



The socioeconomic impact of a pediatric ostomy in Uganda: a pilot study

Arlene Muzira¹ · Nasser Kakembo¹ · Phyllis Kisa¹ · Monica Langer^{2,3} · John Sekabira¹ · Doruk Ozgediz⁴ · Tamara N. Fitzgerald⁵

Accepted: 20 January 2018
© Springer-Verlag GmbH Germany, part of Springer Nature 2018

Abstract

Introduction Multiple pediatric surgical conditions require ostomies in low–middle-income countries. Delayed presentations increase the numbers of ostomies. Patients may live with an ostomy for a prolonged time due to the high backlog of cases with insufficient surgical capacity. In caring for these patients in Uganda, we frequently witnessed substantial socioeconomic impact of their surgical conditions.

Methods The operative log at the only pediatric surgery referral center in Uganda was reviewed to assess the numbers of children receiving ostomies over a 3-year period. Charts for patients with anorectal malformations (ARM) and Hirschsprung's disease (HD) were reviewed to assess delays in accessing care. Focus group discussions (FGD) were held with family members of children with ostomies based on themes from discussions with the surgical and nursing teams. A pilot survey was developed based on these themes and administered to a sample of patients in the outpatient clinic.

Results During the period of January 2012–December 2014, there was one specialty-certified pediatric surgeon in the country. There were 493 ostomies placed for ARM ($n=234$), HD ($N=114$), gangrenous ileocolic intussusception ($n=95$) and typhoid-induced intestinal perforation ($n=50$). Primary themes covered in the FGD were: stoma care, impact on caregiver income, community integration of the child, impact on family unit, and resources to assist families. Many patients with HD and ARM did not present for colostomy until after 1 year of life. None had access to formal ostomy bags. 15 caregivers completed the survey. 13 (86%) were mothers and 2 (13%) were fathers. Almost half of the caregivers ($n=7$, 47%) stated that their spouse had left the family. 14 (93%) caregivers had to leave jobs to care for the stoma. 14 respondents (93%) reported that receiving advice from other caregivers was beneficial.

Conclusion The burden of pediatric surgical disease in sub-Saharan Africa is substantial with significant disparities compared to high-income countries. Significant socioeconomic complexity surrounds these conditions. While some solutions are being implemented, we are seeking resources to implement others. This data will inform the design of a more expansive survey of this patient population to better measure the socioeconomic impact of pediatric ostomies and guide more comprehensive advocacy and program development.

Keywords Burden of disease · Global pediatric surgery · Colorectal congenital anomalies

Arlene Muzira and Nasser Kakembo joint first authors.

Doruk Ozgediz and Tamara N. Fitzgerald joint last authors.

✉ Tamara N. Fitzgerald
tnfitz@hotmail.com

¹ Mulago Hospital, Kampala, Uganda

² Northwestern University, Chicago, IL, USA

³ Anne & Robert H Lurie Children's Hospital of Chicago, Chicago, IL, USA

⁴ Yale University, New Haven, CT, USA

⁵ Department of Surgery, Duke University, Box 3815, DUMC, Durham, NC, USA

Introduction

Multiple pediatric surgical conditions require ostomies in low–middle-income countries (LMIC). These include congenital conditions such as anorectal malformations (ARM) and Hirschsprung’s Disease (HD) or acquired disease such as typhoid-induced intestinal perforation or gangrenous ileocolic intussusception. Patients often present in a delayed fashion, and therefore, many disease processes that would not require an ostomy in a high-income country (HIC), require an ostomy in LMIC [1]. Furthermore, patients often live with their ostomy for a prolonged time due to the high backlog of cases that exist with insufficient surgical capacity [2].

Previous work suggests that only 3% of the surgical need is met for major congenital surgical conditions in Uganda due to substantial resource limitations [3]. In any country, the presence of an ostomy is at minimum a nuisance, and can often have significant psychological, physical and socioeconomic consequences for the patient (Fig. 1). In caring for these patients and their families in Uganda, we frequently witnessed substantial socioeconomic impact of their surgical conditions. Colleagues working in similar settings also report similar experiences with their patients [4].

While there has been an increasing effort to quantify the surgical burden of disease through better estimation of disability-adjusted life years (DALYs) and other quantitative metrics, much less work has focused on the qualitative aspects of the impact of surgical conditions in general, and specifically on children [5–7]. The limited existing work has focused on craniofacial conditions such as cleft lip and palate, musculoskeletal conditions and neurologic impairment. Some of this work has galvanized advocacy efforts by large voluntary organizations to care for children afflicted with these conditions [8–11]. To meet this gap, we performed a review of the operative log for ostomy creation, as well as a chart review for patients with ARM and HD to assess delays in care. We also performed a qualitative pilot study to further assess socioeconomic impact of surgical conditions requiring ostomies as part of an ongoing quality improvement initiative.

Methods

The study was approved by the Institutional Review Board at Mulago Hospital, in Kampala Uganda. This is the major referral hospital in Uganda for pediatric surgery, and at the time was the only hospital in the country with a specialty-certified pediatric surgeon. It receives referrals from all



Fig. 1 Ostomies present significant challenges for children in Uganda. **a** A 3-year-old girl with an anorectal malformation uses cloth rags in lieu of stoma appliances. This is the most common strategy for stoma management in Uganda. **b** A 19-year-old girl with a vestibular fistula and sigmoid colostomy placed in infancy. She has managed the stoma since infancy with cloth rags that have left permanent marks around her waist, pictured here. She has not attended school. She now presents for anoplasty. **c** A 3-year-old girl with Hirschsprung’s Disease who had a transverse colostomy placed in infancy, presents for pull through. She had massive stoma prolapse creating great challenges for stoma care. The family lives 500 km from Kampala, creating challenges for access to care. **d** A 14-year-old boy who had multiple unknown operations for Hirschsprung’s Disease, with end colostomy over the left iliac crest. He has not attended school. He presents for pull through

locations in Uganda and other surrounding countries that have no pediatric surgeons. The Mulago Hospital operative logbook was first reviewed to assess the numbers of children receiving ostomies for ARM and HD, typhoid perforation and ileocolic intussusception over the preceding 3-year period. The logbook is a bound notebook in the operating room that contains an accurate list of all cases performed. It is not a database, however, and does not contain detailed clinical information. The pediatric surgery team has started a database for patients with ARM and HD, which currently contains 92 patients. Charts were reviewed for these patients with ARM and HD to assess delays in seeking and accessing care.

Four focus group discussions (FGD) were held in 2014 with family members of children on the ward with ostomies. Each discussion was held for 30 min with 4–5 family members. The FGD took place in a side room next to the ward. The discussion was led by a Ugandan pediatric surgeon, with

a Ugandan nurse present. Discussions were in the local language. Informed consent and assent was obtained from the patient and responsible caregiver.

Participation was confidential and voluntary. Primary themes covered in the focus group discussions were developed based on anecdotal reports of socioeconomic impact for the patients in our care and existing literature. Theme areas were further refined from discussions with surgical and nursing teams. Notes were transcribed during the focus groups and thematic analysis subsequently performed (Table 1).

Based on the results of the FGD, a brief individual pilot survey (“Appendix”) was developed for use with select patients. This pilot survey was tested initially with a small number of health care staff and patients and modified accordingly. The surveys were completed in person in the outpatient clinic during routine pre- or post-operative visits by a Ugandan pediatric surgeon or ward nurse in a side area of the clinic after the conclusion of their appointment. Families of children who had a stoma were included. There were no additional travel costs incurred by families and there was no compensation for participation.

Results

Review of operative log and medical records

During the period of January 2012–December 2014, there were 493 ostomies placed for ARM ($n=234$), HD ($N=114$), gangrenous ileocolic intussusception ($n=95$) and typhoid-induced intestinal perforation ($n=50$), as obtained from the operative logbook. During this time, there was one board

certified pediatric surgeon and two pediatric surgery fellows in training at Mulago Hospital, and in the country.

92 charts were reviewed for patients with ARM and HD. Table 2 shows the demographics of patients whose charts were reviewed. 54 (59%) were male. The most common tribes represented were Ganda ($n=32$, 35%) and Soga ($n=18$, 20%). 64 (70%) patients were 1–3 years old and 15 (16%) were 4–7 years old. 20 (22%) patients had HD, while 72 (78%) had ARM. The most common ARM were vestibular fistulas ($n=26$, 36%) and imperforate anus ($n=23$, 32%). None of the children with HD had other anomalies, but seven children with ARM (10%) had other anomalies. Two children with imperforate anus had trisomy 21, and sacral anomalies were found in one child with imperforate anus and one with a vestibular fistula. One child with vestibular fistula had polycystic kidneys and one child with a recto-vestibular fistula was born with omphalocele. There was one child with a cloaca who also had club foot and spina bifida.

Figure 2 shows the home locations of the patients, implying the subsequent distances they traveled to reach surgical care. Table 3 shows the post-operative complications associated with posterior sagittal anorectoplasty (PSARP) or pull-through procedures. Anal stenosis after a PSARP was the most common complication.

Many patients with ARM and HD presented late for initial colostomy placement. Figure 3 shows that most patients with HD did not present for a colostomy until 1 year of life or later. Most patients with ARM presented for a colostomy within 1 week of life, but there were many patients who presented at 1 year (mainly those patients with perineal or vestibular fistulas). Figure 4 shows the wait times for PSARP or pull-through procedures. Many children are waiting with colostomies for definitive repair of their colorectal condition.

Table 1 Socioeconomic aspects of care for children with ostomies

Theme	Dimensions	Possible resources required to minimize impact
Understanding of condition and ostomy care	Guilt/shame Misunderstanding of prognosis Cloth rags Hygiene/odor Care requirements	Counseling Context-appropriate educational materials Formalized peer counseling Locally available appliances
Caregiver income	Lost jobs/wages Missed vocational and educational opportunities Assets sold	Insurance mechanisms Improved resource availability in public facilities
Community integration	Isolation Embarrassment Stigmatization Inability to attend school	Community-based educational programs Community awareness through media
Impact on family unit	Spouses leaving the family Abandonment of children Need for help from relatives	Community awareness Education Greater integration with orphanages and group homes
Resources to assist families	Peer-based education Emotional support	Formalizing support networks Patient advocates/coordinators

Table 2 Demographics for anorectal malformations and Hirschsprung's disease

	N	Percent (%)
Gender		
Male	54	59
Female	38	41
Age at the time of study		
< 3 months	3	3
3 months–1 year	4	4
1–3 years	64	70
4–7 years	15	16
8–14 years	5	5
Deceased	1	1
Tribe		
Ganda	32	35
Soga	18	20
Nkole	6	7
Nyoro	5	5
Tooro	5	5
Mukiga	4	4
Other	22	24
Diagnosis		
Hirschsprung's disease	20	22
Sigmoid transition	9	(45)
Transverse colon transition	3	(15)
Not yet determined	9	(45)
Anorectal malformation	72	78
Vestibular fistula	26	(36)
Imperforate anus	23	(32)
Recto-urethral fistula	8	(11)
Rectal atresia	4	(6)
Recto-vesicular fistula	3	(4)
Cloaca	3	(4)
Perineal fistula	2	(3)
Rectovaginal fistula	1	(1)
Associated anomalies		
Hirschsprung's disease	0	
Anorectal malformation		
Any anomaly	7	10
Trisomy 21 (two imperforate anus)	2	3
Sacral anomaly (one imperforate anus, one vestibular fistula)	2	3
Polycystic kidneys (one vestibular fistula)	1	1
Omphalocele (one recto-vesicular fistula)	1	1
Club foot and spina bifida (one cloaca)	1	1

Focus group discussions and survey data

Themes for the FGD were derived from clinical care of the patients and these included: (1) care of the stoma and understanding of the condition; (2) impact on caregiver employment and household income; (3) community integration of

the family and child (school attendance if applicable, inclusion in community social activities); (4) impact on the family unit; (5) resources assisting families to cope with the challenges.

The participants of the FGD were mostly mothers, grandmothers and aunts. Very few fathers or male caregivers were present. The stomas were most commonly managed by purchasing bedsheets, cutting these into pieces and wrapping around the torso of the patient. The fabric pieces were washed and reused. Many caregivers reported extensive time investment to maintain hygiene. Odor and hygiene were among the most concerning issues raised by caregivers. None had access to formal ostomy bags. Many caregivers with ARM and HD were unclear about the etiology of these conditions, although some mothers attributed the illness to complications of pregnancy.

Themes around economic impact were substantial during the focus group discussions. Many of the participants left jobs or sold assets such as livestock (goats, cows) or household items to finance care. Key health-related expenses were upkeep while at the hospital (primarily meals), but also transport, cost of medicines, and radiology studies. Others reported that they had to decline opportunities for further education, vocational training or job opportunities due to responsibilities of being a caregiver. Many of the families borrowed money from relatives, friends, or informal community networks to support health expenses.

Caregivers of school-aged children with stomas reported that their children stayed home from school; caregivers shared hesitations about taking their children out of the home and concerns about stigmatization and visibility in the community. Many caregivers shared that their spouses left the family sometime after creation of the ostomy. This created additional social and financial pressure and required additional support from family and community networks.

Many caregivers referred to the hospital community as a supportive force in helping to care for children on the wards and as outpatients. The areas discussed included: adapting to new stoma care for children (specifically in management of ostomies without appliances), help with anal dilations for children having undergone pull-through or anoplasty, wound care, and communication about resource challenges on the wards that affected wait times and access to the operating room.

The themes developed were used to construct a survey tool regarding the social and economic consequences to the child and his/her caregivers. Fifteen caregivers completed the survey in the clinic. The response rate was 100%; there were no families that refused participation in the survey. 13 (86%) were mothers and 2 (13%) were fathers. Twelve children (80%) had a colostomy for ARM or HD and 3 (20%) had ileostomies for intussusception or typhoid perforation. Ten of the respondents (66%) understood the surgical

Fig. 2 Map of Uganda, showing the home locations of children with Hirschsprung’s disease and anorectal malformations. Families traveled a considerable distance to reach the hospital. (Permission from Google Maps is granted for scholarship purposes)

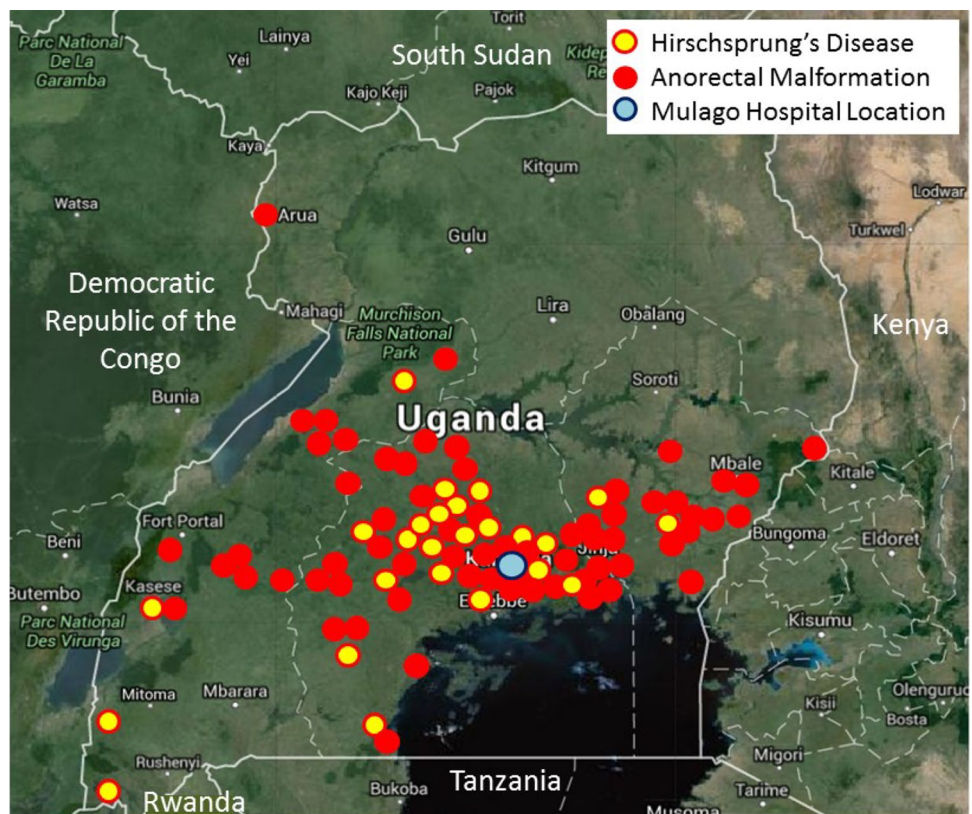


Table 3 Post-operative complications

	N	Percent (%)
Complications after PSARP (20 procedures)		
Anal stenosis	6	30
Wound dehiscence	1	5
Bladder injury	1	5
Sepsis	1	5
Acquired fistula	1	5
Complications after pull-through (13 procedures)		
Anastomotic stenosis	1	7
Persistent constipation	2	15
Wound dehiscence	1	7
Death	1	7

condition necessitating the stoma, but all acknowledged the need for a stoma. While all respondents received nursing advice about stoma care, 14 of the respondents (93%) received additional counseling and advice from other caregivers. Many respondents emphasized the comfort and support offered by other caregivers as critical to their well-being and were grateful for the time and effort shared.

Almost half of the caregivers ($n = 7, 47%$) stated that their spouse had left the family, creating great stress and additional burden. 14 (93%) caregivers had to leave their jobs to care for the stoma. Even those who tried to hire a

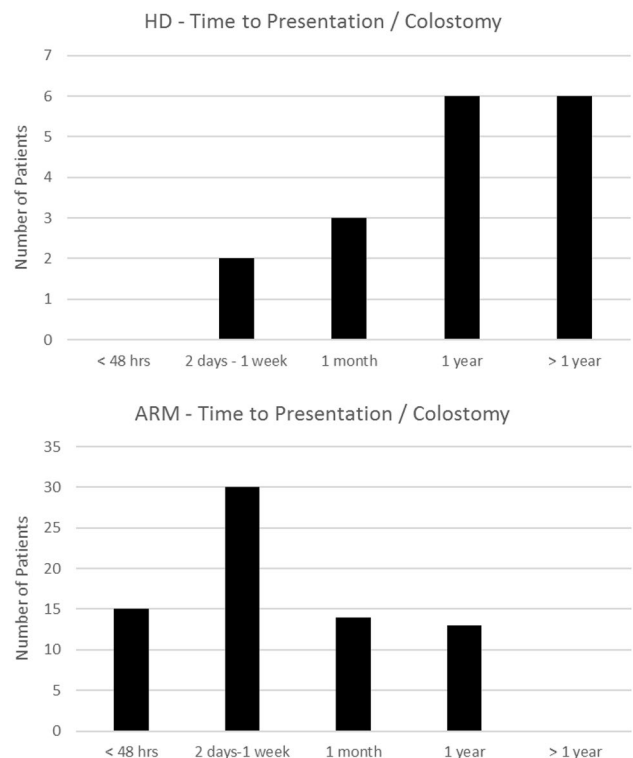


Fig. 3 Delays in initial presentation for colostomy placement

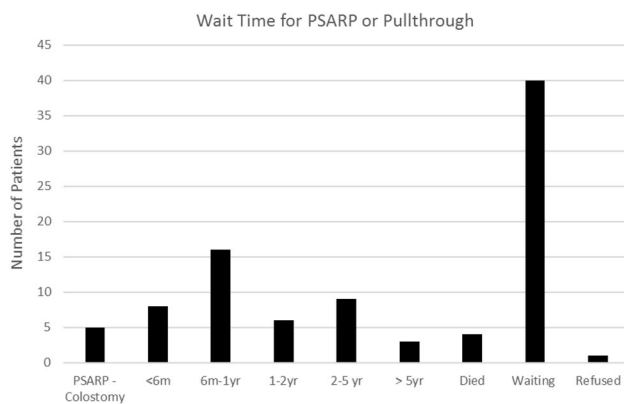


Fig. 4 Wait times for definitive surgery for anorectal malformations and Hirschsprung's disease

nanny stated that this was difficult because the prospective nannies feared the stoma care. Respondents stated they were embarrassed to take their child to social gatherings but did generally take the child to church.

Discussion

Disparity of pediatric surgical conditions

There has been increasing emphasis in recent years to quantify the global burden of surgical disease, resources needed to improve access to care, and potential economic benefit to societies from increased investment in surgery [6]. Less attention has been focused on children's surgery [12]. Our prior work as part of a quality improvement initiative has highlighted the limited coverage for essential neonatal surgical procedures and the high burden and workload associated with congenital colorectal conditions (ARM and HD) [3]. Delayed surgical care for children impacts morbidity and mortality for a wide range of conditions, but we became particularly interested in the impact of ostomies, given the many challenges conveyed by families providing care to these patients.

81 patients (88%) received their initial stoma at Mulago hospital. Children also receive stomas at other hospitals throughout the country that offer general surgery. However, the surgeons at these outside hospitals typically do not have the expertise to perform PSARPs and pull-through procedures and they may not have pediatric anesthesia. In general, very few patients are candidates for one-stage or two-stage procedures. Review of medical records in Uganda and our experience in caring for these patients suggests that many patients with HD present at over 1 year of age and many patients with ARM did not receive a colostomy until months or years after birth. This late presentation results in

profoundly distended and dysfunctional remaining colon. Patients are often malnourished at the time of presentation, as they have not been stooling or eating well. This necessitates a colostomy, and many times a greater loss of ganglionated colon. Furthermore, operating room access is difficult during the day, and almost non-accessible at night or on the weekends. A temporizing stoma, rather than a PSARP or pull-through may be all that the surgical team can perform, as committing to a longer surgery would require cancelling surgery for another child. In contrast, many patients with HD and ARM in high-income countries (HIC) can be treated with a one-stage operation as a neonate.

Surgical need for ostomies are even greater for children in LMIC due the increased frequency of complicated typhoid fever and ileocolic intussusception. Children presenting with typhoid perforation are often too sick to undergo simple repair and require a diverting ostomy. Meanwhile, many of those with intussusception present in a delayed fashion with gangrenous bowel that cannot be simply reduced, nor are they well enough to resect with a primary anastomosis, therefore, requiring a temporary ostomy. Review of the operative log showed that nearly 500 patients received new stomas for these four conditions over 3 years.

Patients travel from all over the country to access care at Mulago hospital, and they do not call before arrival, as there is currently no coordinator or referral service to call. They are generally impoverished patients who live in the countryside and spend a significant amount of their income on travel. When they arrive, the surgical team attempts to perform their needed surgery. However, there is a large backlog of cases. If the backlog is too great, then patients may be asked to return at another time. If the backlog is manageable, families prefer to wait on the surgical ward, as they desire to retain their place in line and avoid further travel expenses. This system does not incur additional expense for the hospital, as the hospital does not provide food for patients and much patient care is performed by the family. For those who practice in high-income countries, it is difficult to imagine a system that cannot prioritize a major surgery for a child with a congenital anomaly. However, in this system with too few surgeons, anesthesia providers and operating room space, all of the patients who are waiting have disabling and life-threatening conditions. A team of just a few surgeons cannot keep up with the overwhelming burden of disease. While elective dates for surgery can be set, in reality they are not practical due to substantial backlog, bookings 8–12 months in advance and the fact that the backlog grows as new emergencies occur [13].

Impoverishing health expenditure

The discussions highlighted a broad economic impact of these conditions on families. Mulago Hospital is a

government-funded institution, and in-patient care is provided free of charge to patients. However, this measure does not negate the potential for catastrophic health expenditure. Nearly all working mothers reported leaving their jobs to care for the child. Many families reported selling assets such as livestock or taking out loans to cover out-of-pocket expenses for health care such as radiologic imaging, travel and lodging expenses. As Mulago Hospital was the only pediatric surgery referral center in the country, many patients traveled long distances, utilizing mainly public transport or motorcycle rides for hire. Once the patients reached the hospital, they often lived on the surgical ward for weeks while they awaited surgery (due to the large backlog of cases preceding them) and recovered from surgery. Sometimes the backlog of cases was too great and patients were asked to return later, if their condition was not life-threatening. These circumstances increase travel expenses, time away from work with lost wages, and increased costs for living away from home. Many patients live on farms and grow much of their own food. Living on the surgical ward necessitates buying local food at city prices.

Protection from impoverishing health expenditure through financial risk protection is a sustainable development goal. However, studies in this area for surgical conditions in LMIC have been minimal, and even fewer devoted to children's surgical conditions [14, 15]. The data shared here suggest a substantial economic burden. We intend to measure this more completely in future investigations. However, the need for improved financial protection, perhaps through improved community insurance mechanisms, is critically important, and poorly characterized for children's surgery in LMIC.

Social isolation and destruction of the family unit

Social integration was an important recurring theme. Most mothers had limited the interaction of their child with others in the community for fear of stigmatization. Almost all school-aged children were removed from school for the duration of the stoma.

An alarming feature noted in discussions was mothers reporting that their spouse had left the family once the stoma was placed. Although not elicited during these discussions and interviews, the pediatric surgery team has also witnessed fathers return to the family once the colostomy has been taken down. The team has also noted that a substantial number of children with these conditions are cared for in local orphanages and group homes. These social sequelae are likely due to the associated stigmatization and the perceived burden associated with caring for children with stomas, as well as the expected prognosis for these children, which may be poorly understood.

Many children and families in LMIC may spend days and weeks longer in the hospital, waiting for surgery (such as anoplasty, pull through or stoma takedown), or recovering from one of these procedures. This is especially true if they come from far, rural areas as the post-operative care, including anal dilations, may not always be reliable. Nearly all mothers emphasized the support from the informal community of other affected families on the hospital ward and in the outpatient setting. The lack of specialized stoma nurses, for example, has meant that families teach each other. The prolonged time on the ward allows for substantial interaction between the treating team and the family, and between families, in the setting of a more communal ward environment than is the case in HIC. The surgical ward is a large room with many beds; sometimes 40–60 patients. Privacy is not an expectation, as it is in many HIC cultures. Families benefited from the network of support that was provided by this arrangement. While not elicited during this study, the surgical team has witnessed that parents who abandoned by their spouses have formed new relationships with one another, and have left together as a new family: two abandoned spouses and two children with colostomies.

Sustainable solutions

Previous work for children with musculoskeletal defects, craniofacial anomalies, and neurological impairments have demonstrated the many dimensions of morbidity associated with these conditions [16, 17]. These studies have emphasized social isolation, loss of dignity, pain and lack of access to basic needs (such as food) as factors that impact disability. Advocacy for these patients, combined with specialized resource coordination has resulted in increased delivery of surgical care and decreased social stigmatization for these patients [18].

The substantial requirements for stoma care are both time consuming and resource intensive for caregivers. While some groups have focused on donations of ostomy supplies from high-income countries to assist these children, more sustainable local solutions are needed. Improvised bag systems have been described elsewhere, [19] but a minority of patients and families in Uganda have used anything other than cloth sheets. A better stool management system may ease the resources required from caregivers and allow children more integration in the community and improved school attendance.

This study highlighted a greater need for education of families regarding the underlying surgical conditions and prognoses. Contextually appropriate education for families, greater support systems and dedicated community outreach programs could improve family cohesion and decrease social isolation. Improved coordination of care may result in decreased financial strain by minimizing unnecessary

journeys to the hospital and lengthy stays waiting for surgery. Even with the limited numbers of surgeons, nurses and other clinical providers, a dedicated team of “patient coordinators” could be very useful in this role. This position could potentially be filled by a current or former caregiver of a child with a stoma. Such an approach has been successful with other stigmatizing conditions such as obstetric fistula [20]. A more integrated programmatic approach to oncology patients in Uganda has also led to improved outcomes for Wilms tumor through better coordination of care [21].

Increasing access to care, through increased surgical and anesthesia providers as well as operating room space, would have a substantial impact on reducing the socioeconomic burden found here. Previous studies have shown that the most effective way to reverse the psychosocial effects of obstetric fistula is to provide surgical repair [22]. An increase in surgical capacity would likely decrease the need for stomas primarily, which could decrease this burden as well. Strategies to improve earlier access to safe surgical care must be developed, as well as improved supportive resources such as pediatric pathology for HD and improved peri-operative care. These measures may facilitate two- or one-stage correction for some of the children with congenital colorectal conditions. In 2015, a pediatric dedicated operating space was created to increase access to the operating room, and this has helped to increase surgical volume and decrease backlog.

The authors are part of a collaboration in pediatric surgery, including pediatric surgeons from Uganda, the United States and Canada. This group has supported local training of two pediatric surgeons, who have subsequently passed their specialty exam in pediatric surgery with the College of Surgeons of East, Central and Southern Africa (COSECSA), and there are four surgeons currently in training. The number of Ugandan pediatric surgeons has increased from one surgeon to four surgeons over the past 5 years with support of this collaboration and a surgeon trained in the PAACS program [23]. These surgeons are performing stoma takedowns, pull-throughs and PSARPs, in addition to other pediatric cases such as solid tumor resections, and other congenital anomalies. Four pediatric surgeons for a population of 39 million people, half of whom are children, is still a small number and the backlog of cases is substantial.

Limitations

This was a limited pilot study. A small number of families were interviewed compared to the number of children with disease. Additional focus groups may help to elicit critical aspects of the quality of life for children with stomas. Greater involvement of social science researchers may also help to refine interview techniques. This may elicit information about the challenges for these patients that can

subsequently guide program development. In addition, the families may have been biased, as discussions were facilitated by members of the treating team. This may have led them to be less truthful about the systems that have led to delayed diagnosis or access to care. In addition, while we did not differentiate between colostomies and ileostomies, or congenital versus acquired diseases, this could be done in a future study. Most of the children with intussusception and typhoid perforation required ileostomies, and children with colorectal conditions required colostomies. The study focused on an urban tertiary hospital with patients who actually reached care. Impact in more rural communities may be even greater. Limited accuracy and completeness of the medical records that were found is typical of public hospitals in LMIC [24, 25]. Finally, the generalizability of these findings to other LMIC is unknown. Nonetheless, given similar challenges in workforce and other resources, we expect similar socioeconomic burden.

Conclusion

493 cases of ostomy creations in addition to many other surgical cases over a 3-year period, is a large volume of colorectal disease for a team consisting of one board certified surgeon and two fellows. The burden of surgical disease in sub-Saharan Africa is staggering, the extent of which is not fully known. When considering the numbers of children who lack access to surgical care, we must also characterize the socioeconomic complexity surrounding these conditions. In Uganda, children with ostomies are socially excluded from their neighbors and relatives. They may be abandoned by their parents. They are removed from school and their education is consequently negatively affected. Families are frequently further impoverished due to loss of income, spousal support and medical expenses. In general, women bear the brunt of this more so than men. Fortunately, many families have found an informal network of support during the prolonged surgical care. Although this study contained just a handful of patients, the findings are profound and may extend to settings with similar disparity challenges. Some solutions, such as increased access to operating room space and increasing workforce are already underway, while others such as hiring a coordinator, also require additional resources. This data will inform the design of a larger more expansive survey of this patient population to better measure the socioeconomic impact of pediatric ostomies and guide more comprehensive advocacy and program development.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Research involving animals This article does not contain any studies with animals performed by any of the authors.

Informed consent Informed consent was obtained from all individual participants included in the study. The study was approved by the Institutional Review Board at Mulago Hospital in Kampala, Uganda.

Appendix

Survey questions.

Demographic information

Age of child.

Gender.

Home district.

Tribe.

Surgical diagnosis.

Previous surgery performed.

Parental education/understanding of condition

Do you understand why your child needed the stoma?

What information about ostomy care have you received?

From whom have you received ostomy care teaching (nurse, doctor, other family member)?

Is your child attending school?

Social inclusion

How did the ostomy affect your social life?

Do you spend more or less time with friends?

Did the ostomy affect if you are invited to social gatherings?

How did the ostomy affect your role in your community?

Did the ostomy affect your attendance at church / mosque?

Preservation of the family unit

Who is the primary caregiver?

Is the father present in the child's life?

If the father has been absent, why?

Is the mother present in the child's life?

If the mother has been absent, why?

How did the ostomy placement affect your relationship with your spouse/significant other?

Financial expenditure

Have you had difficulties finding a nanny for the child? Explain.

From where did you travel to reach the hospital?

How much money did you pay for transportation?

How much money did you spend on food, traveling and while your child was in the hospital?

What is the annual income for your family?

How did you get the money to pay for the trip (loans, selling assets)?

Did you borrow money to pay for the trip? How much? From whom?

References

1. Ameh EAF (2011) Surgical complications of typhoid fever. In: Ameh BS, Lakhoo E, Nwomeh K, Poenaru BD (eds) *Pediatric surgery: a comprehensive text for Africa*. Global Help Organization, Seattle
2. Poenaru D et al (2010) Caring for children with colorectal disease in the context of limited resources. *Semin Pediatr Surg* 19(2):118–27
3. Badrinath R et al (2014) Outcomes and unmet need for neonatal surgery in a resource-limited environment: estimates of global health disparities from Kampala, Uganda. *J Pediatr Surg* 49(12):1825–1830
4. Krois W, Dingemans AJM, Hernández PX, Metzelder ML, Craniotis Rios J, Reck-Burneo CA (2017) Sociodemographics and the impact of a colostomy to indigent families and children with colorectal disorders in Honduras. *J Pediatr Surg*. <https://doi.org/10.1016/j.jpedsurg.2017.05.009>
5. Higashi H et al (2015) The burden of selected congenital anomalies amenable to surgery in low and middle-income regions: cleft lip and palate, congenital heart anomalies and neural tube defects. *Arch Dis Child* 100(3):233–238
6. Meara JG et al (2015) Global surgery 2030: evidence and solutions for achieving health, welfare, and economic development. *Lancet* 386(9993):569–624
7. Poenaru D et al (2015) Quantifying the disability from congenital anomalies averted through pediatric surgery: a cross-sectional comparison of a pediatric surgical unit in Kenya and Canada. *World J Surg* 39(9):2198–206
8. Alavi Y et al (2012) Indignity, exclusion, pain and hunger: the impact of musculoskeletal impairments in the lives of children in Malawi. *Disabil Rehabil* 34(20):1736–1746
9. Awoyale T et al (2016) Quality of life of family caregivers of children with orofacial clefts in Nigeria: a mixed-method study. *Oral Dis* 22(2):116–22
10. Simpamba MM, Struthers PM, Mweshi MM (2016) Access to health care for children with neural tube defects: experiences of mothers in Zambia. *Afr J Disabil* 5(1):267
11. Sims-Williams HJ, Sims-Williams HP, Mbabazi Kabachelor E, Warf BC (2017) Quality of life among children with spina bifida in Uganda. *Arch Dis Child* 102(11):1057–1061. <https://doi.org/10.1136/archdischild-2016-312307>
12. Ozgediz D, Poenaru D (2012) The burden of pediatric surgical conditions in low and middle income countries: a call to action. *J Pediatr Surg* 47(12):2305–2311
13. Poenaru D, Ozgediz D, Gosselin RA (2014) Burden, need, or backlog: a call for improved metrics for the global burden of surgical disease. *Int J Surg* 12(5):483–486
14. Buse K, Hawkes S (2015) Health in the sustainable development goals: ready for a paradigm shift? *Global Health* 11:13
15. Shrimpe MG et al (2016) A global country-level comparison of the financial burden of surgery. *Br J Surg* 103(11):1453–1461

16. Kesande T et al (2014) Prevalence, pattern and perceptions of cleft lip and cleft palate among children born in two hospitals in Kisoro District, Uganda. *BMC Oral Health* 14:104
17. Massenburg BB et al (2016) Barriers to cleft lip and palate repair around the world. *J Craniofac Surg* 27(7):1741–1745
18. Campbell A et al (2014) Scalable, sustainable cost-effective surgical care: a model for safety and quality in the developing world, part III: impact and sustainability. *J Craniofac Surg* 25(5):1685–1689
19. Odigie VI, Yusufu LM (2006) The zaria colobelt and bag. *Niger Postgrad Med J* 13(1):15–6
20. Sullivan G, O'Brien B, Mwini-Nyaledzigbor P (2016) Sources of support for women experiencing obstetric fistula in northern Ghana: a focused ethnography. *Midwifery* 40:162–168
21. Ozgediz D et al (2016) Pediatric surgery as an essential component of global child health. *Semin Pediatr Surg* 25(1):3–9
22. Wilson SM et al (2016) Psychological symptoms and social functioning following repair of obstetric fistula in a low-income setting. *Matern Child Health J* 20(5):941–945
23. Pollock JD et al (2011) Is it possible to train surgeons for rural Africa? A report of a successful international program. *World J Surg* 35(3):493–499
24. Anderson GA et al (2017) Surgical volume and postoperative mortality rate at a referral hospital in Western Uganda: measuring the Lancet Commission on Global Surgery indicators in low-resource settings. *Surgery* 161(6):1710–1719
25. Tumusiime G et al (2017) The quality and utility of surgical and anesthetic data at a Ugandan regional referral hospital. *World J Surg* 41(2):370–379