



Epidemiology and mortality of pediatric surgical conditions: insights from a tertiary center in Uganda

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Abstract

Introduction/purpose The burden of pediatric surgical disease is largely unknown in low- and middle-income countries such as Uganda where access to care is limited.

Methods Implementation of a locally led database in January 2012 at a Ugandan tertiary referral hospital, and review of 3465 prospectively collected pediatric surgical admissions from January 2012 to August 2016.

Results 2090 children (60.3%) underwent surgery during admission. 59% were male and 41% female. 28.6% of admissions were in neonates and 50.4% were in children less than 1 year old. Congenital anomalies including Hirschsprung's, anorectal malformations, intestinal atresias, omphalocele, and gastroschisis were the most common diagnoses (38.6%) followed by infections (15.0%) and tumors (8.6%). Mortality rates were substantially higher than those of high-income countries; for example, gastroschisis and intussusception had mortality rates of 90.1% and 19.7%, respectively. Post-operative mortality was highest in the congenital anomalies group (15.0%).

Conclusion There is a high burden of infant congenital anomalies with higher mortality rates compared to high-income countries. The unit performs primarily specialized procedures appropriate for a tertiary center. We hope that these data will facilitate evaluation of ongoing quality improvement and capacity-building initiatives.

Keywords Global surgery · Burden of disease · Pediatric surgery · Surgical outcomes · Uganda

Introduction

Globally, profound improvements in childhood mortality have occurred over the past few decades [1]. Nonetheless, children living in sub-Saharan Africa remain 15 times more likely to die before the age of five compared with their counterparts in high-income countries (HICs) [2]. Furthermore, the rate of decline in deaths in low- and middle-income

countries (LMICs) due to surgical conditions has not been as pronounced as rates in decline due to infectious causes [3].

It is estimated that 30% of the global burden of disease can be treated surgically; yet, in LMICs, as much as 87% of the surgical need remains unmet [4, 5] and 1.7 billion children lack access to surgical care [6]. The most common cause of death in children under age 5 includes preterm birth complications and congenital anomalies, while injury is the most common cause of death among children age 5–14 [7]. Surgical intervention has the potential to improve outcomes in each of these areas; however, the true burden of pediatric surgical diseases remains largely unknown.

Uganda is located in eastern sub-Saharan Africa and its population of just over 40 million has 50% under the age of 15, a similar demographic to other LMICs [8]. It has the fifth highest fertility rate in the world at 7.2 children per female. The surgical workforce is significantly under-resourced with 0.3 general surgeons per 100,000 people [9]. Currently, there are only four pediatric surgeons, three pediatric anesthesiologists, and two pediatric operating rooms to care for the

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over 20 million children in the country [10]. Over the study period, there were between one and two clinically active, board certified pediatric surgeons at Mulago National Hospital. In addition, the hospital has one dedicated pediatric operating room, no neonatal intensive-care unit (ICU), and four pediatric ICU beds without ventilators.

As in many LMICs, there are sparse data in Uganda regarding the distribution and outcomes of children's surgical conditions. Characterization of disease burden could, therefore, provide an opportunity for advocacy of resource allocation and increased surgical intervention. This is especially true for pediatric surgical conditions where congenital malformations, tumors, injuries, and infections can be fatal if left untreated. We hypothesize that a prospective clinical database can be designed for the local context and can capture the burden of pediatric surgical conditions and outcomes. These data will then inform quality improvement and may guide resource allocation in a country with extremely limited pediatric surgical capacity.

Methods

Creation of clinical database

After obtaining approval from the Mulago Hospital Institutional Review Board, a prospective database was designed and implemented by the pediatric surgeons at Mulago Hospital to include all children, including neonates, admitted or treated by the service regardless of whether they receive an operation. The database contains demographic data including the child's associated tribe, distance traveled to the hospital, referral source, and clinical details such as presenting symptoms, operations, length of stay, and surgical outcomes during the hospitalization ("Appendix 1"). Based on operative logbooks and admission registers, 46 common pediatric surgical disease codes ("Appendix 2") and 50 common surgical codes ("Appendix 3") were prospectively chosen and used to categorize each admission. The database also includes a significant number of diseases classically treated by pediatric surgical subspecialties including plastic surgery, orthopedic surgery, neurosurgery, and urology.

Clinical data for each patient are initially captured on a paper medical record completed by the pediatric surgery trainee or the pediatric surgery consultant physician. The data are digitized and stored using Microsoft Access (Redmond, Washington). The database began as an unfunded qualitative improvement project through the perceived need by the local pediatric surgery team. The project was later funded through a pilot grant that allowed the hiring of a data manager.

Epidemiology analysis

The analysis included all children (< 12 years old based on admission guidelines on the ward) admitted to or treated by the pediatric surgery service at Mulago Hospital in Kampala, Uganda, from January 1, 2012 through August 31, 2016. We performed a descriptive analysis of the 46 surgical disease codes captured in the database including demographic data, operative percentage, post-operative mortality, and overall mortality as well as general information including median travel distance to the hospital. Central tendency was reported in mean value and standard deviation for normal variables and in median value and interquartile range for non-normal variables. All analysis was performed using SPSS Statistics software version 25 (IBM® Corporation, Armonk, NY, USA) and figures were generated using GraphPad Prism 7® (GraphPad Software, Inc., La Jolla, USA).

Results

Between January 2012 and August 2016, the pediatric surgical ward at Mulago Hospital recorded 3465 pediatric surgical admissions. Of these, 3034 (87.6%) were matched with one of the 46 pediatric surgical disease codes, and 2090 (60.3%) underwent surgery during admission. The gender distribution was 59% male ($n=2048$) and 41% female ($n=1417$).

The age distribution is shown in Fig. 1. 28.6% of patients ($n=990$) were neonates less than 1 month old, 41.9% ($n=1451$) were children less than 6 months of age, and 50.4% ($n=1765$) were less than 1 year of age. Only 30% ($n=1040$) of admissions were in children over 3 years of age. The median distance traveled to the hospital was 30 km (Fig. 2). The range of distance traveled to reach care was 0–1000 km; however, only 11 children traveled between 500 and 1,000 km. Surgical conditions were grouped into four broad categories of children's surgery: congenital anomalies, infections, tumors, and trauma and other conditions. The distribution of conditions is shown in Fig. 3; congenital anomalies made up the largest proportion of conditions (38.6%, $n=1337$).

In the initial years to monitor completeness of data collection by the data clerk, periodic audits were performed by the surgical team. A more recent audit of operative logbooks at Mulago Hospital compared to the established clinical database over a 7-month period, from February 2016 to August 2016, revealed that 75.8% of all operations were captured, with the non-recorded operations distributed evenly across disease categories.

Fig. 1 Distribution of age at admission

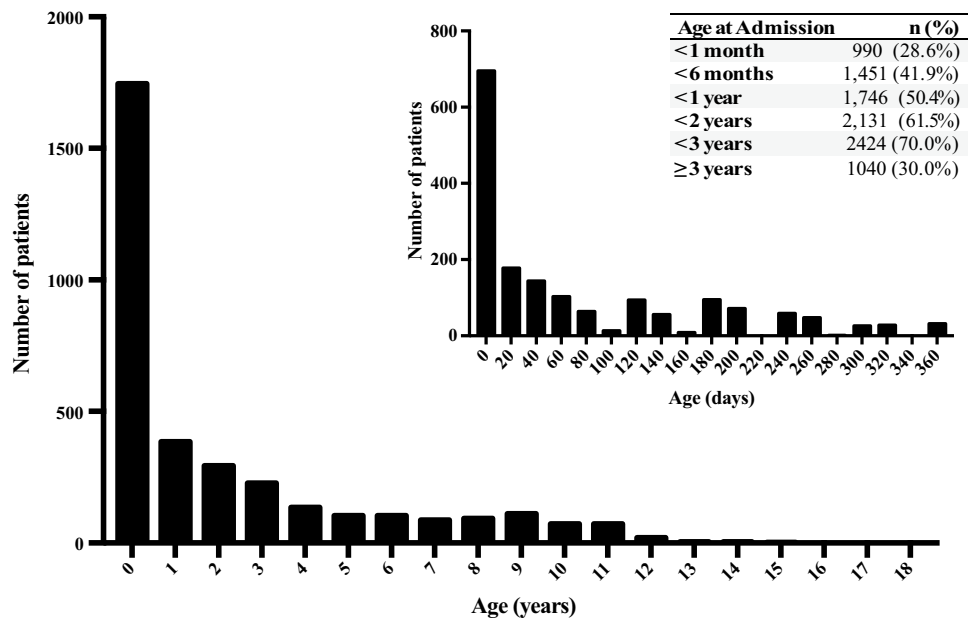
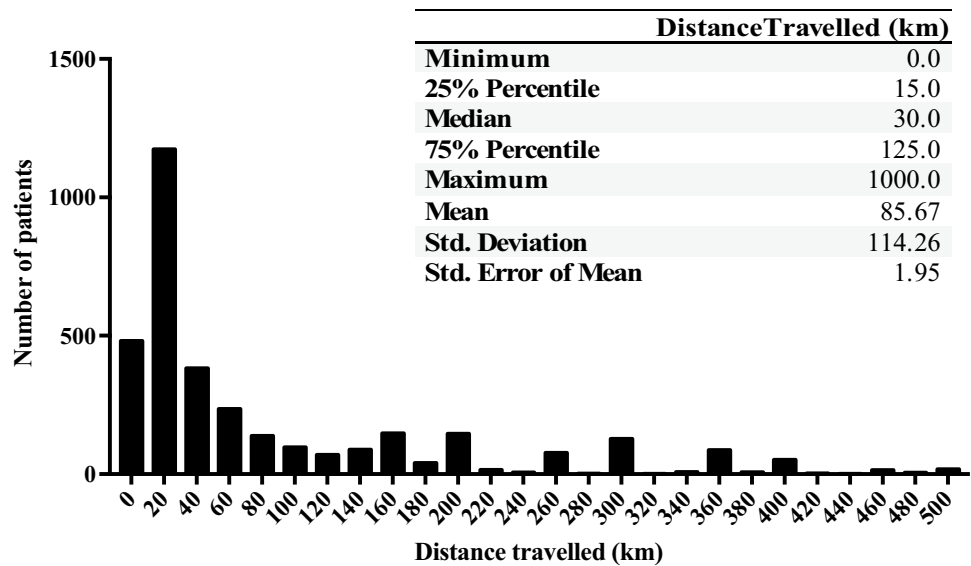


Fig. 2 Access to care: distribution of distance traveled



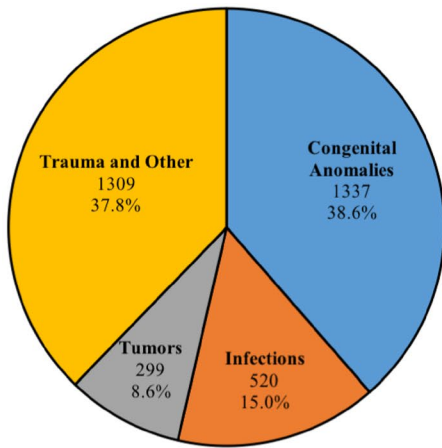
Congenital anomalies

The distribution of congenital anomalies including both post-operative and overall mortality is located in Table 1. The most common congenital anomalies included anorectal malformations ($n=390$), Hirschsprung’s disease ($n=217$), omphalocele ($n=159$), and gastroschisis ($n=151$). In those conditions with a cohort of $n > 15$, the highest mortality rate was seen in gastroschisis ($n=151$) with 90.1% overall mortality. The next highest mortality rates were seen in small bowel atresias (ileal atresia 70.6% overall and 69.2% post-operative, jejunal 59.6%/52.3%) and esophageal atresia

(58.3%/45.5%). This group had the second highest percentage of surgical interventions at 62.7%.

Infections

Infections (Table 2) comprised 15% ($n=520$) of the burden of disease in the study population with the most common being abscesses/cellulitis ($n=298$, 8.6% of overall burden of disease and 57.3% of infections). This was followed by typhoid perforations, appendicitis, necrotizing fasciitis, and primary peritonitis. Within the four subdivisions, this group had the highest percentage of surgical interventions at an overall rate of 74%. Among infections, the highest mortality



	n (%)	Mean age in yrs. (± Standard Deviation)	Male/ Female Ratio	Overall Mortality (%)	Post-Operative Mortality (%)
■ Congenital Anomalies	1337 (38.6%)	0.9 (2.3)	1.19	371 (27.7%)	126 (15.0%)
■ Infection	520 (15.0%)	4.0 (3.8)	1.09	22 (4.2%)	18 (4.7%)
■ Tumors	299 (8.6%)	3.0 (3.1)	0.99	16 (5.4%)	2 (1.9%)
■ Trauma and Other	1309 (37.8%)	2.7 (3.3)	2.22	111 (8.5%)	64 (8.4%)
Total	3465	2.2 (3.2)	1.45	520 (15.0%)	210 (10.0%)

Disease Category	n (%)	Mean age in years (± Standard Deviation)	Male/ Female Ratio	Overall Mortality (%)	Post-Operative Mortality (%)
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Fig. 3 Disease categories: demographics and outcomes

Table 1 Congenital anomalies: surgical intervention and mortality rates

Congenital anomalies	n (%)	Surgical intervention (%)	Overall mortality (%)	Post-operative mortality (%)
Anorectal malformation	390 (29.2)	345 (88.5)	41 (10.5)	31 (9.0)
Hirschsprung's disease	217 (16.2)	175 (80.6)	20 (9.2)	16 (9.1)
Omphalocele	159 (11.9)	20 (12.6)	47 (29.6)	6 (30.0)
Gastroschisis	151 (11.3)	10 (6.6)	136 (90.1)	6 (60.0)
Pyloric stenosis	65 (4.9)	53 (81.5)	6 (9.2)	4 (7.5)
Jejunal atresia	57 (4.3)	44 (77.2)	34 (59.6)	23 (52.3)
Biliary atresia	51 (3.8)	15 (29.4)	25 (49.0)	6 (40.0)
Other low anorectal malformations	49 (3.7)	40 (81.6)	2 (4.1)	2 (5.0)
Duodenal obstruction	46 (3.4)	42 (91.3)	15 (32.6)	13 (31.0)
Undescended testis	41 (3.1)	35 (85.4)	0 (0.0)	0 (0.0)
Esophageal atresia with/without tracheoesophageal fistula	36 (2.7)	11 (30.6)	21 (58.3)	5 (45.5)
Ileal atresia	17 (1.3)	13 (76.5)	12 (70.6)	9 (69.2)
Choledochal cyst	14 (1.0)	6 (42.9)	3 (21.4)	1 (16.7)
Cloaca	12 (0.9)	10 (83.3)	1 (8.3)	1 (10.0)
Mesenteric cysts	11 (0.8)	8 (72.7)	0 (0.0)	0 (0.0)
Thyroglossal cysts	7 (0.5)	6 (85.7)	0 (0.0)	0 (0.0)
Conjoint twins	7 (0.5)	3 (42.9)	4 (57.1)	1 (33.3)
Cloacal exstrophy	4 (0.3)	0 (0.0)	2 (50.0)	0 (0.0)
Colonic atresia	2 (0.1)	2 (100.0)	2 (100.0)	2 (100.0)
Prune belly syndrome	1 (0.1)	0 (0.0)	0 (0.0)	0 (0.0)
Total	1337	838 (62.7)	371 (27.7)	126 (15.0)

Table 2 Infections: surgical intervention and mortality rates

Infections	<i>n</i> (%)	Surgical intervention (%)	Overall mortality (%)	Post-operative mortality (%)
Abscess/cellulitis	298 (57.3)	196 (65.8)	3 (1.0)	3 (1.5)
Typhoid ileal perforation	95 (18.3)	90 (94.7)	15 (15.8)	13 (14.4)
Appendicitis	74 (14.2)	68 (91.9)	0 (0.0)	0 (0.0)
Necrotizing fasciitis	30 (5.8)	12 (40.0)	3 (10.0)	1 (8.3)
Primary peritonitis	23 (4.4)	19 (82.6)	1 (4.3)	1 (5.3)
Total	520	385 (74.0)	22 (4.2)	18 (4.7)

rates were seen in typhoid ileal perforation patients with a rate of 15.8% overall mortality and 14.4% post-operative mortality.

Tumors

The most common tumors captured in our database were Wilms tumors (41.8%, *n* = 125) followed by sacrococcygeal teratomas (14.4%, *n* = 43) (Table 3). The tumors with the highest percentage of surgical intervention were ovarian tumors (85.7% operative rate) and sacrococcygeal tumors (76.7% operative rate). Overall, tumor resections had the lowest post-operative mortality rate compared to other disease categories, with only 1.9% post-operative mortality. Two post-operative deaths were noted in our database; one in a patient with Wilms tumor and one in a patient with a sacrococcygeal teratoma.

Trauma and other conditions

The ‘Trauma and other conditions’ category included 878 (67.1%) patients with diseases that were assigned one of the 46 pediatric surgical codes, and 428 (32.8%) that were listed as “uncategorized”. “Uncategorized” conditions largely represent conditions specific to the surgical specialties including neurosurgery, orthopedic surgery,

and otolaryngology, as well as low-incidence conditions. Among the categorized conditions, inguinal hernias were the most common (*n* = 247, 18.9%) followed by intussusception (*n* = 228, 17.5%), and umbilical hernias (*n* = 102, 7.8%). Sub-group analysis demonstrated that 31.6% (*n* = 78) of inguinal and 31.4% (*n* = 32) of umbilical hernias were incarcerated at the time of surgery. Intussusception had a 94.7% (*n* = 202) operative rate with hernias and hydroceles also above a 75% operative rate (Table 4). The highest mortality in this category was for intussusception with a 19.7% overall mortality and 19% post-operative mortality.

Discussion

Database

Recent initiatives have stressed the importance of research in global surgery [11, 12], including the Global Initiative for Children’s Surgery (GICS) which directly recommended the creation of prospective database development [13]. The database described in this report details the local disease burden and represents an effective method to collect and analyze data. Recently, some groups have performed multi-institutional audits on select surgical conditions, such as a recent study of abdominal emergencies in children [14].

Table 3 Tumors: surgical intervention and mortality rates

Tumors	<i>n</i> (%)	Surgical intervention (%)	Overall mortality (%)	Post-operative mortality (%)
Wilms tumor	125 (41.8)	37 (29.6)	4 (3.2)	1 (2.7)
Sacrococcygeal teratoma	43 (14.4)	33 (76.7)	1 (2.3)	1 (3.0)
Other lymphomas	29 (9.7)	9 (31.0)	2 (6.9)	0 (0.0)
Burkitt’s lymphoma	26 (8.7)	2 (7.7)	6 (23.1)	0 (0.0)
Cystic hygroma/lymphatic malformation	24 (8.0)	5 (20.8)	1 (4.2)	0 (0.0)
Rhabdomyosarcoma	23 (7.7)	12 (52.2)	1 (4.3)	0 (0.0)
Hemangioma	15 (5.0)	1 (6.7)	1 (6.7)	0 (0.0)
Other teratomas	7 (2.3)	2 (28.6)	0 (0.0)	0 (0.0)
Ovarian tumors	7 (2.3)	6 (85.7)	0 (0.0)	0 (0.0)
Total	299	107 (35.8)	16 (5.4)	2 (1.9)

Table 4 Trauma and other conditions: surgical intervention and mortality rates

Trauma and other conditions	<i>n</i> (%)	Surgical intervention (%)	Overall mortality (%)	Post-operative mortality (%)
Uncategorized	431 (32.9)	162 (37.6)	55 (12.8)	17 (10.5)
Inguinal hernias	247 (18.9)	204 (82.6)	5 (2.0)	3 (1.5)
Intussusception	228 (17.4)	217 (95.2)	45 (19.7)	42 (19.4)
Umbilical hernias	102 (7.8)	81 (79.4)	0 (0.0)	0 (0.0)
Constipation/fecal impaction	70 (5.3)	5 (7.1)	0 (0.0)	0 (0.0)
Blunt abdominal trauma	66 (5.0)	15 (22.7)	2 (3.0)	0 (0.0)
Other forms of trauma	50 (3.8)	26 (52.0)	1 (2.0)	1 (3.8)
Rectal prolapse	41 (3.1)	11 (26.8)	1 (2.4)	0 (0.0)
Hydrocele	25 (1.9)	21 (84.0)	1 (4.0)	1 (4.8)
Splenic rupture	23 (1.8)	10 (43.5)	1 (4.3)	0 (0.0)
Post-circumcision hemorrhage or sepsis	15 (1.1)	8 (53.3)	0 (0.0)	0 (0.0)
GERD	11 (0.8)	0 (0.0)	0 (0.0)	0 (0.0)
Total	1309	760 (58.1)	111 (8.5)	64 (8.4)

To categorize broad conditions and outcomes, however, we developed a simple implementation strategy with paper charts and select disease codes (<50) which cover the majority of general pediatric surgical pathology in Uganda. Previous work has suggested a limited group of surgical disease codes to collect data in LMICs, but has not been described for pediatric general surgery [15, 16]. This strategy does result in 12.4% of our database being ‘uncategorized,’ but these conditions are mainly limited to diagnoses in the other children’s surgical subspecialties or low-incidence disease.

As mentioned above, a comparison of operative logbooks did show an underestimate of our operative percentages; approximately 25% of operations were left out of the database with the missing cases distributed evenly across categories. Even so, we chose to focus on a ward-based database compared to operative logbook analysis alone, given that a substantial portion of children may not need an operation and non-surgical cases would otherwise be missed. Our database, therefore, demonstrates the broader demand for surgical evaluation and care, rather than only operative need [17]. In addition, other work, including a recently piloted electronic medical record, has shown that retrospective review of paper charts is generally unreliable in these settings and prospective data collection is needed for more in-depth clinical data [18]. A recent 1-month report of a surgical registry using electronic medical records showed that efforts to collect prospective data are accurate and feasible in low-resource settings [19].

Access to care

Distance is a major barrier to care in low-resource areas, and the WHO recommends that surgical care be available within 50 km [9, 20, 21]. As depicted in Fig. 2, the median

distance traveled by patients was 30 km, which is within this range. This was a largely unexpected result, but may be due to patients from further away seeking local care due to a variety of reasons including cost, transportation, and the referral system. Regional referral hospitals may be providing emergency surgical care in older children for intussusception, typhoid perforation, appendicitis, abscess drainage, and some trauma care. However, previous work in the western region has demonstrated minimal pediatric surgical activity in regional hospitals [22]. As Mulago Hospital is the national referral hospital and the only hospital during the majority of the study with a dedicated pediatric operating room and staff, we are confident that our database captured the majority of referrals that reached definitive care, especially for congenital anomalies and tumors. Our findings of 50% of patients being under 1 year of age highlight this pattern. Timely access to care is imperative due to the emergent nature of many pediatric surgical conditions as evidenced by the rate of incarcerated hernias in our database (32% of hernias). Increased distance to health care facilities causes delays in presentation of patients and increased rates of morbidity and mortality [23, 24].

Burden of disease and mortality

This analysis of 4.5 years of pediatric surgical admissions is one of the longest periods studied in sub-Saharan Africa. Sixty percent of children had an operation, with a surgical disease burden of 990 distinct presentations per year and 550 operations per year. While the Lancet Commission on Global Surgery outlines an estimated global surgical need of 5000 procedures per 100,000 people [4], the pediatric or neonatal surgical share has not been estimated. Our previous estimates suggest that only 3.5% of the neonatal surgical

need is being met, implying a substantial hidden mortality. More recent estimates from Ugandan regional hospitals showed a low surgical volume [25], and substantial unmet need in community surveys [26, 27].

The distribution of pediatric surgical conditions is similar to other groups in sub-Saharan Africa with a large proportion of congenital anomalies. Unlike these studies, however, our database only included children under 12 years of age, resulting in a younger age distribution. This combined with the fact that our institution is a tertiary referral center with dedicated pediatric surgeons and pediatric anesthesiologists likely contributed to a higher representation of congenital anomalies compared to the other highly represented group of trauma patients in other studies [18, 28]. Highlighting this point, 61.5% of our patients were under 2 years old, compared to studies in Malawi and Gambia, where mean ages were 6.9 [18] and 5.2 years [28], respectively.

We compared disease-associated mortality rates and post-operative mortality, the latter of which has been identified as a measure of success of surgical care systems by the Lancet Commission, but is still less frequently reported [29]. Overall, 60.3% of the patients in our database received an operation with a total post-operative mortality rate of 10.0%. Within the most commonly presenting category of congenital anomalies, 62.7% of patients received an operation. In our setting, patients with congenital anomalies had a 27.7% overall mortality and a post-operative mortality rate of 15%. Our mortality rates for congenital anomalies were higher overall for congenital anomalies compared to recent pooled African data [30]. This may be attributed to a combination of Mulago Hospital's status as a tertiary referral center as mentioned above, therefore, seeing a higher number of neonatal emergencies such as atresias as compared to low ARMs or Hirschsprung's which can potentially be initially treated by providers with less specialized training. Also contributing to our high mortality rate may be the delay in presentation due to referral to the tertiary center and the higher risk of complications during and after neonatal surgery compared to older patients [31]. Our patients' mean age of admission with congenital anomalies was 10 months old compared to 3.9 years in Gambia [28]. Hirschsprung's disease and anorectal malformations were the most common congenital anomalies with Hirschsprung's in our setting more frequently represented than previous literature [18, 28]. The high mortality rate seen for gastroschisis was congruent with previous reports [26]. The large difference, however, between the overall mortality rate of 90.1% and the post-operative mortality rate of 60.0% for gastroschisis should not be mainly attributed to advantages of undergoing surgical management. The majority of these cases are commonly managed non-operatively and mortality likely reflects the overall clinical status of the infant and the timing of presentation. In addition, factors most likely to decrease mortality

may be improved referral patterns for emergent neonatal care, total parenteral nutrition, and availability of intensive-care resources including trained personnel, ventilators, and critical care medications such as pressors, resources which are not readily available in most LMICs [26].

In our database, 74% of the patients presenting with a surgical infection received surgical intervention, the highest rate of surgical management among the disease categories, and almost twice as high as the surgical management rates observed in the surrounding region [18]. Overall and post-operative mortality rates for the category were 4.2% and 4.7%, respectively, displaying the lowest overall mortality compared to the rest of the disease categories. In contrast, mortality rates show little difference in overall or post-operative management, which may be attributed to multiple factors including late presentation of disease and conditions such as abscesses/cellulitis that made up the majority (57.3%) of infections. Potential sources of mortality in surgical infections in addition to late presentation may include lack of appropriate antibiotic therapy due to resource constraints, quality control of medications, limited imaging modalities to assess for the degree of infection, and limited critical care support.

Tumors and masses were the least common category of pediatric surgical diseases, representing 8.6% of the patients. In comparison to the other categories, these conditions received the lowest percentage of surgical intervention (35.8%) and maintained the second lowest overall mortality at 5.4% following infections. This is likely due to the admission of patients mainly to obtain medical work ups, such as biopsies for masses, followed by discharge or transfer for oncologic management or palliation rather than admission for definitive surgical care. For those who received surgical intervention, post-operative mortality was lowest of all groups at 1.9%. Because previous databases from the region have classified tumors and masses in terms of their stage of malignancy and not by the type of neoplasm [18, 28], it is difficult to compare these data with the region. In addition, all diagnoses within this category had overall and post-operative mortality rates below 7% with the exception of Burkitt's lymphomas having an overall in-hospital mortality of 23.1% and a post-operative in-hospital mortality of 0.0%. Mortality in this category is mainly attributed to the advanced stages of disease, paucity of chemotherapy and/or radiation treatment, and lack of intensive-care resources to manage multi-system organ dysfunction. Some cases may be missed due to the logistics of record keeping as a small number may have gone to the oncology ward post-resection; however, abandonment of therapy also remains a substantial challenge for oncologic care in LMICs.

Trauma and other conditions made up 37.8% of the conditions represented in the database. Compared to other studies over similar time periods [18, 28, 32, 33], trauma and

other conditions made up a smaller portion of our database. This underrepresentation can be partially attributed to the exclusion of burns that are managed via the plastic surgery ward, as well as the admission of some older children to adult wards at Mulago Hospital. Trauma was included in this larger section due to its lower prevalence in the database as well as the way the database was coded without a more injury-specific breakdown of traumatic injuries, therefore, limiting a more granular analysis. Within this category, inguinal hernias (18.9%), intussusception (17.4%), and umbilical hernias (7.8%) were most common. 31.6% of inguinal and 31.4% of umbilical hernias had associated diagnoses of incarceration or strangulation at time of diagnosis, depicting a longer standing and more severe disease presentation for close to a third of the patients. This also suggests a backlog of elective cases at the hospital. In contrast, cases falling under “other forms of trauma” such as animal-afflicted injuries or bites, and lacerations and trauma from falls and road traffic crashes, had an unexpectedly low overall mortality but a higher percentage of post-operative mortality (Table 4). Considering the trends of higher overall and surgical mortality associated with trauma in sub-Saharan Africa [18, 32, 34], our database may also be underrepresenting the mortality associated with trauma. This could be ascribed to patients’ admission to other wards, or mortality during the pre-hospital course or during emergency room management and thus not captured in our database. In addition to the coded diseases, the most common presentation in this category was “uncategorized” which was assigned to all conditions addressed by surgical subspecialties such as neurosurgery, orthopedic surgery, and otolaryngology, covering 32.9% of presentations within this category. The high proportion covered by subspecialty cases also highlights the importance of expanding the surgical code repertoire in future databases via interdisciplinary collaborations. Potential sources of mortality in this category include lack of imaging modalities to fully assess traumatic injuries [35], lack of fluoroscopic reduction options for intussusception patients, lack of critical care support, and overall late presentations of patients to the ward.

Overall, since its establishment in 2012, the database has spurred a number of quality improvement initiatives and clinical protocols specifically focusing on the areas of infrastructure (both in human capital and dedicated pediatric operating rooms), service delivery, training [36], and research. It has allowed the establishment of over ten interdisciplinary collaborations between HIC and LMIC surgeons and trainees, and catalyzed more in-depth analyses of morbidity, mortality, and socioeconomic aspects of care critical for advocacy efforts [37].

Limitations

One of our main limitations is that this is a single-center study. Nonetheless, we believe that we captured a representative sample of neonates and young children who accessed surgical care given this was the sole center for specialized pediatric surgical care during the majority of the study period. Miscoding may have affected data, although reviews were conducted in 1–2-week intervals by local surgeons. Our comparison to the logbooks during a 7-month period also shows that the database missed approximately 24% of operative cases during this time causing an underestimation of the burden of disease and also the operative output. The missing cases were most likely due to difficulty in establishment of an optimal workflow for the data clerks who assisted with this project and the challenges of capturing complete information on all cases given high patient turnover, maintaining consistent oversight, logistical challenges posed by hospital renovation that caused operations to occur in as many as five locations over the study period, and the overall challenge in sustaining consistently accurate data collection over a long time period. The percentage of children undergoing operations may then be closer to 75–80% as opposed to the 60% shown in our results. More detailed outcome data beyond discharge for all conditions were beyond the scope of this initial analysis, but are needed in future studies. Risk adjustment by including weight, anesthesia risk, blood transfusion rates, and sepsis, for example, would be even more helpful, and although proposed for the LMIC setting, has not been piloted in any pediatric surgery unit [38–41]. We hope to pilot these variables in the future. Finally, more specific audits for certain conditions may help to elucidate interventions that may be improved to help decrease pre-operative and post-operative morbidity and mortality.

Conclusion

Our findings show that a prospective database can be successfully implemented and maintained over an extended period of time (4.5 years) in a low-resource setting. The project characterizes the spectrum of the local disease burden and basic mortality outcomes of 3465 patients presenting to the pediatric surgical ward. It also demonstrates the importance of a prospective data collection system in assessing distinct surgical conditions including associated mortality rates. These data allow the quantification of the current and potentially avertable burden of surgical disease as well as to guide resource allocation and specialized training in pediatric surgery in the region. It provides data for children’s surgery and anesthesia advocacy, surgical service implementation, and resource allocation. These efforts are especially

needed for congenital malformations and neonatal patients who may require staged operations, multidisciplinary teams, and advanced coordination of long-term care. Scaling these types of data can also inform progress toward broader targets in global child health.

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Compliance with ethical standards

Conflict of interest There are no conflicts of interest for any of the authors.

Research involving human participants and/or animals This article does not contain any studies with human participants performed by any of the authors.

Informed consent No informed consent was necessary for this study.

Appendix 1: Data fields

Demographic information	Admission information	Disposition
Patient ID	Ward of admission	Outcome
Date patient case logged	Chief complaint on admission	Transfer
Patient serial number	Duration of symptoms	Discharge date
Patient name	Complications	Total days hospitalized
Date of birth	Complication type	Last update to notes
Date of admission	Final diagnosis	
Age	Disease code	
Sex	Disease category	
Tribe	Surgical management	
Village	Date of surgery	
District	Surgical code	
Distance traveled		
Mode of referral		
Phone number		

Appendix 2: Pediatric surgical conditions collected in database

Code	Condition
1	High anorectal malformation
2	Vestibular anus
3	Other low anorectal malformations
4	Hirschsprung’s disease
5	Intussusception
6	Sacrococcygeal teratoma
7	Other teratomas
8	Wilms tumor
9	Biliary atresia
10	Gastroschisis
11	Omphalocele
12	Burkitt’s lymphoma
13	Other lymphomas
14	Umbilical hernia
15	Inguinal hernia
16	Hydrocele
17	Blunt abdominal trauma
18	Splenic rupture
19	Other forms of trauma
20	Necrotizing fasciitis
21	Abscess/cellulitis
22	Rectal prolapse
23	Pyloric stenosis
24	Hemangioma
25	Constipation/fecal impaction
26	Esophageal atresia with TOF
27	Duodenal obstruction
28	Jejunal atresia
29	Ileal atresia
30	Colonic atresia
31	Cloaca
32	Cystic hygroma/lymphatic malformation
33	Appendicitis
34	GERD
35	Primary peritonitis
36	Typhoid ileal perforation
37	Ovarian tumors
38	Cloacal exstrophy
39	Post-circumcision hemorrhage or sepsis
40	Prune belly syndrome
41	Thyroglossal duct cyst
42	Mesenteric cysts
43	Undescended testicle
44	Rhabdomyosarcoma
45	Choledochal cyst

Code	Condition
46	Conjoint twins
00	Other non-coded conditions

Appendix 3: Surgical codes

Code	Type of surgery
1	Colostomy creation
2	Ileostomy creation
3	Stoma refashioning
4	Colostomy closure
5	Ileostomy closure
6	Hydrocelectomy
7	Herniotomy
8	Herniotomy and resection and anastomosis
9	Swenson procedure
10	Soave procedure
11	Duhamel procedure
12	Pull through and closure of stoma
13	Rectal biopsy
14	Excision/trucut biopsy
15	Colostomy and rectal biopsy
16	PSARP
17	PSARP and SCT excision
18	Anoplasty
19	EUA and dilatation
20	Incision and drainage, skin graft, and debridement
21	Laparotomy
22	Laparotomy and reduction
23	Laparotomy, resection, and stoma
24	Laparotomy, resection, and anastomosis
25	Laparotomy, drainage, and lavage
26	Laparotomy and splenectomy
27	Laparotomy and excision
28	Laparotomy reduction and anastomosis
29	Duodenoduodenostomy
30	Duodenal web excision
31	Excision of SCT
32	Gastrojejunostomy
33	Cystgastrostomy
34	Orchiopexy
35	Appendectomy
36	Plication of rectal prolapse
37	Redo circumcision

Code	Type of surgery
38	Redo PSARP
39	Nephrectomy
40	Pyloromyotomy
41	Umbilical/epigastric hernia repair
42	Excision of splenic cyst
43	Kasai procedure
44	Omphalocele repair
45	Gastroschisis repair
46	Rectal polyp excision
47	Esophageal atresia and TOF repair
48	Emergency separation of twins
49	Posterior sagittal anorecto-vagino-urethroplasty
50	Lavage and tension sutures

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