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# Validated questionnaires suggest sexual dysfunction in adult females with a history of anorectal malformation

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## Background

- The psychosocial and sexual well-being of adult women with a history of anorectal malformation (ARM) is largely unknown due to sparse data and data from questionnaires that have not been validated
- ARM are a spectrum of diagnoses that affect 1 in 5000 live births<sup>1</sup>
- Surgical improvements in care have resulted in an emphasis on long term outcomes and topics such as sexual well-being in this population

## Objective

- This study aims to describe the landscape of sexual function and sexual self-image in this population.

**Hypothesis:** We hypothesize that women with a history of ARM will have sexual dysfunction and body dysmorphia on validated questionnaires

## Methods

- Inclusion criteria: ≥18 years old and a diagnosis of ARM (cloaca, rectovestibular fistula, rectoperineal fistula)
- Exclusion criteria: Cloacal Exstrophy
- 52 patients met criteria, 15 patients consented and completed validated questionnaires: Female Sexual Function Index (FSFI) and Female Genital Self-Image Scale (FGSIS)

## Results

- Age range 21-56, median age 34yo
- Mean total FSFI score (N=12 -> 3 didn't report sexual activity): 20.7 ± 7.0 (higher scores indicate more sexual function)
- Mean FGSIS (N=15): 15.6 ± 4.8 (higher scores indicate a more positive genital self-image)

## Conclusions

- Mean FSFI score of this population is below cutoff of ≤ 26.55 (specificity=0.733; sensitivity=0.889)<sup>2</sup> suggesting relevant sexual dysfunction
- High mean Satisfaction Domain score may suggest satisfaction with emotional closeness and overall sex life

## Main Points and Key Takeaways

- Our cohort of patients, women with ARM, had a mean FSFI score indicative of sexual dysfunction
- The mean FGSIS score for our cohort indicates dissatisfaction with genitalia appearance and providers should be prepared to discuss these concerns with patients
- We are addressing the low N for this study by reaching out to more patients who meet criteria
- We are in the process of launching a qualitative study to better understand the experiences of this population and plan to develop a disease-specific measure of sexual function to better serve this population

## Disclaimers and Acknowledgements

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## Data: Total and Domain Scores of FSFI and FGSIS

Total and Domain Scores (Range)	N	Mean	Standard Deviation	Median
FSFI Total (2-36)	12	20.7	7.0	19.3
FSFI Desire Domain (1.2-6)	12	2.9	1.0	3.0
FSFI Arousal Domain (0-6)	12	3.8	1.5	3.6
FSFI Lubrication Domain (0-6)	12	3.4	2.0	3.75
FSFI Orgasm Domain (0-6)	12	3.1	2.3	2.8
FSFI Satisfaction Domain (0.8-6)	12	4.0	1.2	4.2
FSFI Pain Domain (0-6)	12	3.5	2.5	4.6
FGSIS Total (7-28)	15	15.6	4.8	15

## Limitations

- We have a small sample size of N=15 (28.8% of the eligible participants completed the questionnaires) which limits the power of the study
- We are collaborating with another researcher who has a research registry where we were able to identify more eligible participants who we are in the process of inviting to participate in the study to get a larger N

## Future Directions

- We are in the process of launching a qualitative study to better understand the experience of women with ARM that current questionnaires cannot capture
- Our ultimate goal is to develop a disease-specific measure of sexual function to better serve this population

### References:

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