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Long term bowel function after repair of anorectal malformations in Uganda



Felix Oyania^{a,*}, Alfred Ogwal^a, Stella Nimanya^a, Arlene Muzira^a, Nasser Kakembo^a, Phyllis Kisa^a, John Sekabira^b

^a Makerere University College of Health Sciences, Department of Surgery, P.O.BOX 7072, Kampala, Uganda

^b Mulago National Referral Hospital, Department of Surgery, P.O.BOX 7072, Kampala, Uganda

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ABSTRACT

Background: Anorectal malformations (ARMs) are common congenital anomalies cared for at Mulago Pediatric Surgery Unit (PSU), similar to other sites in the region. All patients undergo staged repairs and complete treatment at older ages compared to high-income countries (HICs). This is the first study to examine long-term bowel function in our patients and compare with HICs.

Methods: A retrospective cohort study was conducted of all children 3–12 years old with ARMs who had repair between January 2012 and June 2017 and who completed surgical repair at least 6 months prior to the study. Bowel function was measured using the fecal continence scoring system derived from Rintala and Lindahl (1995). As in prior studies, patients were classified by score into four categories: Poor (6–9); Fair (9–11); Good (12–17); and Normal (18–20).

Results: Median follow up was 2 years post stoma closure. Long-term bowel function was Normal/Good in 65% (C.I 27, 45), and Fair/Poor 35% (C.I 55, 73), with soiling in 49% (C.I 40, 59), constipation in 23% (C.I 16, 32); and incontinence in 39% (C.I 30, 39). There was no statistically significant association between bowel function and multiple demographic, social, and clinical factors. Median age at completion of treatment (stoma reversal) was 2.3 years old, and median duration of colostomy (interval between stoma placement and takedown) was 1.8 years.

Conclusion: Despite definitive repair at older age and almost two years of living with a stoma, our patients achieve fair long-term bowel function. Nonetheless, improved follow up and timely management of complications may improve outcomes soiling, incontinence and constipation.

Level of evidence: Level II.

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Anorectal malformations (ARMs) are common congenital anomalies seen on the pediatric surgery unit at Mulago Hospital, a national referral hospital in Kampala, Uganda, comprising a substantial clinical burden [1]. However long-term bowel function has not been assessed despite the fact that 5–6 patients with ARMs are admitted per month, and 15–20 children complete definitive surgical management per year. Good bowel function outcomes have been reported in 75% of patients in a high income country [2], 71.30% in a middle income country [3] and 71.5% in a low income country [4]. Good outcomes are defined as having occasional staining and infrequent accidents (staining less than once per week, no change of underwear required) [6]. Our patients are often repaired at older ages owing to substantial challenges of delayed surgical access, unmet surgical needs, backlogs of patients

[7–11] and limited specialists with only four (4) practicing pediatric surgeons currently in the whole country. We hypothesized that long-term bowel function after repair is still favorable despite later definitive correction compared to high-income countries (HICs). In addition, we sought to describe social, clinical and patient factors and evaluate their association with bowel function after surgical correction. This study is part of an initiative to create a better support system for patients with ARMs. In our setting, there is no formal bowel management program for constipation and incontinence, and the only available medical treatment option is to use enemas. We have previously documented substantial burden on families caring for children with ARMs [12].

1. Methods

This was a retrospective cohort study of children between 3 and 12 years who had surgical correction of an ARM between January 2012 and June 2017. Patients were contacted by phone to come to the clinic, and those already attending clinic were recruited. The study was conducted between December 2017 and February 2018.

* Corresponding author. Tel.: +256 774666222.

E-mail addresses: oyafel@icloud.com (F. Oyania), oalfred4@gmail.com (A. Ogwal), stellahalyce@gmail.com (S. Nimanya), arlenemzr@gmail.com (A. Muzira), kakembon@ymail.com (N. Kakembo), phyllis.kisa@gmail.com (P. Kisa), jsekabira@yahoo.co.uk (J. Sekabira).

1.1. Study setting

The study was conducted at Mulago Hospital, Pediatric Surgical Out-patient Department (PSOPD). The Clinic sees an average of 51 patients and reviews 12 patients with ARMs per week (Hospital Records). Pediatric Surgery Unit (PSU) comprises one senior consultant, two consultants, one Fellow and nurses. PSU clinic runs every Wednesday with referrals from across the entire country and neighboring countries especially Democratic Republic of Congo, South Sudan and Rwanda where new cases and old patients are assessed and reviewed respectively. The clinic is run by the senior consultant, consultants, fellow, residents also known as senior house officers (SHOs) while rotating in Pediatric Surgery, and nurses. The clinic day is also used as a teaching session for the residents and the medical students.

We started with a pilot study to evaluate feasibility of follow up, showing that 8 of 10 patients who completed treatment could be reached by telephone, using their details from Pediatric Surgery Unit (PSU) data base which has been used successfully in previous studies [12,13]. The database was initiated in 2012 and was used to identify diagnosis and classify ARMs according to the Krickbeck classification [14,15].

Participants who had undergone definitive repair were contacted via telephone and requested to come to the pediatric PSOPD to participate in the study voluntarily without compensation. Patients who finished colostomy closure, often the third stage of repair in our setting, at least 6 months prior to the study were recruited. Medical records were not sufficient to identify patients treated before 2012. Children between 3 and 12 years old and clinically diagnosed with ARM who completed surgical treatment and attending PSOPD were included. We selected this age range because toilet training should be initiated at about age 2; hence a 3-year-old child should have initiated toilet training. The PSU only admits children younger than 12 years of age. Those with ARM and associated spina bifida, presacral mass or a redo PSARP were excluded. More participants were accessed through patients who identified other possible eligible study participants. Through this we were able to reach patients previously lost to follow up and strengthen the existing network among these patients. We explained clearly to all participants that we were conducting a survey, what the purpose was, and that there was no financial compensation.

Makerere University School of Medicine Research Ethics Committee (SOMREC) approved the research with registration number #REC REF 2017-166. Written informed consent forms were obtained from parents and assent for children above 8 years, and anonymous translated consent forms were given to non-English speaking respondents. The Principal Investigator and Research Assistant collected the data.

The study tool focused on bowel function (normal, incontinence, constipation and soiling). This was derived from a previously validated standardized questionnaire [6]. Patients were classified according to their scores into four categories [6] as Poor (6–9): use daily enemas because of severe constipation or had constant soiling; Fair (9–11): intermittent daily soiling or staining; Good (12–17): having occasional staining and infrequent accidents (staining less than once per week, no change of underwear required); and Normal (18–20). Basic demographic data were collected. Patients were also assessed for some factors thought to affect functional outcomes such as patient factors (age and gender), clinical factors (type of ARM), and social factors (education level of the parents and family setting). Parental/caregiver features assessed were age, gender, and education level.

In this study, and for the purpose of discussing complications related to operative technique, we assumed that most colostomies are performed at Mulago and all PSARPs are performed by the trained pediatric surgeons. Contrast studies (distal colostogram) are only done for cases where the fistula is not visible such as rectourethral fistula in males.

Data were entered using EPI Data version 3.1 and the raw data were securely stored to maintain confidentiality and later exported to STATA Version 14.0 for analysis. Means with standard deviations for normally

distributed data, or medians with interquartile range for data not normally distributed were calculated for continuous variables. Frequencies and proportions/percentages for categorical variables were also measured. For continuous variables, mean values for long-term bowel function were compared using a two-sample t test, and median values compared using Wilcoxon-Mann-Whitney test. For categorical variables, Chi-square test (or Fisher's exact test for small cell counts less than 5) were used. P values were presented and values less than 0.05 were considered statistically significant.

2. Results

We recruited 142 participants. 120 were eligible and 21 patients were excluded, of which 16 had missing contact information, 2 had a redo PSARP, 1 had an associated anomaly and 2 were awaiting colostomy reversal. 22 patients could not be reached. Of the patients recruited one patient had neoanus misplaced slightly off sphincter complex and was able to be rescheduled for redo PSARP. 3 patients had died; however, the parents reported the cause of death as not related to ARM. One died at 4 years from an unknown illness, the second at 5 years old from a febrile illness reported as malaria by the parents; and the third died at 3 years 7 months old owing to unknown causes.

There were 58% male and 42% female children. 44% females and 56% males had voluntary bowel movements (VBM) 57% had a colostomy placed within the first two weeks of life, 23% within 2–4 weeks old and 20% more at more than 4 weeks old. 46% participants came from a rural setting while 54% were from an urban setting. 66% had PSARP before 2 years old, 30% between 2 and 4 years, and 4% more than 4 years. 38% had colostomy closure at 2 years, 51% at 2–4 years and 11% more than 4 years old.

Of the caregivers, 97% were biological parents, 3% were other relatives, 74% were females and 24 males. 60% were educated to the secondary school level and 40% below primary level (Tables 1, 2). The most common type of ARM was rectourethral bulbar type (20) in males and vestibular fistula (21) in females (Table 3).

The median follow up was 2 years after colostomy closure. Bowel function at time of assessment was Good in 65% (CI 27, 45) and Poor in 35% (55, 73) with soiling in 49% (CI 40, 59), constipation in 23% (CI 16, 32), and incontinence in 39% (CI 30, 39) (Table 4). There was no

Table 1
Participant characteristics and demographics.

	Frequency (n = 99)	percentage
Age at Colostomy placement (Weeks)		
<2 weeks	56	57
2–4 weeks	23	23
>4 weeks	20	20
Gender		
Male	57	58
Female	42	42
Residence		
Rural	46	46
Urban	53	54
Caregiver		
Parents	89	90
Others	10	10
Age at PSARP (years)		
<2	65	66
2–4	30	30
>4	4	4
Age at Colostomy Reversal (years)		
<2	37	38
2–4	49	51
>4	11	11

Table 2
Caregivers' characteristics.

	Frequency (n = 99)	Percentage
Relationship of Caretaker to the Participant		
Parents	96	97
Others	3	3
Gender		
Male	26	26
Female	73	74
Education level		
Primary and below	40	40
Secondary and tertiary	59	60

statistically significant association between social, clinical, patient factors and bowel function (Tables 5, 6). (See Table 7.)

3. Discussion

This study measured long-term outcomes of bowel function after repair of ARMs at a tertiary center in Uganda. Of the 99 participants, 65% had good outcomes (as defined by prior validated scoring criteria), 61% had continence, 77% had no constipation and 51% had no soiling. Despite later presentation and delayed repair compared with HICs, and staged repair for all ARMs, outcomes were comparable to other studies that found 71%–75% good outcomes [2,3], all done in higher and middle income settings. For this study anyone with a good or normal score was considered a good outcome and those with poor or fair outcome were categorized as poor outcome.

The paper by Pena et al. used their own tool to evaluate bowel function. The paper by Ciongradi et al. from Romania defined a slightly different scale ranging from good to acceptable, and poor. They defined as “good” as presence of voluntary defecation, no or occasionally soiling, absent or mild constipation; “acceptable” as presence of bowel movement, rare soiling, moderate constipation; and “poor” as absence of voluntary defecation, moderate to severe soiling and any degree of constipation. The exact scoring system that was used was not further specified.

Kigo et al. used Pena's grading system, but “voluntary bowel movement”, was defined as the act of feeling the urge to use the toilet to have a bowel movement, the capacity to verbalize it, and to hold the bowel movement until the patient reaches the bathroom. The exact definitions for “good” and “poor” were not well-defined in their study. All these studies were retrospective with variation in the study period

Table 3
Frequency of types of ARMs according to Krickenbeck classification.

Types of ARMs	Frequency
Male groups	
Perineal (cutaneous fistula)	9
Rectourethral fistula: <i>Bulbar</i>	21
Rectourethral fistula: <i>Prostatic</i>	0
Rectovesical fistula	3
No fistula	12
Anal stenosis	12
Female groups	
Perineal (cutaneous) fistula	2
Vestibular fistula	20
Cloaca	2
No fistula	4
Anal stenosis	5
Rare/regional variants	
Pouch Colon	0
Rectovaginal fistula	9
H-type fistula	0
Others	0

Table 4

Poor outcomes expressed as frequencies with the percentages in brackets.

Fecal soiling: Passing of changeable quantities of stool to the underwear one or more times a day.

Incontinence: Involuntary bowel motions.

Constipation: Having two or less motions per week.

Outcome	Yes (%)	No (%)	Confidence interval (CI)
Soiling	49 (49)	50 (51)	(40, 59)
Constipation	23 (23)	76 (77)	(16, 32)
Social Problems	45 (45)	54 (55)	(36, 55)
Incontinence	39 (39)	60 (61)	(30, 49)

and sample size. All scoring systems used focused on soiling, constipation and incontinence. Although not an exact comparison, we thought these scoring systems would be appropriate starting point to compare our outcomes.

Our study may have shown slightly worse outcomes because those who develop treatable complications return late, families have fatigue from going through multiple stages of surgeries, and they also lack adequate information about the importance of continuous follow up. Some parents believe treatment is complete after stoma reversal, and others confessed during the study they thought those complications were normal because their children already had a problem at birth that could not be improved. This could also mean poor compliance to dilatation following anoplasty and toilet training especially. In many settings, patients are started on bowel management regimens as a normal part of post-anoplasty care. As our patients are less likely to follow up and we have no defined bowel management program at this time. Therefore, some portion of our slightly worse outcomes may be attributed to the lack of bowel management.

3.1. Factors associated with bowel function

3.1.1. Age and epidemiology

In our study, most patients presented later than in HICs, where some low anomalies such as perineal and vestibular fistula may be corrected in one stage, and those who undergo staged correction often complete definitive repair in infancy. A recent study in western Uganda demonstrated delayed diagnosis (presenting >48 h after birth) in 63.38% of patients [16]. With delayed presentation, not being able to perform primary repair may adversely impact long-term functional outcome. We hope that with improved awareness and advocacy our patients will start presenting earlier and we can consider one stage repair for low anomalies. In one study, more than 79% of children who had a colostomy placed before the age of 1 month achieved voluntary bowel movements (VBM), while 61.1% of the patients achieved VBM when a colostomy was created after 5 years of age [4].

Given a generally accepted estimated incidence of ARM of one in 3000–5000 births, 300 to 500 children are born a year with ARM in Uganda given current birth rates. However, only 100 children completed treatment over that period in our study, translating to a met need of 4%–7% assuming Mulago was the only site for definitive repair, which it was for the majority of the study period. A previous analysis of major neonatal surgical conditions in our setting estimated 3.5% of the need for neonatal surgery is met by the health system [17], hence an urgent need for capacity building to bridge this gap.

3.1.2. Gender

Our study showed 44% females and 56% males had VBM. A related study found that 77.0% girls achieved VBM compared to 63.8% of boys [4]. Girls commonly have low types of ARMs which are usually associated with constipation. In another study, constipation was more prevalent in the group with perineal, vestibular fistula and imperforate anus, but it was associated with good bowel control [3]. It is possible that many of the patients with poor outcome actually have overflow pseudoincontinence from untreated constipation owing to poor

Table 5
Bivariate analysis of long-term outcomes of bowel function with child's demographics and characteristics.

	Poor outcome (n = 35)	Good outcome (n = 64)	OR (95% C.I)
Age at colostomy placement weeks)			
<2 weeks	19 (54)	37 (58)	1.79 (0.66–4.79)
2–4 weeks	11 (31)	12 (19)	1.00
>4 weeks	5 (14)	15 (23)	2.75 (0.75–10.11)
Gender			
Male	21 (60)	36 (56)	0.86 (0.37–1.98)
Female	14 (40)	28 (44)	1.00
Residence			
Rural	19 (54)	27 (42)	1.00
Urban	16 (46)	37 (58)	1.63 (0.71–3.73)
Next of kin			
Parents	32 (91)	57 (89)	0.76 (0.18–3.16)
Others ²	3 (9)	7 (11)	1.00
Age at PSARP (years)			
<2	24 (69)	41 (64)	0.57 (0.06–5.79)
2–4	10 (29)	20 (31)	0.67 (0.06–7.25)
>4	1 (2)	3 (4)	1.00
Age at Colostomy reversal (years)			
<2	12 (35)	25 (40)	0.78 (0.18–3.48)
2–4	19 (56)	30 (48)	0.59 (0.14–2.51)
>4	3 (9)	8 (13)	1.00

Bivariate analysis of long term outcomes of bowel function with age at colostomy placement, PSARP, colostomy reversal; gender residence and next of kin. Outcomes expressed as frequencies with the percentages in brackets.

compliance to dilatation and follow-up following anoplasty, and toilet training especially for girls with vestibular fistulae.

3.2. Social factors

3.2.1. Education level of the parents

In our study, 40% and 60% parents had below and above primary level of education with 42% and 58% VBM, respectively. Since the mother's role in toilet training is such an important part of care, we thought better functional outcome may be achieved with higher maternal education level [14]. Specifically, home care of the colostomy, serial anal dilation, and compliance with follow-up appointments we thought might be associated with education level. In developing countries, especially for patients from low economic strata, the conventional practice of three stage repair (colostomy–PSARP–colostomy closure) effectively means long duration of treatment, significant costs in terms of time and resources, difficult social, environmental, and psychological stress to parents and this could affect functional outcome. One study found that of all colostomies performed, only 52% completed all stages of reconstruction [18]. Neonatal colostomy seems to worsen the clinical outcomes of these patients [18] for the same reasons. We did show that the median age of stoma reversal was more than two

years old, and that children lived nearly two years with a stoma, also highlighting the importance of home care and burden on the families. We have previously shown the burden of stomas on families in our setting [19].

3.2.2. Family setting: urban and rural

Forty-six and 54% of the patients came from rural and urban settings with 42% and 58% VBM respectively. In this study, most of the participants were from the East (outside the central region) and outcomes were poorer in regions far from the city, although this finding did not reach statistical significance. Accessibility to health care services by the urban population is easier, quicker and reliable right from the delivery period, for treatment and follow-up for any complications. This is worsened by the fact that treatment for ARMs is centralized in the National Referral Hospital owing to the few pediatric surgeons in the country [20–27]. A child born in rural areas cannot access services as easily compared to those close to the point of care, except through surgical outreach programs often organized by visiting pediatric surgeons. With better counseling, care coordination, referral, capacity building, and stoma support groups, long-term bowel function may be improved. We have since conducted pediatric emergency care workshops for front-line provider at more rural hospitals and initiated a parent-led stoma support group, with hopes to scale this activity in the future [28].

Table 6
Bivariate analysis of long-term outcomes of bowel function with caretaker's characteristics.

	Poor outcome (n = 35)	Good outcome (n = 64)	OR (95% C.I)
Relationship of Caretaker to Participant			
Parents	33 (94)	63 (98)	3.82 (0.33–43.68)
Others	2 (6)	1 (2)	1.00
Gender			
Male	5 (14)	21 (33)	1.00
Female	30 (86)	43 (67)	0.34 (0.12–1.01)
Education Level			
Primary and below	13(37)	27 (42)	1.00
Secondary and tertiary	22 (63)	37 (58)	0.81 (0.35–1.89)

3.3. Clinical factors

Table 7
Frequency of types of ARMs functional outcome.

Types of ARMs	Functional outcome	
	Poor (n = 35), (35%)	Good (n = 64), (65%)
No fistula	7 (20)	9 (14)
Rectourethral fistula: <i>Prostatic</i>	8 (22)	6 (9)
Rectovaginal fistula	2 (6)	7 (11)
Rectovesical fistula	7 (20)	1 (2)
Vestibular fistula	4 (11)	11 (17)
Anal stenosis	2 (6)	13 (20)
Rectourethral fistula: <i>Bulbar</i>	2 (6)	7 (11)
Cloaca	0 (0)	2 (3)
Perineal (cutaneous) fistula	3 (9)	8 (13)

3.3.1. Type of ARMs

The most common malformation in boys and girls were rectourethral bulbar and vestibular types, respectively. This finding is similar to that in a study by Kayima et al. [16]. Our study did not find a statistically significant association between long-term bowel function and the type of ARMs. This is in contrast to other studies [3,29,30]. We also noticed that rare diagnoses, such as rectovaginal fistula, were common and therefore pose a possibility that these cases were either misdiagnosed or confused with vestibular fistula. There was no prostatic fistula found in the database for those recruited. This could have been an error by data entry in our database or may reflect the practical difficulty in precise identification of specific position of the prostate in the urethra in such small children.

3.4. Limitations

Since the study data were collected via the caregivers' recall, there was a potential for recall bias. We used major events such as elections and public holidays to refresh the memories of the caregivers.

Selection bias may also have been a factor because some could not be reached. To overcome this, the study team recruited and identified eligible study participants through the existing network of study participants at the time. Also, the cohort followed was not randomly selected, and this too might have affected results. Specifically, fewer of the poorer, and/or isolated rural families may have been included in the study.

Also, this evaluation only captures a snapshot of bowel function outcomes at one point in time, as opposed to changes over a longer period in childhood. The short follow-up period for some patients, such as six months in some patients may have also affected assessment.

Furthermore, this study did not consider associated anomalies, which may have contributed to functional outcomes. For example, diagnosis of genetic syndromes may be missed in our setting, and studies such as spinal ultrasound to assess for tethering of the spinal cord are not routinely obtained owing to cost and resource constraints.

We acknowledge that other scoring systems such as those mentioned previously, exist and could also be useful; however, the advantages of this score are twofold. First the questionnaires are completed by patients or parents; the assessment is thus observer-independent. Second, a physical examination is not required. And as stated previously, the other scoring systems focus on similar dimensions of function, and we thought these would be appropriate comparisons for our study.

4. Conclusion

Despite definitive repair at older age and almost two years of living with a stoma, our patients achieve fair long-term bowel function. Nonetheless, improved follow up and timely management of complications may improve outcomes in terms of soiling, incontinence and constipation. There was no statistically significant association of bowel function with demographic factors, education level of the caregivers, type of malformation, and age at repair. Nonetheless, with improved follow up, awareness, counseling of families and social support programs, as well as more trained pediatric surgeons to reduce the backlog and unmet surgical need, outcomes can be improved in our setting.

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Conflict of interest

None.

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