Unique Evaluation and Management Considerations for Adolescents with Late Gynecologic and Colorectal Issues in the Setting of Anorectal Malformations

Wendy Jo Svetanoff

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Submitting/Presenting Author (must be a trainee): Wendy Jo Svetanoff
Primary Email Address: wsvetanoff@cmh.edu

☐ **Medical Student**
☐ **Resident/Psychology Intern (≤ 1 month of dedicated research time)**
☐ **Resident/Ph.D/post graduate (> 1 month of dedicated research time)**
X Fellow

Primary Mentor (one name only): Rebecca M Rentea, MD MS
Other authors/contributors involved in project: Ashli Lawson, MD; Joseph J Lopez, MD; Kayla B Briggs, MD; James A Fraser, MD; Christina Low Kapalu, PhD; John Gatti, MD; Anne-Marie Priebe, DO; Julie Strickland, MD MPH

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Describe role of Submitting/Presenting Trainee in this project (limit 150 words): I participated in data collection, performed data analysis, and formulated the initial version of the abstract.

Background, Objectives/Goal, Methods/Design, Results, Conclusions limited to 500 words

Background: Females born with anorectal malformations (ARMs) and bladder exstrophy have a greater incidence of Mullerian and genital anomalies requiring early gynecologic assessment and frequent surgical intervention. However, there is little guidance for management considerations of pubertally identified Mullerian anomalies in these patients

Objectives/Goal: We sought to assess the unique colorectal, gynecologic, and psychological issues present during the adolescent years.

Methods/Design: A retrospective review was performed of 10-25 year old female patients born with an ARM, cloaca, or exstrophy that presented to our multidisciplinary clinic between 2009 and 2019. Data abstracted included the presenting problem, history, imaging studies, psychological evaluation, fertility and sexuality concerns, gynecologic cosmesis, and management.

Results: Twelve patients were identified; all presented with gynecologic concerns. The median age at re-presentation was 14.6 years (IQR 12.7, 15.3). Nine patients had ARM, including 2 with cloaca and 4 with cloacal exstrophy. Since re-presentation colorectal revisions included posterior sagittal anorectoplasty (n=1), resection of bowel attached to urogenital sinus (n=1), and appendicostomy revisions (n=1).

Gynecologic issues included dysmenorrhea (n=8), obstructed Mullerian anomaly (n=6) and introital stenosis from prior surgery (n=3). Compared to the younger children with ARMs, this population had concerns about vaginal and introital cosmesis, fertility, gender identity, sexuality, and mental health. Multiple clinical visits were required to achieve consensus among patients and providers prior to operative intervention, which included vaginal reconstruction (n=5) and hysterectomy of obstructed uterine horns (n=2). The median time from first clinic visit to gynecologic reconstruction was 5 years (1.8, 6.9). Thus, an overarching theme was the need for a cohesive multidisciplinary team, including the surgical subspecialists, gastroenterologists, and psychologists, with a heightened awareness of increasing patient autonomy in the adolescent period.

Conclusions: Patients with ARM, cloaca, or exstrophy may re-present during adolescence with unique gynecologic or colorectal concerns. Goal directed long-term follow-up is required for early identification of psychological and reproductive issues. The adolescent should be actively involved in the decision making process, and the physician team should have a heightened awareness of psychological and reproductive issues and of long-term concerns and needs.