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Quantifying delays and self-identified barriers to timely access to pediatric surgery at Mbarara Regional Referral Hospital, Uganda☆

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ABSTRACT

Purpose: Favorable surgical outcomes depend on timely access to care. This study quantifies these delays and explores caregiver barriers to access in a Ugandan facility.
Methods: An interviewer-facilitated survey was administered over 8 months to consecutive pediatric surgical families at Mbarara Regional Referral Hospital (MRRH). Delays were classified using the Three Delays Model: care-seeking, arrival at health facility, and from surgical consultation to surgery. Barriers at each stage were explored with caregivers.
Results: The survey included 174 patients. Family members were first to recognize disease in 90%, but only 14% sought medical attention immediately. Delays in seeking care predominated (median 30 days), mostly attributed to home treatments (51%) and other responsibilities (28%). After referral decision, 80% of caregivers brought their child to MRRH immediately (median time to arrival <24 h). Upon MRRH arrival, 57% of patients were assessed the same day, and time to surgery was relatively short (median 4 days). Despite free under-5 care, out-of-pocket payments (between $1–42 USD) were reported by 64%.
Conclusions: Care-seeking delays dominate access to pediatric surgical care in Uganda, and cost remains a significant barrier. Primary provider education and advocacy for increased resources would be useful interventions to improve timeliness of pediatric surgical care.
Level of Evidence: Level II.

In Uganda, half of the population are children aged 15 and younger [1]. It has been estimated that in low- and middle-income countries (LMICs) including Uganda, 40–85% of children will require surgery by the age of 15 [2,3]. There remain substantial disparities in mortality from pediatric surgical conditions in LMICs [4]. Some of this increase in mortality and morbidity is directly attributable to delayed presentation to care [5–9].

Mbarara Regional Referral Hospital (MRRH) is one of two referral centers in Uganda with pediatric surgical expertise. Previous data from MRRH showed that 54% of outpatient referrals to pediatric surgery were for congenital anomalies, and the average age of referral was 2.8 years [10]. Abdominal wall hernias (inguinal, umbilical, and epigastric) comprised 34% of referrals, with an average age at referral of 4.0 years. Children with tumors represented 11% of outpatient referrals, with an average age at referral of 6.1 years. Given the relatively late ages of presentation previously documented in this setting, we chose to further evaluate the causes for delays in care using the Three Delays Model.

The Three Delays Model has been adopted in global surgery from the maternal mortality literature [11]. It describes health care delays in three categories: care-seeking (type I), arrival at an appropriate health facility (type II), and provision of definitive care (type III). This model has already been used to evaluate delays in pediatrics, specifically in Uganda [9]. By applying the Three Delays Model to pediatric surgical patients at MRRH, the relative contribution of each delay can be determined. Frequently cited barriers to care could then be explored with families to further characterize the cause for delays. Avenues for improved access to timely surgical care could then be identified for further study and implementation.

Our hypothesis was that care-seeking (type I) delays have the greatest impact on Ugandan children receiving timely surgical care. The purpose of this study was to: 1) identify the relative contributions of type I, II, and III delays and 2) identify barriers to timely care in all three stages.

1. Material and methods

The study design was approved by the Queen's University Health Sciences Research Ethics Board (TRAQ 6015925) and the Mbarara University of Science and Technology Research Ethics Committee.

An interviewer-facilitated survey was administered over 8 months to consecutive new pediatric surgical families assessed at Mbarara Regional Referral Hospital (Appendix A). Families were prospectively enrolled at first interaction with the pediatric surgery service at MRRH (via clinic, emergency department, or inpatient pediatric ward referral).

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Delay I is time from first identifying a medical concern to seeking medical attention

Delay II is the time from initial medical care seeking to arrival at MRRH

Delay III is the time from arrival at MRRH to the date of surgery.

Fig. 1. Three Delays Model [11].

The survey was administered either immediately upon enrollment in the study or during the hospital stay, and the dates of definitive surgical interventions were tracked for each patient. The survey was administered in English, with a local language (Angkole) translation available when needed. A single facilitator conducted all interviews and transcribed them into a secure database after assigning a patient code to anonymize the data.

Delays in care were classified using the Three Delays Model (See Fig. 1).

The care-seeking delay (type I) was calculated as the time from when the family first became aware of the abnormality to their first attempt at seeking care outside the home. Type II delays comprised the time from when the families were referred to MRRH for expert surgical opinion until their arrival at the facility. Finally, the type III delay was calculated as the time between first arrival at MRRH and the date of the first surgical procedure. International surgery delay benchmarks do not exist; however, the Canadian Pediatric Surgical Wait Times Taskforce has produced guidelines for target surgical wait times in Canadian pediatric patients [12]. These targets were used to determine whether the target "Wait 2" (equivalent to Type III delay) was met in the study population. Descriptive statistics were used to determine the relative contribution of each type of delay. Barriers at each stage were explored with caregivers using qualitative data analysis.

2. Results

Consecutive admissions to pediatric surgery at Mbarara Regional Referral Hospital were enrolled in the study between October 2016 and May 2017. An interviewer-facilitated survey was administered to 174 patients and their families.

Sixty-seven children were diagnosed with congenital anomalies, 45 patients had abdominal wall hernias, 22 had tumors, and 40 had miscellaneous surgical conditions. Three diagnoses were not recorded. See Appendix B for details of patient diagnoses.

2.1. Relative contributions of delays

Complete data to determine the length of all three types of delay existed in 143 of the 174 surveyed patients, while at least one type of delay could be accurately determined in all patients.

The average time from first identifying an abnormality to time of surgery (delays I + II + III) was 288 days across all diagnoses (range 0–3655 days, median 91 days). Overall delays varied widely within and between diagnostic groups, as shown in Table 1. Fig. 1

The distribution of delay types showed a predominance of care-seeking delays as seen in Table 2 and Fig. 2. Type I delays accounted for a 52% contribution to the overall delay, with Type II and Type III accounting for 25% and 23% respectively.

Table 1
Delay periods by diagnosis.

	Average	Median	Range
Congenital anomalies; n = 67	248 days	66 days	0–2247 days
Abdominal wall hernias; n = 45	360 days	87 days	1–3655 days
Tumours; n = 22	418 days	237 days	0–1463 days
Miscellaneous acute conditions; n = 40	173 days	43 days	0–1095 days
ALL diagnoses	288 days	91 days	0–3655 days

2.2. Barriers associated with each delay

2.2.1. Antenatal and perinatal characteristics

Our survey identified that every mother had at least one interaction with the healthcare system during pregnancy. Ninety-five mothers reported receiving care by a nurse (56%), while 79 received care from a physician (45%). Only 30% of mothers reported undergoing a prenatal ultrasound during pregnancy. Positive ultrasound results included four multiple pregnancies, five pregnancies with a transverse lay, and oligohydramnios in a mother whose child was identified sometime after birth to have an anorectal malformation. No congenital anomalies were detected among those mothers undergoing a prenatal ultrasound.

Among parents who reported site of delivery, 48% of children were delivered in a hospital, 11% in a clinic, and 9% at home. Nineteen infants were delivered by caesarean section: 5 planned and 14 as emergency procedures. Most births were attended by midwives (83%), and a minority had a physician (12%), traditional healer/birth attendant (5%), or nurse (3%) present. Some families reported multiple parties present at birth. Only 6% of births were attended by friends/family alone. Mothers and their infants were kept in hospital a median of 2 days (range 0–5) after birth.

2.2.2. Delay I

Thirty-eight children were noted to have an anomaly at birth (22%), but in only 17 of the 38 were these anomalies first noted by a healthcare professional (midwife, nurse, or doctor); the remainder were recognized by the family. In total, of the 156 anomalies that were ultimately identified, 90% were first noted by parents, with mothers being the first to recognize the abnormality in 134 children.

Although families were very astute at noticing an abnormality, they rarely understood or recognized its significance, cause or need for treatment. At the outset, 51% of parents attempted to treat their child at home. Seventy-three (42%) tried local herbs or remedies, while 11 families (6%) gave the child antibiotics or antihelmintics. Even when families ultimately did seek care outside of the home, only a minority went directly to MRRH (18%); most were first seen in clinics or district hospitals lacking pediatric surgical facilities. Recommendations at initial outside consultation included referral to MRRH in only 36 cases, with 24 families immediately advised that their child would require surgery.

2.2.3. Delay II

The majority of families (n = 148, 85%) came to MRRH Pediatric Surgery via a referral. Most referrals were made by other physicians (118, 80%). A minority were referred by nurses (13, 9%) or self-referred (27, 18%).

Eighty percent of parents (n = 139) followed through and sought the recommended care, once they were given a care plan. However, there were a number of factors that contributed to delays, even with/without the intent to follow through (see Table 3). These factors were not mutually exclusive, with some parents reporting multiple causes of delays while some families did not identify any specific factors.

2.2.4. Delay III

Even after patients reached the pediatric surgical facility, there remained several barriers to definitive surgical care. Of the 174 patients, 119 required pre-operative investigations (68%), 15 had to purchase surgical supplies (9%), and 11 had to purchase medications for their child after arrival to MRRH (6%). Direct out-of-pocket costs to families