

A CROSS-SECTIONAL STUDY OF SEXUAL FUNCTION AND FERTILITY STATUS IN ADULTS WITH CONGENITAL GENITOURINARY ABNORMALITIES

Hypothesis / aims of study

In this study, we investigated the sexual function and fertility status of adult patients with congenital genitourinary abnormalities (CGUA) in a tertiary transitional urology care setting.

Study design, materials and methods

This cross-sectional study included adult patients with congenital spinal dysraphism and other forms of CGUA who were referred to a single tertiary transitional care clinic. Of the 164 total referred patients, 72 patients consented and filled out questionnaires between 2013-2017. Patients were offered and received assistance in completing questionnaires by research coordinators. The questionnaires included questions about education level, functional status, bowel and bladder continence, partnership, sexual function, and fertility status. The questionnaires for males included the Sexual Health Inventory for Men (SHIM) whereas the female questionnaires included the Brief Index of Sexual Functioning for Women (BISF-W).

Results

Of the 72 patients administered questionnaires, 64 (88.9%) responded to questions pertaining to their sexuality and fertility status. 4 patients were excluded from analysis because of poor cognitive ability and/or functional status, which was defined as an education level of pre-elementary and cumulative self-care score of ≤ 12 respectively. 60 participants (25 males, 35 females) ranging in age from 15-75 years (mean 24.7 years, SD 8.9) remained.

Males: 23 of the 25 male participants (92%) responded to the sexual function questionnaire (Table 1). 16 men had myelomeningocele (MMC), 1 lumbar meningocele, 1 sacral agenesis, 1 cloacal exstrophy, and 4 had other CGUA. 10 men (43.5%) reported a history of sexual activity, with 6 (26.1%) being currently sexually active. 16 (69.6%) expressed a desire to become or continue being sexually active, and 12 (52.2%) wanted to learn more about sexuality and/or fertility. The most commonly unanswered questions by male participants were those regarding further sexuality/fertility education (n=4).

17 of the 25 male participants (68%) responded to the fertility questionnaire. At the time of investigation, 14 men (82.4%) were unmarried, 2 (11.8%) were married, and 1 (5.9%) was widowed. None of the men had fathered biological children. 5 (29.4%) reported using a form of contraception, of which all specified condoms. None of the men had ever received fertility counselling, and 10 (58.8%) had never heard of assisted reproductive technologies (ART).

10 of the 25 male participants (40%) completed the SHIM questionnaire in entirety. The mean SHIM score was 16.5 (range 10-24, SD 3.5). 1 man (10%) had no erectile dysfunction (ED), 5 (50%) had mild, 3 (30%) had mild/moderate, 1 (10%) had moderate, and none had severe ED. 5 men (20%) partially completed the SHIM questionnaire, so a composite score could not be calculated. The remaining male participants (40%) left the questionnaire blank despite being offered assistance in filling it.

Females: 34 of the 35 female participants (97.1%) responded to the sexual function questionnaire. 20 women had MMC, 2 tethered cord, 2 bladder exstrophy, 2 cloacal exstrophy, and 8 had other CGUA. 9 women (26.5%) reported a history of sexual activity, with 5 (14.7%) being currently sexually active. 9 (26.5%) expressed desire to become or continue being sexually active, and 7 (20.6%) wanted to learn more about sexuality and/or fertility. The most commonly unanswered questions by female participants were those regarding further sexuality/fertility education (n=10) and the desire to become/continue being sexually active (n=4).

27 of the 35 female participants (77.1%) responded to the fertility questionnaire (Table 1). 14 (51.9%) had previously seen an obstetrics/gynecology specialist, and 11 (40.7%) reported using a form of birth control, with the majority (n=7, 63.6%) taking oral contraceptives. At the time of investigation, 25 (92.6%) were unmarried, and 1 (3.7%) was married. The married woman was the only participant who had been pregnant and given birth to children. 1 woman (3.7%) affirmed receiving fertility counselling in the past, and 15 (55.6%) women had never heard of ART.

27 of the 35 female participants (77.1%) responded to the BISF-W questionnaire. 7 (25.9%) currently had a sexual partner, with 4 (14.8%) reporting sexual activity in the past month. 11 women (40.7%) 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 7 dimensions: 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). Of the 7 dimensions, D1 and D2 had the highest response rate (n=24, 88.9%). Descriptive statistics of the D1 and D2 scores are given in Table 2.

| | All subjects (n=57) | Female participants (n=34) | Male participants (n=23) |
|---|------------------------|-------------------------------|-----------------------------|
| History of sexual activity | 19 (33.3%) | 9 (26.5%) | 10 (43.5%) |
| Currently sexually active | 11 (19.3%) | 5 (14.7%) | 6 (26.1%) |
| Desire to become/continue being sexually active | 25 (43.9%) | 9 (26.5%) | 16 (69.6%) |
| Desire to learn about sexuality/fertility | 19 (33.3%) | 7 (20.6%) | 12 (52.2%) |

TABLE 2. Descriptive statistics (mean, SD, and range) for BISF-W D1 and D2 scores in all women and in the subsets of women with partners and without partners

| Dimension | Descriptive Statistics | All subjects (n=24) | With partners (n=7) | Without partners (n=17) | t statistic (p-value) |
|---|------------------------|---------------------|---------------------|-------------------------|-----------------------|
| D1 Thoughts/Desire Possible score range: 0-12 | Mean | 1.29 | 3.29 | 0.47 | 3.305 (<0.01) |
| | SD | 2.27 | 2.69 | 1.50 | |
| | Range | 0-9 | 1-9 | 0-6 | |
| D2 Arousal Possible score range: 0-8 | Mean | 1.42 | 3.57 | 0.53 | 4.492 (<0.001) |
| | SD | 2.04 | 1.90 | 1.33 | |
| | Range | 0-5 | 0-5 | 0-4 | |

Interpretation of results

Our study demonstrates that adult patients with CGUA generally lacked knowledge about sexuality and fertility despite their interest in these topics. Regardless of gender, over half of participants had never heard of ART, and only 1 had received prior fertility counselling. 1/3 of participants wanted to learn more about sexuality and/or fertility. 24.6% (n=14) of participants were not currently sexually active but wanted to become sexually active.

A possible explanation for the discrepancy between participants' knowledge of and desire to learn about sexuality and fertility could be their hesitancy to ask healthcare professionals about such topics. In addition, 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. Only 40% of male participants completed the SHIM questionnaire, a standard diagnostic aid for ED screening. This poor response rate could reflect participants' discomfort addressing sexuality and fertility in a healthcare setting. Many adults with CGUA do not receive sexual education in school, and only a small fraction report receiving sexual education specific to their diagnoses either from home, clinic, or school. [1, 2] Discussion of sexuality and fertility should occur early in adolescence in order to promote patient comfort with such topics. [3] Furthermore, these questionnaires may be too difficult and detailed for this patient population. Improvement of standard sexuality questionnaires may be indicated.

Concluding message

Adults with CGUA desire more sexuality and fertility education but are hesitant to address 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. Modification or updates may need to be considered.

References

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Disclosures

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