despite in-person assistance from research coordinators. However, the BISF-W is a much more comprehensive questionnaire compared to the SHIM, so the lower response rate is understandable. The lower response rates for different domains may be due to proximity to the end of the survey or related to embarrassment about answering the questions.

Our findings suggest that health status might not affect sexual function in adults with CGUA to the degree suggested in the literature. Their delay in sexual activity may be more attributed to a lack of education or opportunity. Social stigma of disability also likely influences how this patient population views and pursues sexual activity.

Overall

Our study found that adult patients with CGUA are generally interested in sexuality and fertility, yet they lacked knowledge about these topics. Regardless of gender, over half of participants had never heard of ART, and only one had received prior fertility or conception/contraception counselling. One-third of participants wanted to learn more about sexuality and/or fertility and almost one-fourth of participants were not currently sexually active but wanted to become sexually active in the future.

A possible explanation for the discrepancy between participants' knowledge of and desire to learn about sexuality and fertility could be the lack of education provided by healthcare professionals or through the school system. Studies have shown that only 5–47% of adults with spinal dysraphism have discussed sexuality with a physician.[8,11,12,21] Of the adults who had not spoken with a physician, Sawyer et al found that 93% "would [have] definitely" discussed these issues had the conversation been initiated by their doctor.[8] Furthermore, while most adults with spinal dysraphism receive general sexual education in school, only a small fraction report receiving sexual education specific to

their diagnoses.[8] Healthcare providers are the best source for this disease-specific sexual education.

A considerable challenge of this study was getting participants to complete questionnaires pertaining to their sexuality and fertility status. Despite assistance with filling out questionnaires, many participants still left them unanswered. Questions pertaining to subjective desires and interests as opposed to objective facts were left blank more often. This poor response rate could reflect participants' discomfort addressing sexuality and fertility in a healthcare setting. Discussion of these issues early in adolescence is recommended to promote patient comfort with sexuality and fertility.[23]

Furthermore, the validated sexual function questionnaires had significantly lower response rates than the questionnaires addressing fertility, partnership, and other aspects of reproductive function. This could be due to the format of answer choices. Participants were much more likely to respond to questions with yes/no answer choices as opposed to multiple-choice questions. With these considerations in mind, improvement of the current standard sexuality questionnaires is highly needed. Disease-specific questionnaires may be warranted to better assess sexual function in certain patient populations, and answer choices should be simplified when possible to increase response rates.

Limitations

Our study has several limitations. Cognitive problems in the spinal dysraphism population have been reported in the literature, but no intelligence test was administered prior to enrollment in the study. Rather a self-report questionnaire was used to assess education level. Additionally, some participants received help from their parents in filling out questionnaires, which may have influenced their responses. Also, the only validated questionnaires used in the study were the SHIM and BISF-W. The questionnaires used to assess fertility, partnership, and other aspects of reproductive function were not validated. Finally, an important limitation was our small sample size and select patient population. While our sample size was comparable to those of previous studies in this patient population, it limits the generalizability of results and could be improved with future multi-institutional studies.

Conclusion

For the millennial patients, health status might not affect sexual function in adults with CGUA to the degree suggested in the literature. Their delay in sexual activity may be more attributed to a lack of education or opportunity. While adults with CGUA desire more sexuality and fertility education, they are uncomfortable addressing these sensitive topics in our current healthcare environment. This study revealed a need for medical providers to discuss sexual and reproductive health with adult CGUA patients earlier and in more detail. Additionally, current sexuality questionnaires are difficult for this patient population to complete despite assistance. Modifications are needed. Disease-specific questionnaires may be warranted to better assess certain patient populations.

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Correspondence: Dr. Rose Khavari, Houston Methodist Hospital, Houston, TX, United States; rkhavari@houstonmethodist.org

Appendix 1. For Female Patients

IDENTIFYING INFORMATION

Patient Last Name: _____
Patient First Name: _____
Date of Visit: ____ / ____ / ____ (MM/DD/YYYY)

Zip Code (5 digits): _____

DEMOGRAPHIC INFORMATION

1. **Date of Birth:** ____ / ____ / ____ (MM/DD/YYYY)
2. **Place of Birth:**
   State/Territory: _____
   Or Country: _____
3. **Ethnicity**: (Choose one)
   ☐ Hispanic or Latino
   ☐ Not Hispanic or Latino
4. Race
   ☐ White
   ☐ Black of African American
   ☐ Asian
   ☐ Native Hawaiian or Pacific Islander
   ☐ American Indian or Alaska Native
   ☐ Other
   ☐ Unknown

MEASUREMENTS

Weight: _____
Height: (Choose One)
☐ Arm Span: _____cm
☐ Recumbent: _____cm
☐ Standing: _____cm

HEALTH INSURANCE

Type of Insurance: (Check all that apply)

- ☐ Straight commercial insurance
- ☐ Commercial insurance HMO
- ☐ Commercial insurance PPO
- ☐ Straight Medicaid
- ☐ Medicaid HMO
- ☐ Other: _____
- ☐ Straight Medicare
- ☐ Medicare HMO
- ☐ State High Risk Plan
- ☐ Tricare/Other Military
- ☐ Uninsured

MARITAL AND EMPLOYMENT STATUS

Employment Status:

- ☐ Employed Full-time
- ☐ Employed Part-time
- ☐ Occasional Worker
- ☐ Volunteer
- ☐ Not Employed

If not Employed:

- ☐ Child or Student
- ☐ Homemaker
- ☐ Seeking work, but not currently working
- ☐ Permanently Disabled
- ☐ Retired

Marital Status:

- ☐ Single
- ☐ Married
- ☐ Partner
- ☐ Divorced/Separated
- ☐ Widowed

EDUCATION

Is patient a current student? ☐ Yes ☐ No

Education level:

- ☐ Pre-elementary
- ☐ Primary/Secondary
  - ☐ Grade (1-12)
- ☐ Technical School
- ☐ Some college
- ☐ College Degree
- ☐ Advanced Degree
- ☐ Other: _____

Has an IEP? (Current primary/secondary students only)

☐ Yes ☐ No

MOBILITY

Ambulation Status:

- ☐ Community ambulatory – The patient walks indoors and outdoors for most activities and may need crutches or braces or both. Uses a wheelchair only for long trips out of the community.
- ☐ Household ambulatory – The patient walks only indoors and with apparatus. Able to get in and out of the chair and bed with little if any assistance. May use the wheelchair for some indoor activities at home and school and for all activities in the community.
- ☐ Therapeutic ambulatory – The patient walks only for a therapy session in school or in the hospital. Otherwise uses a wheelchair to get from place to and to satisfy all needs for transportation.
- ☐ Non-ambulator – Uses a wheelchair exclusively for transportation, but usually can transfer from chair to bed.

What is the highest level of bracing used to ambulate on a daily basis?

- ☐ SMO – Supra-Malleolar Orthosis
- ☐ AFO – Ankle Foot Orthosis
- ☐ KAFO – Knee Ankle Foot Orthosis
- ☐ HKAFO – Hip Knee Ankle Foot Orthosis
- ☐ RGO – Reciprocating Gait Orthosis
- ☐ Not Applicable

Does patient use a wheelchair?

- ☐ Yes
- ☐ No

Please indicate primary type of wheelchair?

- ☐ Self-propelled manual wheelchair
- ☐ Self-propelled chair with power assist
- ☐ Attendant only propelled wheelchair
- ☐ Power wheelchair or scooter

If the patient is a therapeutic or non-ambulator, is the patient able to transfer from a wheelchair to another level surface without assistance?

- ☐ Yes
- ☐ No

Does the patient use braces or assistive devices?

- ☐ Braces
- ☐ Assisted devices

BLADDER MANAGEMENT

Present Bladder Management

☐ No management
☐ Clean intermittent catheterization

A. Is a surgically-created catheterizable channel used?

☐ Yes
☐ No

B. If performing CIC, it is mostly performed by:

☐ Patient
☐ Caregiver

☐ Voluntary/Intentional void in toilet
☐ Vesicostomy
☐ Crede
☐ Indwelling catheter
☐ Urostomy bag
☐ Condom catheter

Age at which CIC Began:

☐ Less than 1 year
☐ 1 year to less than 3 years
☐3 years to less than 6 years
☐ 6 years to less than 9 years
☐ 9 years less than 12 years
☐ Older than 12 years

Has the patient been instructed to void or catheterize on a schedule?

☐ Yes
☐ No

Are any of the following medications currently prescribed?

☐ Yes
☐ No

If yes, which groups?

☐ Anti-cholinergics (Ditropan, Detrol, Vesicare, etc.)
☐ Alpha blocker
☐ Alpha agonist
☐ Daily antibiotic

Quantify frequency of urinary incontinence during the day over the last month (when not having a urinary tract infection):

☐ Cannot assess
☐ Greater than or equal to once per day **(daily)**
☐ Less than once per day, more than or equal to once per week **(weekly)**
☐ Less than once per week, greater than or equal to once per month **(monthly)**
☐ Less than once per month **(less than monthly)**
☐ Never

Undergarment worn during the day:

☐ Underwear only
☐ Underwear with pad
☐ Protective undergarment (diaper, pull-up)

Over the past month during the night, (when not having a urinary tract infection), the patient has had urinary incontinence:

☐ Yes
☐ No

Has the patient been recommended to have Botox injection into the bladder:

☐ Yes
☐ No

Has the patient had Botox injection in the past?

☐ Yes
Dates: _____
☐ No

BOWEL MANAGEMENT

Is patient currently on a bowel management program?

☐ Yes
☐ No

As part of the present bowel Management program, patient takes Oral medications:

☐ Stimulant (senna, Miralax [glycolax, PEG, polyethylene glycol])
☐ Softener (Colace [docusate/dioctyl]), Mineral oil)
☐ Bulking agents/Fiber
☐ None

As part of the present bowel management program, patient uses the following:

	A. Patient Uses	**B. Completely Independently**
Suppository	☐	☐
Standard rectal enema	☐	☐
Cone rectal enema	☐	☐
Digital simulation	☐	☐
Timed evacuation	☐	☐
Disimpaction	☐	☐
Antegrade enema	☐	☐
Mini-enemas (Enemeez, theravac)	☐	☐
None	☐	☐

Quantify frequency of stool incontinence over the last month when not ill.

☐ Cannot assess
☐ Greater than or equal to once per day **(daily)**
☐ Less than once per day, more than or equal to once per week **(weekly)**
☐ Less than once per week, greater than or equal to once per month **(monthly)**
☐ Less than once per month **(less than monthly)**
☐ Never

BOWEL PROGRAM HISTORY

Age at which first bowel program initiated:

Patient's age at the time: _____

☐ Never on a bowel program

VISIT HISTORY QUESTION

Number of multidisciplinary SB clinic visits since the last SB Registry visit. This will be entered on the report submission screen at the time you submit your report.

☐ First visit ☐ 2-3 times
☐ Not first visit ☐ 4-5 times
☐ 1 time ☐ 6 or more times

VISIT HISTORY QUESTION

Number of Emergency Room visits since last intake: _____

Number of hospitalizations since last visit: _____

Reasons: _____
_____
_____
_____

Daily Activities

FUNCTIONAL STATUS

1. Total Assist: *Perform few (<25%) activities independently* **2. Maximal Assist:** *Perform some (<50%) activities independently* **3. Moderate Assist:** *Perform many (50-75%) activities independently*	**4. Minimal Assist:** *Perform most (>75%) activities independently* **5. With Supervision:** *Able to perform all activities independently only with supervision assistance*	**6. Moderate Independence:** *Perform all activity independently, but need extra time or devices* **7. Complete Independence:** *Perform all activity independently in a timely manner*

SELF CARE	**Total Assist**	**Maximal Assist**	**Moderate Assist**	**Minimal Assist**	**With Supervision**	**Moderate Independ.**	**Complete Independ.**
Feeding	1	2	3	4	5	6	7
Grooming	1	2	3	4	5	6	7
Bathing	1	2	3	4	5	6	7
Dressing Upper Body	1	2	3	4	5	6	7
Dressing Lower Body	1	2	3	4	5	6	7
Toileting	1	2	3	4	5	6	7

SPHINCTER CONTROL	**Total Assist**	**Maximal Assist**	**Moderate Assist**	**Minimal Assist**	**With Supervision**	**Moderate Independ.**	**Complete Independ.**
Bladder Management	1	2	3	4	5	6	7
Bowel Management	1	2	3	4	5	6	7

MOBILITY, TRANSFERS	**Total Assist**	**Maximal Assist**	**Moderate Assist**	**Minimal Assist**	**With Supervision**	**Moderate Independ.**	**Complete Independ.**
Bed to chair, wheelchair	1	2	3	4	5	6	7
Toilet	1	2	3	4	5	6	7
Tub/Shower	1	2	3	4	5	6	7
Car Transfer	1	2	3	4	5	6	7

MOBILITY LOCOMOTION	**Total Assist**	**Maximal Assist**	**Moderate Assist**	**Minimal Assist**	**With Supervision**	**Moderate Independ.**	**Complete Independ.**
Walking or Wheelchair	1	2	3	4	5	6	7
Stairs	1	2	3	4	5	6	7

SEXUAL FUNCTION **(Ask only if patient is 18 years or older and is consenting to answer in private)**

Is the patient currently sexually active?	Yes	☐	No	☐
Has the patient ever been sexually active?	Yes	☐	No	☐
Does the patient have desire to become or continue to be sexually active?	Yes	☐	No	☐
Does the patient have a desire to learn about:				
Sexuality:	Yes	☐	No	☐
Fertility:	Yes	☐	No	☐
Does the patient have any biological children?	Yes	☐	No	☐
If Yes:	**If Yes and Fertile:**			
How many? _____	**How many pregnancies?**		_____	
	How many deliveries?		_____	
	Type of delivery:		_____	
	Health of children:		_____	
	Full Term? Yes	☐	No	☐

Sexual Function

BRIEF INDEX OF SEXUAL FUNCTION - WOMEN

Please mark the circle next to the choice that best answers the question.

1. Do you currently have a sexual partner?
    - Yes
    - No
2. Have you been sexually active in the past month?
    - Yes
    - No

During the past month…

3. How frequently have you had sexual thoughts, fantasies, or erotic dreams?
    - Not at all
    - Once
    - 2 or 3 times
    - Once a week
    - 2 or 3 times a week
    - Once a day
    - More than once a day

4. How frequently have you felt a desire to engage in sexual activity?
    - Not at all
    - Once
    - 2 or 3 times
    - Once a week
    - 2 or 3 times a week
    - Once a day
    - More than once a day

5. During the past month, how frequently have you become aroused by sexual experiences?
    - Have not engaged in sexual activity
    - Not at all
    - Seldom, 25% of the time
    - Sometimes, 50% of the time
    - Usually, 75% of the time
    - Always become aroused

6. How frequently have you become anxious or inhibited during sexual activity with a partner?
    - I have not had a partner
    - Not at all anxious or inhibited
    - Seldom, 25% of the time
    - Sometimes, 50% of the time
    - Usually, 75% of the time
    - Always become anxious or inhibited

7. Which of the following experiences you have engaged in during the last month?
    - Erotic kissing
    - Sexual fantasy
    - Masturbation alone
    - Mutual masturbation
    - Petting and foreplay
    - Oral sex (giving or receiving)
    - Vaginal penetration or intercourse
    - Anal sex

8. Who has usually initiated your sexual activity with your partner?
    - I have not had a partner
    - I have not had sex with partner during the last month
    - I usually have initiated activity
    - My partner and I have equally initiated activity
    - My partner usually has initiated activity

9. Have you felt pleasure from any forms of sexual experience?
    - I have not had a partner
    - Have not had sexual experience during the past month
    - Have not felt any pleasure
    - Seldom, 25% of the time
    - Sometimes, 50% of the time
    - Usually, 75% of the time
    - Always felt pleasure

10. How often do you reach orgasm with sexual activity?
    - Have not engaged in sexual activity
    - Not at all
    - Seldom, 25% of the time
    - Sometimes, 50% of the time
    - Usually, 75% of the time
    - Always reach orgasm

11. Has the frequency of sexual activity with a partner been:
    - I have not had a partner
    - Less than you desired
    - As much as you desired
    - More than you desired

12. Have you experienced the following? If so, please indicate how often: (Never (0% of the time), Seldom (25% of the time), Sometimes (50%), Usually (75% of the time), Always (nearly 100% of the time)
    - Bleeding or irritation after vaginal penetration or intercourse, _____%
    - Lack of vaginal lubrication
    - Pain penetration or intercourse, _____%
    - Difficulty reaching orgasm
    - Involuntary urination, _____%
    - Headaches after sexual intercourse, _____%
    - Vaginal infections, _____%

13. Which of the following factors have influenced your level of sexual activity?
    - My own health problems (for example, infections or illness)
    - My partner's health problems
    - Conflicts in relationship
    - Lack of privacy
    - Other, please specify: _____

14. Overall, have you been satisfied with your sexual relationship with your partner?
    - Very satisfied
    - Somewhat satisfied
    - Neither satisfied nor dissatisfied
    - Somewhat dissatisfied
    - Very dissatisfied

15. Overall, do you think your partner has been satisfied with your sexual relationship?
    - Very satisfied
    - Somewhat satisfied
    - Neither satisfied nor dissatisfied
    - Somewhat dissatisfied
    - Very dissatisfied

16. Which of the following best describes your sexual experience?
    - Entirely heterosexual
    - Largely heterosexual, some homosexual experience
    - Largely heterosexual, but considerable homosexual experience
    - Equally heterosexual and homosexual
    - Largely homosexual, but considerable heterosexual experience
    - Largely homosexual, some heterosexual experience
    - Entirely homosexual

17. Which of the following best describes your sexual desires?
    - Entirely heterosexual
    - Largely heterosexual, some homosexual desire
    - Largely heterosexual, but considerable homosexual desire
    - Equally heterosexual and homosexual
    - Largely homosexual, but considerable heterosexual desire
    - Largely homosexual, some heterosexual desire
    - Entirely homosexual

Fertility

FEMALE FERTILITY/PREGNANCY

1. Have you ever been seen by a gynecologist?
☐ Yes
☐ No

2. Have you ever been seen by an OBGYN?
☐ Yes
☐ No

3. Are you on any form of Birth control?
☐ Yes
☐ No
If yes, what type?
☐ Oral contraceptives
☐ Intrauterine Device (IUD)
☐ Implant (Implanon)
☐ Barrier Method (condoms)
☐ Other: _____

4. Have you ever been pregnant?
☐ Yes
☐ No
If yes, how many times have you been pregnant? _____

5. Have you delivered any children?
☐ Yes
☐ No
If yes, what kind of delivery did you have?
☐ Vaginal, *How many* _____
☐ C-section, *How many* _____

6. Have you ever received conception/ fertility counseling?
☐ Yes
☐ No

7. Have you ever heard of Assisted Reproductive Technology (In Vitro Fertilization)?
☐ Yes
☐ No

8. What is your marital status
☐ Never married/ single
☐ Currently married
☐ Divorced
☐ Separated
☐ Widowed

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PRIMARY DIAGNOSIS **Medical Record**

6. **Type of Spina Bifida or Neurourological Abnormality:** (Choose one)

- ☐ Myelomeningocele
- ☐ Meningocele
- ☐ Bladder Extrophy
- ☐ Cloacal Extrophy
- ☐ Posterior Urethral Valve
- ☐ Other _____

PRENATAL CLOSURE

8. **Prenatal Closure:**

- ☐ Yes
- ☐ No

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SURGERIES AND PROCEDURES

Source of date: **A = Actual from Chart, E = Estimated, U = Unknown**. Enter the actual date. If the actual date cannot be determined, enter the estimated date (from patient) or unknown (1/1/1900).
Surgeries with an * will require all historical surgical dates to be entered.

34. Neurosurgery	**Date** (MM/DD/YYYY)	**Source of date**
☐ *Shunt placement	____ / ____ / ____	_____
Type:		
☐ Other: _____		
☐ Shunt revision	____ / ____ / ____	_____
☐ Other (spina bifida repair, EVD, etc.) _____	____ / ____ / ____	_____

35. Urology Surgery	**Date** (MM/DD/YYYY)	**Source of date**
☐ *Bladder Augmentation	____ / ____ / ____	_____
Bowel Segment Used: _____		
☐ *Appendicovesicostomy	____ / ____ / ____	_____
☐ *Vesicostomy	____ / ____ / ____	_____
☐ Vesicostomy Closure	____ / ____ / ____	_____
☐ *Anti-Reflux Procedure	____ / ____ / ____	_____
☐ *Bladder Outlet Procedure	____ / ____ / ____	_____
☐ *Stone Surgery/Removal	____ / ____ / ____	_____
☐ *Orchiopexy / Orchiectomy	____ / ____ / ____	_____
☐ *Ilevesicostomy	____ / ____ / ____	_____
☐ Other _____	____ / ____ / ____	_____

36. GI Surgery	**Date** (MM/DD/YYYY)	**Source of date**
☐ *MACE	____ / ____ / ____	_____
☐ *Ileostomy	____ / ____ / ____	_____
☐ *Colostomy	____ / ____ / ____	_____
☐ Gastrostomy	____ / ____ / ____	_____
☐ *Cecostomy button / Chait tube	____ / ____ / ____	_____
☐ Other _____	____ / ____ / ____	_____

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URODYNAMICS, CREATININE, ULTRASOUND AND CYTOGRAPHY

37. Urodynamics **Date** (MM/DD/YYYY) **Source of Date**

☐ **Urodynamics Date:** ____ / _____ / ____ _____

Findings: Bladder
- ☐ Hostile
- ☐ Intermediate
- ☐ Safe (but not normal)
- ☐ Normal
- ☐ Information not available

Bladder Neck/Outlet
- ☐ Open
- ☐ Closed
- ☐ Not able to determine
- ☐ Information not available

Pressure at which detrusor leakage noted
- ☐ < 40 cm H20
- ☐ ≥ 50 cm H20

LAB RESULTS

38. Serum Creatinine Date: ____ / ____ / ____ **GFR:** _____

Results (Numeric values only): _____

IMAGING STUDIES

Medical Record

39. Ultrasound

☐ Yes
☐ No
Date: ____ / ____ / ____ (MM/DD/YYYY)

Degree of Hydronephrosis:

Left Kidney:	Right Kidney:
☐ None	☐ None
☐ Mild (SFU1-2)	☐ Mild (SFU1-2)
☐ Moderate (SFU 3)	☐ Moderate (SFU 3)
☐ Severe (SFU 4)	☐ Severe (SFU 4)
☐ Not able to determine	☐ Not Able to Determine

40. Vesicoureteral Reflux

☐ Yes
☐ No
Date: ____ / ____ / ____ (MM/DD/YYYY)

Results:

VUR Left:	VUR Right:
☐ No VUR	☐ No VUR
☐ Mild (1-2)	☐ Mild (1-2)
☐ Moderate (3)	☐ Moderate (3)
☐ Severe (4-5)	☐ Severe (4-5)

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Appendix 2. For Male Patients

IDENTIFYING INFORMATION

Patient Last Name: _____
Patient First Name: _____
Date of Visit: ____ / ____ / ____ (MM/DD/YYYY)

Zip Code (5 digits): _____

DEMOGRAPHIC INFORMATION

1. **Date of Birth:** ____ / ____ / ____ (MM/DD/YYYY)
2. **Place of Birth:**
   State/Territory: _____
   Or Country: _____
3. **Ethnicity**: (Choose one)
   - ☐ Hispanic or Latino
   - ☐ Not Hispanic or Latino
4. Race
   - ☐ White
   - ☐ Black of African American
   - ☐ Asian
   - ☐ Native Hawaiian or Pacific Islander
   - ☐ American Indian or Alaska Native
   - ☐ Other
   - ☐ Unknown

MEASUREMENTS

Weight: _____
Height: (Choose One)
- ☐ Arm Span: _____cm
- ☐ Recumbent: _____cm
- ☐ Standing: _____cm

HEALTH INSURANCE

Type of Insurance: (Check all that apply)

- ☐ Straight commercial insurance
- ☐ Commercial insurance HMO
- ☐ Commercial insurance PPO
- ☐ Straight Medicaid
- ☐ Medicaid HMO
- ☐ Other: _____
- ☐ Straight Medicare
- ☐ Medicare HMO
- ☐ State High Risk Plan
- ☐ Tricare/Other Military
- ☐ Uninsured

MARITAL AND EMPLOYMENT STATUS

Employment Status:

- ☐ Employed Full-time
- ☐ Employed Part-time
- ☐ Occasional Worker
- ☐ Volunteer
- ☐ Not Employed

If not Employed:

- ☐ Child or Student
- ☐ Homemaker
- ☐ Seeking work, but not currently working
- ☐ Permanently Disabled
- ☐ Retired

Marital Status:

- ☐ Single
- ☐ Married
- ☐ Partner
- ☐ Divorced/Separated
- ☐ Widowed

EDUCATION

Is patient a current student? ☐ Yes ☐ No

Education level:

- ☐ Pre-elementary
- ☐ Primary/Secondary
  - ☐ Grade (1-12)
- ☐ Technical School
- ☐ Some college
- ☐ College Degree
- ☐ Advanced Degree
- ☐ Other: _____

Has an IEP? (Current primary/secondary students only)

☐ Yes ☐ No

MOBILITY

Ambulation Status:

- ☐ Community ambulatory – The patient walks indoors and outdoors for most activities and may need crutches or braces or both. Uses a wheelchair only for long trips out of the community.
- ☐ Household ambulatory – The patient walks only indoors and with apparatus. Able to get in and out of the chair and bed with little if any assistance. May use the wheelchair for some indoor activities at home and school and for all activities in the community.
- ☐ Therapeutic ambulatory – The patient walks only for a therapy session in school or in the hospital. Otherwise uses a wheelchair to get from place to and to satisfy all needs for transportation.
- ☐ Non-ambulator – Uses a wheelchair exclusively for transportation, but usually can transfer from chair to bed.

What is the highest level of bracing used to ambulate on a daily basis?

- ☐ SMO – Supra-Malleolar Orthosis
- ☐ AFO – Ankle Foot Orthosis
- ☐ KAFO – Knee Ankle Foot Orthosis
- ☐ HKAFO – Hip Knee Ankle Foot Orthosis
- ☐ RGO – Reciprocating Gait Orthosis
- ☐ Not Applicable

Does patient use a wheelchair?

- ☐ Yes
- ☐ No

Please indicate primary type of wheelchair?

- ☐ Self-propelled manual wheelchair
- ☐ Self-propelled chair with power assist
- ☐ Attendant only propelled wheelchair
- ☐ Power wheelchair or scooter

If the patient is a therapeutic or non-ambulator, is the patient able to transfer from a wheelchair to another level surface without assistance?

- ☐ Yes
- ☐ No

Does the patient use braces or assistive devices?

- ☐ Braces
- ☐ Assisted devices

BLADDER MANAGEMENT

Present Bladder Management

☐ No management
☐ Clean intermittent catheterization

A. Is a surgically-created catheterizable channel used?

☐ Yes
☐ No

B. If performing CIC, it is mostly performed by:

☐ Patient
☐ Caregiver

☐ Voluntary/Intentional void in toilet
☐ Vesicostomy
☐ Crede
☐ Indwelling catheter
☐ Urostomy bag
☐ Condom catheter

Age at which CIC Began:

☐ Less than 1 year
☐ 1 year to less than 3 years
☐3 years to less than 6 years
☐ 6 years to less than 9 years
☐ 9 years less than 12 years
☐ Older than 12 years

Has the patient been instructed to void or catheterize on a schedule?

☐ Yes
☐ No

Are any of the following medications currently prescribed?

☐ Yes
☐ No

If yes, which groups?

☐ Anti-cholinergics (Ditropan, Detrol, Vesicare, etc.)
☐ Alpha blocker
☐ Alpha agonist
☐ Daily antibiotic

Quantify frequency of urinary incontinence during the day over the last month (when not having a urinary tract infection):

☐ Cannot assess
☐ Greater than or equal to once per day **(daily)**
☐ Less than once per day, more than or equal to once per week **(weekly)**
☐ Less than once per week, greater than or equal to once per month **(monthly)**
☐ Less than once per month **(less than monthly)**
☐ Never

Undergarment worn during the day:

☐ Underwear only
☐ Underwear with pad
☐ Protective undergarment (diaper, pull-up)

Over the past month during the night, (when not having a urinary tract infection), the patient has had urinary incontinence:

☐ Yes
☐ No

Has the patient been recommended to have Botox injection into the bladder:

☐ Yes
☐ No

Has the patient had Botox injection in the past?

☐ Yes
Dates: _____
☐ No

BOWEL MANAGEMENT

Is patient currently on a bowel management program?

☐ Yes
☐ No

As part of the present bowel management program, patient uses the following:

As part of the present bowel Management program, patient takes Oral medications:

☐ Stimulant (senna, Miralax [glycolax, PEG, polyethylene glycol])
☐ Softener (Colace [docusate/dioctyl]), Mineral oil)
☐ Bulking agents/Fiber
☐ None

	A. Patient Uses	**B. Completely Independently**
Suppository	☐	☐
Standard rectal enema	☐	☐
Cone rectal enema	☐	☐
Digital simulation	☐	☐
Timed evacuation	☐	☐
Disimpaction	☐	☐
Antegrade enema	☐	☐
Mini-enemas (Enemeez, theravac)	☐	☐
None	☐	☐

Quantify frequency of stool incontinence over the last month when not ill.

☐ Cannot assess
☐ Greater than or equal to once per day **(daily)**
☐ Less than once per day, more than or equal to once per week **(weekly)**
☐ Less than once per week, greater than or equal to once per month **(monthly)**
☐ Less than once per month **(less than monthly)**
☐ Never

BOWEL PROGRAM HISTORY

Age at which first bowel program initiated:

Patient's age at the time: _____

☐ Never on a bowel program

VISIT HISTORY QUESTION

Number of multidisciplinary SB clinic visits since the last SB Registry visit. This will be entered on the report submission screen at the time you submit your report.

☐ First visit
☐ Not first visit
☐ 1 time
☐ 2-3 times
☐ 4-5 times
☐ 6 or more times

VISIT HISTORY QUESTION

Number of Emergency Room visits since last intake: _____

Number of hospitalizations since last visit: _____

Reasons: _____
_____
_____
_____

FUNCTIONAL STATUS

1. Total Assist: *Perform few (<25%) activities independently*	**4. Minimal Assist:** *Perform most (>75%) activities independently*	**6. Moderate Independence:** *Perform all activity independently, but need extra time or devices*
2. Maximal Assist: *Perform some (<50%) activities independently*	**5. With Supervision:** *Able to perform all activities independently only with supervision assistance*	**7. Complete Independence:** *Perform all activity independently in a timely manner*
3. Moderate Assist: *Perform many (50-75%) activities independently*		

SELF CARE	**Total Assist**	**Maximal Assist**	**Moderate Assist**	**Minimal Assist**	**With Supervision**	**Moderate Independ.**	**Complete Independ.**
Feeding	1	2	3	4	5	6	7
Grooming	1	2	3	4	5	6	7
Bathing	1	2	3	4	5	6	7
Dressing Upper Body	1	2	3	4	5	6	7
Dressing Lower Body	1	2	3	4	5	6	7
Toileting	1	2	3	4	5	6	7
SPHINCTER CONTROL	**Total Assist**	**Maximal Assist**	**Moderate Assist**	**Minimal Assist**	**With Supervision**	**Moderate Independ.**	**Complete Independ.**
Bladder Management	1	2	3	4	5	6	7
Bowel Management	1	2	3	4	5	6	7
MOBILITY, TRANSFERS	**Total Assist**	**Maximal Assist**	**Moderate Assist**	**Minimal Assist**	**With Supervision**	**Moderate Independ.**	**Complete Independ.**
Bed to chair, wheelchair	1	2	3	4	5	6	7
Toilet	1	2	3	4	5	6	7
Tub/Shower	1	2	3	4	5	6	7
Car Transfer	1	2	3	4	5	6	7
MOBILITY LOCOMOTION	**Total Assist**	**Maximal Assist**	**Moderate Assist**	**Minimal Assist**	**With Supervision**	**Moderate Independ.**	**Complete Independ.**
Walking or Wheelchair	1	2	3	4	5	6	7
Stairs	1	2	3	4	5	6	7

SEXUAL FUNCTION **(Ask only if patient is 18 years or older and is consenting to answer in private)**

Is the patient currently sexually active?	Yes	☐	No	☐	
Has the patient ever been sexually active?	Yes	☐	No	☐	
Does the patient have desire to become or continue to be sexually active?	Yes	☐	No	☐	
Does the patient have a desire to learn about:					
Sexuality:	Yes	☐	No	☐	
Fertility:	Yes	☐	No	☐	
Does the patient have any biological children?	Yes	☐	No	☐	
If Yes:	**If Yes and Fertile:**				
How many? _____	**How many pregnancies?**		_____		
	How many deliveries?		_____		
	Type of delivery:		_____		
	Health of children:		_____		
	Full Term?	Yes	☐	No	☐

SEXUAL HEALTH INVENTORY – MEN (SHIM)

Please mark the circle next to the choice that best answers the question.

During the past 6 months…

1. How do you rate your confidence that you could keep an erection?
    - Very low
    - Low
    - Moderate
    - High
    - Very high

2. When you had erections with sexual stimulation, how often were your erections hard enough for penetration?
    - Almost never or never
    - Much less than half the time
    - About half the time
    - Much more than half the time
    - Almost always or always

3. During sexual intercourse, how often were you able to maintain your erection after you had penetrated your partner?
    - Almost never or never
    - Much less than half the time
    - About half the time
    - Much more than half the time
    - Almost always or always

4. During sexual intercourse, how difficult was it to maintain your erection to completion of intercourse?
    - Extremely difficult
    - Very difficult
    - Difficult
    - Slightly difficult
    - Not difficult

5. When you attempted sexual intercourse, how often was it satisfactory to you?
    - Almost never or never
    - Much less than half the time
    - About half the time
    - Much more than half the time
    - Almost always or always

MALE FERTILITY

1. Have you fathered any biological children through intercourse?

☐ Yes
☐ No
If so, how many? _____

2. Do you use any form of contraception?

☐ Yes
☐ No
If yes, what type?
- ☐ Condoms
- ☐ Spermicide
- ☐ Partner contraception (IUD, Pills)
- ☐ Other: _____

3. **Have you ever heard of Assisted Reproductive Technology (In Vitro Fertilization)?**

☐ Yes
☐ No

4. Have you ever received conception fertility counseling?

☐ Yes
☐ No

5. What is your marital status?

☐ Never married/ single
☐ Currently married
☐ Divorced
☐ Widowed

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PRIMARY DIAGNOSIS **Medical Record**

6. **Type of Spina Bifida or Neurourological Abnormality:** (Choose one)

- ☐ Myelomeningocele
- ☐ Meningocele
- ☐ Bladder Extrophy
- ☐ Cloacal Extrophy
- ☐ Posterior Urethral Valve
- ☐ Other _____

PRENATAL CLOSURE

8. **Prenatal Closure:**

- ☐ Yes
- ☐ No

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SURGERIES AND PROCEDURES

Source of date: **A = Actual from Chart, E = Estimated, U = Unknown**. Enter the actual date. If the actual date cannot be determined, enter the estimated date (from patient) or unknown (1/1/1900).
Surgeries with an * will require all historical surgical dates to be entered.

34. Neurosurgery	**Date** (MM/DD/YYYY)	**Source of date**
☐ *Shunt placement	____ / ____ / ____	_____
Type:		
☐ Other: _____		
☐ Shunt revision	____ / ____ / ____	_____
☐ Other (spina bifida repair, EVD, etc.) _____	____ / ____ / ____	_____

35. Urology Surgery	**Date** (MM/DD/YYYY)	**Source of date**
☐ *Bladder Augmentation	____ / ____ / ____	_____
Bowel Segment Used: _____		
☐ *Appendicovesicostomy	____ / ____ / ____	_____
☐ *Vesicostomy	____ / ____ / ____	_____
☐ Vesicostomy Closure	____ / ____ / ____	_____
☐ *Anti-Reflux Procedure	____ / ____ / ____	_____
☐ *Bladder Outlet Procedure	____ / ____ / ____	_____
☐ *Stone Surgery/Removal	____ / ____ / ____	_____
☐ *Orchiopexy / Orchiectomy	____ / ____ / ____	_____
☐ *Ilevesicostomy	____ / ____ / ____	_____
☐ Other _____	____ / ____ / ____	_____

36. GI Surgery	**Date** (MM/DD/YYYY)	**Source of date**
☐ *MACE	____ / ____ / ____	_____
☐ *Ileostomy	____ / ____ / ____	_____
☐ *Colostomy	____ / ____ / ____	_____
☐ Gastrostomy	____ / ____ / ____	_____
☐ *Cecostomy button / Chait tube	____ / ____ / ____	_____
☐ Other _____	____ / ____ / ____	_____

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URODYNAMICS, CREATININE, ULTRASOUND AND CYTOGRAPHY

37. Urodynamics **Date** (MM/DD/YYYY) **Source of Date**

☐ **Urodynamics Date:** ____ / _____ / ____ _____

Findings: Bladder
- ☐ Hostile
- ☐ Intermediate
- ☐ Safe (but not normal)
- ☐ Normal
- ☐ Information not available

Bladder Neck/Outlet
- ☐ Open
- ☐ Closed
- ☐ Not able to determine
- ☐ Information not available

Pressure at which detrusor leakage noted
- ☐ < 40 cm H20
- ☐ ≥ 50 cm H20

LAB RESULTS

38. Serum Creatinine Date: ____ / ____ / ____ **GFR:** _____

Results (Numeric values only): _____

IMAGING STUDIES **Medical Record**

39. Ultrasound

☐ Yes
☐ No
Date: ____ / ____ / ____ (MM/DD/YYYY)

Degree of Hydronephrosis:

Left Kidney:
- ☐ None
- ☐ Mild (SFU1-2)
- ☐ Moderate (SFU 3)
- ☐ Severe (SFU 4)
- ☐ Not able to determine

Right Kidney:
- ☐ None
- ☐ Mild (SFU1-2)
- ☐ Moderate (SFU 3)
- ☐ Severe (SFU 4)
- ☐ Not Able to Determine

40. Vesicoureteral Reflux

☐ Yes
☐ No
Date: ____ / ____ / ____ (MM/DD/YYYY)

Results:

VUR Left:
- ☐ No VUR
- ☐ Mild (1-2)
- ☐ Moderate (3)
- ☐ Severe (4-5)

VUR Right:
- ☐ No VUR
- ☐ Mild (1-2)
- ☐ Moderate (3)
- ☐ Severe (4-5)

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