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Methods families use to raise funds for anorectal malformation treatment at a single public referral hospital in Southwestern Uganda

Felix Oyania ,[1] Anthony N Eze,[2] Sarah Ullrich,[3] Meera Kotagal,[3] Doruk Ozgediz[4]

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[1]Surgery, Mbarara University of Science and Technology Faculty of Medicine, Mbarara, Uganda
[2]Duke University Medical Center, Durham, North Carolina, USA
[3]Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio, USA
[4]University of California San Francisco, San Francisco, California, USA

Correspondence to
Dr Felix Oyania; oyafel@icloud.com

ABSTRACT

Background In Uganda, only two public hospitals provide pediatric surgery services. With less than 10 pediatric surgeons serving approximately 20 million children in Uganda, most patients with anorectal malformations (ARMs) must make several trips to the hospital before undergoing surgery. As a result, households borrow money, sell assets, or solicit contributions from friends and relatives to meet healthcare expenses. We used a cross-sectional study to examine methods families use to raise funds for the treatment of ARMs at a single institution in Southwestern Uganda.

Methods This cross-sectional study was conducted in the pediatric surgery unit at a Regional Referral Hospital/University Teaching Hospital in Southwestern Uganda from June 2021 to July 2023. Participants included caretakers of children presenting with ARMs for treatment at our referral hospital.

Results A total of 157 participants were enrolled. Mothers were the main caregivers (77.9%) present at the hospital. Out of a median monthly household income of UGX200 000 (US$51.68), families spent a median of UGX50 000 (US$12.92) to travel to the hospital. To raise funds for healthcare expenses, 68% of households reported selling assets.

Conclusion Families sell household assets to afford ARMs treatment in Southwestern Uganda. Financial protection by the government through a national child health insurance policy would shield families from substantial health-related expenditures and decrease this burden. In addition, targeted policy to strengthen pediatric surgical capacity through workforce expansion and skills training such as the Pediatric Emergency Surgery Course, may minimize costs, improve timeliness of care, and prevent case cancellations.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Patients in most low- and middle-income countries (LMICs) incur financial burdens when seeking care from multiple centers before reaching the right place that can provide definitive anorectal malformations care. This results in substantial health-related expenses incurred by the household, threatening households' financial capacity to maintain subsistence needs already severely limited. This exacerbates the poverty levels of communities that are already impoverished.

WHAT THIS STUDY ADDS

⇒ To raise funds for healthcare expenses, 68% of households sold assets, and no participant has health insurance. The most common household assets owned by the families to raise funds were chicken/ducks (57%) and goats/sheep (53%).

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ A significant amount of money is spent on several trips to healthcare centers in LMICs before receiving surgical care due to limited pediatric surgeons and perioperative resources. It is investing in capacity building through more pediatric surgeons and anesthesia providers to fill these gaps in regional hospitals where pediatric surgical capacity is necessary to reduce the financial burden on families. Additionally, a targeted policy that will build and strengthen pediatric surgical capacity through advocating for a national child health insurance policy for universal healthcare coverage may reduce the financial burden on families.

INTRODUCTION

In Uganda, a low-income country (LIC), all healthcare services are free in public hospitals. A national health insurance scheme is currently unavailable. Patients incur financial burdens when seeking care from multiple centers before reaching the right place, one of only two public hospitals in Uganda that can provide definitive anorectal malformations (ARMs) care. Only two public hospitals in Uganda provide pediatric surgery services. With only less than 10 pediatric surgeons for approximately 20 million children in Uganda, most patients with ARMs must make several trips to the hospital before they can get treated. Mbarara Regional Referral Hospital (MRRH) is a 600-bed public government-funded referral hospital located in Southwestern Uganda with a catchment population

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of over 4 000 000 people. Additionally, it receives patients from the Democratic Republic of Congo, including up to 1/3 of our patient census being refugees from the Nakivale Refugee Settlement, one of the largest refugee settlements in the region. The pediatric surgery unit (PSU) comprises one pediatric surgeon, 14 pediatric beds, and three neonatal beds and treats an average of 309 patients each month, 3–5 of which are stoma-related, 1–3 patients with ARMs per month. The unit carries out an average of 100 procedures each month, with 10%–15% of operations on the PSU on refugee children.

These challenges highlight the gap in surgical access, high unmet surgical needs, and large backlogs of patients.[1–6] Moreover, patients presenting for subsequent ARMs-related surgeries, such as definitive repair (anoplasty) and stoma closure, often experience cancellations. Such surgeries are considered elective cases and are often canceled due to emergency cases and insufficient operating room time and space, among other factors.[7–15]

Families may make several trips to travel long distances before they can obtain the intended surgical care.[6 16–19] This leads to situations where households borrow money, sell their assets, or receive contributions from friends and relatives to meet healthcare expenses, known as distress health financing. Moreover, the loss of wages, income, and time of patient and caregiver constitute other indirect medical costs.[20] These challenges could be mitigated through national health insurance schemes currently unavailable in Uganda. Additionally, families have to travel long distances to seek care for ARMs. They spend money on lodging plus meals during their hospital stay. Families pay out-of-pocket (OOP) for investigations that are not carried out free of charge at the hospital and purchase supplies that are often out of stock.[6 17 18 21] This results in substantial health-related expenses incurred by the household,[20 22–24] threatening households' financial capacity to maintain subsistence needs which are already severely limited.[20 23 25 26] This exacerbates the poverty levels of communities that are already impoverished.

We conducted a cross-sectional study at a single institution in Southwestern Uganda to examine methods used by families to raise funds for the treatment of ARMs .

METHODS

Study design and setting

This was a cross-sectional study designed to examine the association between treatment of ARMs and methods used by families to raise funds in seeking treatment in Southwestern Uganda conducted in the PSU, department of surgery, MRRH/Mbarara University Teaching Hospital in Southwestern Uganda. We recruited participants from June 2021 to July 2023.

Participants and data sources

Study subjects included caretakers of children presenting with ARMs for treatment at our referral hospital. We included all caretakers of children who presented to our clinic after completion of ARMs surgical treatment and excluded those presenting for subsequent stages of surgeries or completed surgeries somewhere else because we could not follow them up to complete the survey. We obtained a convenience sample of all children who met the inclusion criteria.

Primary data was collected from study participants. Interviews were completed by all caretakers who presented to clinic reviews after completion of ARMs surgical treatment, defined as after the last surgery, either posterior sagittal anorectoplasty (PSARP) for single-stage repairs or colostomy reversal for the staged procedure during the study period. We obtained information such as age at diagnosis, age at the time of seeking care, sex of the child, main caretaker, place of residence (the rural—area that is located outside towns, the urban—areas related locations in towns/cities), age at completion of the surgery, cost incurred during treatment, how funds were raised for treatment, distance traveled, trips to the hospital (several travels to the hospital for a surgical procedure) before receiving surgical care and cost per trip. Cost per trip meant trips for a surgical procedure; two trips before the procedure indicated two canceled procedures.

Statistical methods

To ensure the quality of the data collected, questionnaires were cross-checked daily for completeness, with checks for missing information. The data collected were coded with unique identifiers, and a database was designed using Research Electronic Data Capture (REDCap).[27] The entered data were exported to Stata V.18.0 for data cleaning and analysis.

To assess the association between treatment of ARMs and methods used by families to raise funds in seeking treatment in Southwestern Uganda, descriptive analyses of participant responses were calculated with categorical variables reported as frequencies with percentages and continuous variables reported as mean with standard deviation (SD) or median with interquartile range (IQR). Patient and guardian characteristics were compared by patient gender and healthcare expense-related factors compared with categories of household income. Group comparisons were performed using χ^2 tests, Fischer's exact test, Wilcoxon rank-sum tests, and Kruskal-Wallis tests, as appropriate. P values less than 0.05 were considered statistically significant.

Missing values were handled using listwise deletion, removing cases with incomplete data, and analyzing the remaining data. As such, percentages may not add up to 100%.

RESULTS

We enrolled 213 participants in this study: 65 postcolostomy reversal, 22 during PSARP, and 29 during colostomy

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reversal. Of these, 56 were lost to follow-up. We included 157 participants, of which 59% were male and 41% were female. Overall, mothers were the main caregivers (77.9%) presenting with the child to the hospital. Females were significantly older than males at colostomy placement (17.5 months *v.s.* 3 months, $p<0.001$) and colostomy reversal (30 months *v.s.* 17 months, $p=0.047$). There was a statistically significant difference in travel distance between males and females. After getting a colostomy placement, patients waited a median time of 11.9 months before getting PSARP, while a colostomy reversal followed 4 months later. Patients lived with a colostomy for a median of 18.5 months. The patients made a median of 1 trip before colostomy formation, two trips before PSARP, and one trip before colostomy reversal (table 1). No significant difference in number of trips before each procedure was observed between income groups (table 2).

Out of a median monthly household income of UGX200 000 (US$51.68), families spent a median of UGX50 000 (US$12.92) for one-way travel to the hospital. The median distance traveled by our patients to the hospital was 198 km and most patients coming from a rural residence (72.9%). Most patients traveled with either a taxi, also known as a matatu (73.9%), or a motorcycle, also known as boda-bodas (66.2%), while

Table 1 Baseline characteristics of participants

Variables	Female (*n*=65)	Male (*n*=92)	All patients (*N*=157)
Main caregiver, *n* (%)			
Mother	46 (71.9)	74 (82.2)	120 (77.9)
Father	12 (18.8)	12 (13.3)	24 (15.6)
Others*	6 (9.4)	4 (4.4)	10 (6.5)
Median age, median (IQR)			
At colostomy formation (days)	17.5 (5.0-165.0)	3.0 (2.0-5.0)	5.0 (2.0-20.0)
At PSARP (months)	15.0 (9.0-36.0)	12.0 (6.0-29.0)	13.0 (7.0-36.0)
At colostomy reversal (months)	30.0 (16.0-50.0)	17.0 (10.5-42.5)	24.0 (12.0-48.0)
Median time interval (months), median (IQR)			
Colostomy formation to PSARP	11.9 (5.3–23.8)	11.9 (5.9–28.9)	11.9 (5.8–26.8)
PSARP to colostomy reversal	5.0 (3.0-12.0)	4.0 (3.0-9.0)	4.0 (3.0-9.5)
Colostomy formation to reversal	21.0 (9.3-36.0)	16.9 (9.4–42.4)	18.5 (9.3–39.8)
Median distance traveled (km), median (IQR)	303.0 (111.0-389.0)	181.0 (64.0-375.0)	198.5 (80.0-385.0)
Median cost of travel (UGX1000), median (IQR)	54.0 (30.0-70.0)	50.0 (25.0-64.0)	50.0 (29.0-69.0)
Mode of travel, *n* (%)			
Motorcycle/boda-boda	45 (69.2)	59 (64.1)	104 (66.2)
Bus	18 (27.7)	19 (20.7)	37 (23.6)
Taxi/matatu	48 (73.9)	68 (73.9)	116 (73.9)
Ambulance	1 (1.5)	7 (7.6)	8 (5.1)
Bicycle (None)	0 (0.0)	0 (0.0)	0 (0.0)
Walking (None)	0 (0.0)	0 (0.0)	0 (0.0)
Guardian education level, *n* (%)			
No formal education	6 (9.4)	6 (6.7)	12 (7.8)
Primary	38 (59.4)	53 (58.9)	91 (59.1)
Secondary	16 (25.0)	21 (23.3)	37 (24.0)
Tertiary	4 (6.2)	10 (11.1)	14 (9.1)
Residence type, *n* (%)			
Rural	50 (78.1)	63 (69.2)	113 (72.9)
Urban	14 (21.9)	28 (30.8)	42 (27.1)
Median household income (UGX1000), median (IQR)	200.0 (100.0-300.0)	200.0 (100.0-450.0)	200.0 (100.0-400.0)

Percentages may not add up to 100 due to rounding or missing values.
*Other tribes represent patients coming from outside the Southwestern region of Uganda.
PSARP, posterior sagittal anorectoplasty.

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Table 2 Categories items sold by families to raise funds

Variables	Household monthly income (UGX1000)					
	<100 (*n*=30)	100–200 (*n*=35)	200–300 (*n*=29)	300–400 (*n*=26)	>400 (*n*=37)	All patients (*N*=157)
Median number of trips prior to, median (IQR)						
Colostomy formation	1 (1–3)	1 (1–2)	1 (1–2)	1 (1–1)	1 (1–2)	1 (1–2)
PSARP	2 (1–4)	1 (1–3)	2 (1–3)	2 (1–3)	2 (1–4)	2 (1–4)
Colostomy reversal	1 (1–1)	1 (1–1)	1 (1–2)	1 (1–1)	1 (1–2)	1 (1–1)
Median cost of travel to the hospital (UGX1000), median (IQR)	60 (40–80)	50 (24–68)	50 (32–72)	40 (24–60)	38 (25–69)	50 (29–69)
Median distance traveled (km), median (IQR)	355 (114–389)	213 (64–389)	322 (148–382)	177 (80–366)	117 (67–312)	199 (80–385)
Residence type, *n*(%)						
Rural	22 (73)	26 (74)	21 (72)	21 (84)	23 (64)	113 (73)
Urban	8 (27)	9 (26)	8 (28)	4 (16)	13 (36)	42 (27)
Median value of assets sold (UGX1000), median (IQR)	400 (127–1500)	325 (250–1400)	750 (300–2170)	490 (300–1300)	1500 (530–3250)	530 (250–1600)
Assets owned, *n* (%)						
Radio/TV	6 (20)	19 (54)	19 (66)	14 (54)	25 (68)	83 (53)
Chickens/ducks	16 (53)	18 (51)	17 (59)	16 (62)	22 (59)	89 (57)
Goats/sheep	12 (40)	22 (63)	14 (48)	13 (50)	22 (59)	83 (53)
Cows	6 (20)	9 (26)	11 (38)	4 (15)	11 (30)	41 (26)
Bicycle	11 (37)	8 (23)	3 (10)	7 (27)	15 (41)	15 (28)
Motorcycle	0 (0)	5 (14)	3 (10)	6 (23)	12 (32)	26 (17)
Refrigerator	1 (3)	2 (6)	0 (0)	0 (0)	4 (11)	7 (4)
Washing machine, *n* (%)						
Car	0 (0)	0 (0)	0 (0)	1 (4)	1 (3)	2 (1)
Other†	4 (13)	4 (11)	3 (10)	6 (23)	1 (3)	18 (11)
How funds were raised, *n* (%)						
Savings	1 (3)	0 (0)	2 (7)	1 (4)	3 (8)	7 (4)
Loans from relative	1 (3)	0 (0)	1 (3)	1 (4)	1 (3)	4 (3)
Loans from bank/other institution	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Loan from moneylender	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Medical insurance	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Employer paid	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Median amount borrowed (UGX1000), median (IQR)	8 (60–500)	200 (100–300)	200 (100–500)	200 (50–500)	185 (100–690)	200 (100–500)
Sold assets for medical care, *n* (%)	20 (67)	22 (63)	22 (79)	19 (73)	22 (61)	105 (68)
Assets sold, *n* (%)						
Land	6 (20)	5 (14)	7 (24)	2 (8)	10 (27)	30 (19)
Food crops	3 (10)	0 (0)	3 (10)	1 (4)	1 (3)	8 (5)

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Table 2 Continued

Variables	Household monthly income (UGX1000)					
	<100 (*n*=30)	100–200 (*n*=35)	200–300 (*n*=29)	300–400 (*n*=26)	>400 (*n*=37)	All patients (*N*=157)
Cash crops	1 (3)	2 (6)	3 (10)	1 (4)	2 (5)	9 (6)
Radio/TV	1 (3)	3 (9)	0 (0)	1 (4)	0 (0)	5 (3)
Chickens/ducks	1 (3)	1 (3)	3 (10)	3 (12)	1 (3)	9 (6)
Goats/sheep	7 (23)	9 (26)	10 (34)	6 (23)	7 (19)	39 (25)
Cows	5 (17)	5 (14)	7 (24)	3 (12)	8 (22)	28 (18)
Bicycle	0 (0)	1 (3)	0 (0)	0 (0)	1 (3)	2 (1)
Other*	2 (7)	2 (6)	2 (7)	4 (15)	2 (5)	12 (8)

Percentages may not add up to 100 due to rounding or missing values.
*Bricks, mattress, plates.
†Pig, land, rabbits.
PSARP, posterior sagittal anorectoplasty.

only 5.0% were transported via an ambulance (table 1). When comparing travel costs among household income groups, no significant difference was noted in the median cost of travel (p=0.313). Although the difference was not significant, individuals with the lowest household income (<UGX100 000) spent the most portion (>50%) of their income to travel to the hospital with a median expense of UGX60 000 over a median distance of 355 km from predominantly rural settings (73.3%). The median value of assets sold was UGX530 000 (US$136.95), which was not significantly different across income groups. The most common goods owned by the families of patients were radio (53%), chicken/ducks (57%) and goats/sheep (53%). To raise funds for healthcare expenses, 68% of households sold assets, 4% used their savings, and 3% took out a loan from a relative. The median amount borrowed was UGX200 000 (US$51.72). The most commonly sold assets were goats/sheep (25%), land (19%), and cows (18%). Other assets sold by less than 10% of the population were food crops, cash crops, radio/TV, chickens/ducks, bicycles, bricks, mattress, and plates. (table 2)

DISCUSSION

Overall, mothers were the main caregivers presenting with the child to the hospital. In most of our patient population, mothers are burdened with the care of children while in the hospital. This is even worse when the child suffers congenital anomalies, which often are blamed on the mother. We have seen some fathers abandon their families—wives and children when a child with a congenital anomaly is born.[28] We have not established if or when these families reunite when the anomalies are corrected. Patients lived with a colostomy for a median of 18.5 months. This has not improved from our previous study, which showed a median colostomy duration of 21 months.[29]

Out of a median monthly household income of UGX200 000 (US$51.68), families spent a median of UGX50 000 (US$12.92) for one way to travel to the hospital, approximately 25% of their income. The median distance traveled by our patients to the hospital was 198 km and mostly from a rural residence (72.9%). Most patients traveled with either a taxi (73.9%) or a motorcycle, also known as boda-bodas (66.2%), while only 5.0% were transported via an ambulance. Patients incur significant expenses due to long-distance travel using multiple transport means to reach our hospital.[6 16–19] A considerable amount of money is spent on several trips (travels to and from the hospital for surgical procedures) before receiving surgical care. This is primarily due to limited pediatric surgeons and perioperative resources,[1–6 26] such as insufficient operating room time and space, among others.[6 7 9 10 12 15 30] Additionally, some of the means of transport are not safe, further exposing them to road traffic accidents. We have managed cases of children getting fractures on their way to scheduled surgery for ARMs during these several

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trips to access surgery from long distances. Investing in capacity building through more pediatric surgeons and anesthesia providers to fill these gaps in regional hospitals where pediatric surgical capacity is necessary to reduce the financial burden on families. Our team is working with collaborators, partners, and charity organizations on these initiatives to improve access to care.

Overall, patients made a median of one trip before colostomy formation, two trips before PSARP, and one trip before colostomy reversal. Individuals with the lowest household income (<UGX100 000) spent the most portion (>50%) of their income to travel to the hospital with a median expense of UGX60 000 over a median distance of 355 km from predominantly rural settings (73.3%). This makes the already impoverished families poorer, eventually failing to maintain their households' subsistence needs.[6 20 23 25 26 31 32] We have only two public hospitals in Uganda that provide pediatric surgery services, with less than 10 pediatric surgeons for about 20 million children in Uganda, explaining the reasons for the several trips far from the hospital[6 17 18] (online supplemental figure 1). In addition to the capacity-building needs mentioned above, a targeted policy that will build and strengthen pediatric surgical capacity through advocating for a national child health insurance policy for universal healthcare coverage may reduce the financial burden on families. An additional aspect of capacity strengthening is enhancing the training of primary healthcare providers. To address this, the Pediatric Emergency Surgery Course (PESC) has been providing regional hospital training,[33 34] and more funding is needed to sustain and scale this training program.

In Uganda, an LIC, all healthcare services are free in public hospitals. However, patients often pay OOP for investigations that are not available at the hospital and purchase supplies that are usually out of stock.[6 17 18 21] Families travel long distances to seek pediatric surgical care and spend money on lodging plus meals during their hospital stay. This results in substantial health-related expenses incurred by the households[22–24] that threaten households' financial capacity to maintain subsistence needs (catastrophic health expenditure),[23 25 26] which are already threatened. To raise funds for healthcare expenses, families resort to distressed health financing as a coping strategy, such as selling assets and taking out loans from relatives. Most families come from rural settings without formal employment but rely on household assets. None had health insurance and paid OOP and sold assets.[32 35] In LIC settings, assets such as land in rural communities are customary property inherited from parents, meaning the land keeps being fragmented depending on the number of children in the family. If families keep selling their land for treatment, with time, they will have no land for farming and grazing the cattle/goats. This likely reduces care-seeking behaviors by poorer and less educated patients, which predominantly defines our patient population. This has also been demonstrated in nonsurgical conditions of public health importance, and now we have found the situation is even dire in surgical patients.[18 36 37]

The main limitation of this study was recall bias since most patients were in their last stages of treatment. Strategies to address these design concerns included training the interviewers on using survey form through a pilot study involving 10 participants.

In conclusion, families sell household assets to seek care for ARMs treatment in Southwestern Uganda. Financial protection by the government through a national child health insurance policy would shield families from substantial health-related expenditures and decrease this burden. In addition, targeted policy to strengthen pediatric surgical capacity through workforce expansion and skills training, such as the PESC, may minimize costs, improve timeliness of care, and prevent case cancellations.

X Felix Oyania @Felix Oyania

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ORCID iD
Felix Oyania http://orcid.org/0000-0003-4773-7790

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