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## Barriers to Pediatric Surgical Care in Low-Income Countries: The Three Delays' Impact in Uganda



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### ABSTRACT

**Background:** We sought to understand the challenges in accessing pediatric surgical care in the context of the “three delays” model at the Pediatric Surgery Outpatient Clinic (PSOPC) at a tertiary hospital in Kampala, Uganda.

**Materials and methods:** An outpatient database was established at the weekly PSOPC. A survey regarding prior healthcare visits and barriers to care was additionally administered to clinic patients and inpatients.

**Results:** Patients first sought healthcare a median of 56 d before the current visit to the PSOPC. A majority (52%) of patients first sought care at another health facility, and 17% of those surveyed had presented to the PSOPC three or more times for their current medical issue. Of 240 patients with a new issue or due for their next surgery, 10% were admitted to the ward, with only 54% receiving definitive care. Included in the most commonly needed surgeries for PSOPC patients were herniotomy (16% inguinal; 14.9% umbilical), orchiopexy (6.3%), posterior sagittal anorectoplasty (6.3%), and colostomy closure (4.4%), with the range of patient ages at the time of presentation reflecting delays in care. Patient expenditures associated with travel to the hospital showed inpatients coming from significantly further away, with higher costs of travel and need to borrow or sell assets to cover travel costs, when compared with PSOPC patients.

**Conclusions:** Patients face significant delays in accessing and receiving definitive surgical care. Associated burdens associated with these delays place patients at risk for catastrophic health expenditures. Infrastructure and capacity development are necessary for improvement in pediatric surgical care.

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### Introduction

The burden and backlog of care for pediatric surgery in low- and middle-income countries are not well understood but is a

metric to assess met and unmet need when engaging in capacity building and infrastructure development. Estimating prevalence of surgical conditions among the population is difficult, given financial and geographic challenges in

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accessing care and the challenge of centralized record keeping.<sup>1</sup> However, recent estimates suggest a prevalence of 7.4% of the Ugandan pediatric population living with an untreated surgical condition,<sup>2</sup> and countries in sub-Saharan African represent the highest need for surgical care, as well as hold significant limitations in accessing care.<sup>3</sup>

Challenges in health access can be described through three levels of delay: (1) the decision to seek care; (2) accessing a health facility; and (3) receiving adequate care.<sup>4</sup> In our experience at Mulago Hospital, each of these delays is evident: in the late presentation of many children with surgical conditions and our delays in delivering care, given the high number of presenting patients and insufficient surgical workforce. We therefore sought to better characterize the delays in care our patients experience before arriving at essentially the single facility nationally able to provide definitive care and the delays they experience in receiving that care once they arrive at the hospital.

Infrastructure development continues to focus on identifying distinct levels of healthcare facilities capable of providing differing levels of care, as well as a referral system that streamlines access to the appropriate facility.<sup>5,6</sup> We analyzed surgical conditions and access to definitive care at the national referral hospital, one of two centers with a dedicated pediatric surgery unit in the country. Secondarily, we assessed the burden of accessing care in patients presenting to the outpatient clinic and those directly admitted to the surgical ward.

## Methods

After approval from the Mulago Hospital Institutional Review Board, an outpatient database was established to prospectively include all patients presenting to the weekly pediatric surgery outpatient clinic (PSOPC). This database includes patient demographics, diagnosis, admission status, and assessment of care needed, as well as a pilot intake survey centered around barriers to care (time traveled, cost of transport, prior PSOPC visits, prior healthcare facilities visited). Verbal and signed consent, available in English and Luganda, was obtained by the survey collector, a bilingual nurse. The survey was verbally administered to family members accompanying the patient, with preference given to a parent, on arrival to the PSOPC. The survey instrument included estimates for time and cost of travel to reach the PSOPC, number of previous visits to other health facilities as well as to Mulago Hospital PSOPC. Survey respondents were also asked whether or not they had borrowed money or sold assets to pay for transit for the current visit to Mulago Hospital. Data were manually recorded by the survey collector and entered into the database. The same survey was administered to ward patients, who were asked to estimate the time and cost of travel to reach the inpatient ward. For patients not conversant in Luganda or English, spoken by the survey collector, informal interpreters were used—typically other nurses or family members. No patients were excluded due to inability to complete the survey because of language issues.

Data from records obtained from patients presenting to the Mulago Hospital PSOPC and ward between June and August 2016 were reviewed. The study was approved by the Mulago Hospital Institutional Review Board. This period was chosen to estimate a census of the pediatric surgery outpatient

department ahead of planned constructions of the hospital to plan for sufficient ward capacity. Currency is reported as Ugandan shillings (UGX) and converted to US dollars (USD) using purchasing power parity (1 2016 USD = 1098 UGX). Gross domestic product using purchasing power parity per capita in 2016 was 1716 USD.<sup>7</sup> Statistical analysis was performed using GraphPad Prism, version 7.0 (GraphPad Software Inc), with data reported as means and range, and statistical significance was determined using two-tailed, unpaired t-tests, with reported P values. Distribution of district origin of patients was visualized by maps created with GeoLytics software (GeoLytics, Inc, East Brunswick, NJ; 2018).

## Results

During the study period, nine weekly outpatient clinics occurred, with 313 visits representing 263 unique patients. Of the patients evaluated, 65% were men. The median age of patients presenting to the clinic was 1.5 y (range 0–15 y) with 37% <1 y of age and 37% between 1 and 4 y of age (Table 1). Records from 81 patients who were admitted directly to the pediatric surgery ward as inpatients were obtained of 159 patients admitted in that period. Two hundred and eight patients (79%) presented with a new concern, 32 (12%) were due for next surgery in a staged procedure, and 23 (9%) came for a postoperative follow-up (Table 1). Of the 208 with a new concern, 139 had an issue that would require surgical intervention either soon or eventually (Table 1).

### First delay

The majority of patients' conditions were first identified by a parent (62%) or a medical provider (22%; Table 2). Medical care was first sought a median of 56 d before the date patients were interviewed at Mulago PSOPC while awaiting care (Table 2).

**Table 1 – Patient demographics.**

Patients	N = 263, n (%)
Age (y)	
<0.5	45 (17.1)
0.5–1	53 (19.8)
1–2	51 (19.4)
2–4	45 (17.1)
4–6	22 (8.9)
6–8	20 (7.6)
>8	28 (10.6)
Gender	
Female	91 (34.6)
Male	172 (65.4)
Status	
New issue	208 (79.1)
New issue that requires surgery	139 (52.9)
Requires next stage of surgical process	32 (12.2)
Postoperative follow-up	23 (8.7)

### Second delay

Half of the patients (52%) in the PSOPC had visited another healthcare facility before attending the Mulago PSOPC. Of these patients, 15% were referred from another department at Mulago, 36% had visited a regional public hospital, 20% a private hospital, and the remainder had gone to clinics or more than one location (up to 5) before coming to Mulago (Table 2). Thirty-six percent of patients who had visited other healthcare facilities had made at least two visits before being referred to Mulago (Table 2). A majority of patients (61%) in the PSOPC were presenting with a new complaint, whereas 17% had presented to the PSOPC 3 or more times for the medical issue (Table 2).

### Third delay

After the visit to the PSOPC, of 240 patients with either a new issue or due for their next surgery, 24 patients (10%) were admitted to the ward (Table 2). Of these patients, 13 (54.2%) recovered or received surgery, 9 (37.5%) had their surgery postponed, one patient died, and one ran away (Table 2). Of the remaining 216 not admitted to the ward, the 56% of patients in need of surgery in the near future were denied due to ward capacity, equipment issues, or told to return for surgical camps (Table 3). In addition, 12.5% each awaited laboratory or imaging results or did not need surgery; 11.1% were referred to other clinics (Table 3). The median time instructed before return for patients not admitted was 4 wk, with 23% were told to come back in <4 wk.

### Presenting surgical conditions

The most frequently seen conditions in the PSOPC were umbilical and inguinal hernias (13.7% and 12.9%, respectively), anorectal malformations (ARMs; 10.6%), masses (9.1%), and Hirschsprung's disease (6.1%); cryptorchidism and hydrocele each represented 4.9% of the presenting conditions (Data not shown). Included in the most commonly needed surgeries noted in records were herniotomy (16% inguinal; 14.9% umbilical), orchiopexy (6.3%), PSARP (6.3%), and colostomy closure (4.4%; Supplementary Table 1). Median age of patients with inguinal hernias awaiting herniotomy was 2.5 y (range 2 mo to 11 y; 25th percentile 1 y, 75th percentile 6 y;  $n = 31$ ; Supplementary Table 1). Median time parents reported having been aware of the problem was 18 mo (inguinal hernia) and 9 mo (cryptorchidism). Median age of patients presenting with umbilical hernias was 11 mo of age (range 1 mo to 11 y;  $n = 35$ ) with only six patients (17%) aged  $\geq 4$  y (Supplementary Table 1). Patients with ARMs awaiting PSARP were a median of 1 y old (range 3 mo to 11 y); those with either ARM or Hirschsprung's disease awaiting colostomy closure were median age of 1.8 y (range 9 mo to 6 y; Supplementary Table 1).

### Burden of accessing care

To access the Mulago PSOPC, patients reported a median round-trip cost of 6000 UGX (5.46 USD) for transportation (range 0-140,000 UGX; Supplementary Table 2).<sup>7</sup> Patients reported median travel time of 1 h (max 30 h). A majority of

**Table 2 – Delays in reaching definitive surgical care.**

	n (%)
Condition first noted by:	
Parent	164 (62.4)
Medical provider	58 (22.1)
Family member	17 (6.5)
Community member	12 (4.6)
Child (patient)	6 (2.3)
No response	6 (2.3)
Number of visits before Mulago	
1	70 (51.9)
2	27 (20.0)
3	12 (8.9)
$\geq 4$	9 (6.7)
No response	17 (12.6)
Other health facility visits	
Mulago department	20 (14.8)
Private clinic	26 (19.3)
Private hospital	27 (20.0)
Public clinic	5 (3.7)
Public hospital	49 (36.3)
Multiple types	5 (3.7)
No response	3 (2.2)
Months since first sought care*	
<1 mo	60 (43.2)
1-3 mo	21 (15.1)
3-6 mo	24 (17.3)
6 mo to 1 y	12 (8.6)
1-2 y	11 (7.9)
>2 y	11 (7.9)
Number of visits at Mulago OPD	
0	159 (60.5)
1	31 (11.8)
2	22 (8.4)
3	16 (6.1)
$\geq 4$	29 (11.0)
No response	6 (2.3)
Admitted†	
No	216 (90)
Yes	24 (10)
Received surgery	13 (6)
Surgery postponed	9 (4)
Died	1 (0.5)
Left against medical advice	1 (0.5)

\* 139 respondents.

† Admitted with "new issue" or "due for next surgery."

patients (85%) took one or two vehicles to arrive to the PSOPC (Supplementary Table 2). Forty-eight patients (18.3%) reported borrowing money from their community or family, and 16 (6.1%) reported selling something they own (Figure).

Records of the 81 records from patients admitted directly to the ward were reviewed. These patients had a median travel

**Table 3 – Contributing factors to delays in delivery of care.**

Reason denied admission	n (%)
Surgical care needed	121 (56)
Ward full	70 (32.4)
Return for surgical camp	12 (5.6)
Equipment broken	3 (1.4)
Awaiting labs, imaging	27 (12.5)
No response	9 (4.2)
Surgery needed, but not in near future	18 (8.3)
Continue follow-up	4 (1.9)
No surgery needed	27 (12.5)
Refer to another clinic	24 (11.1)
No response	22 (10.2)

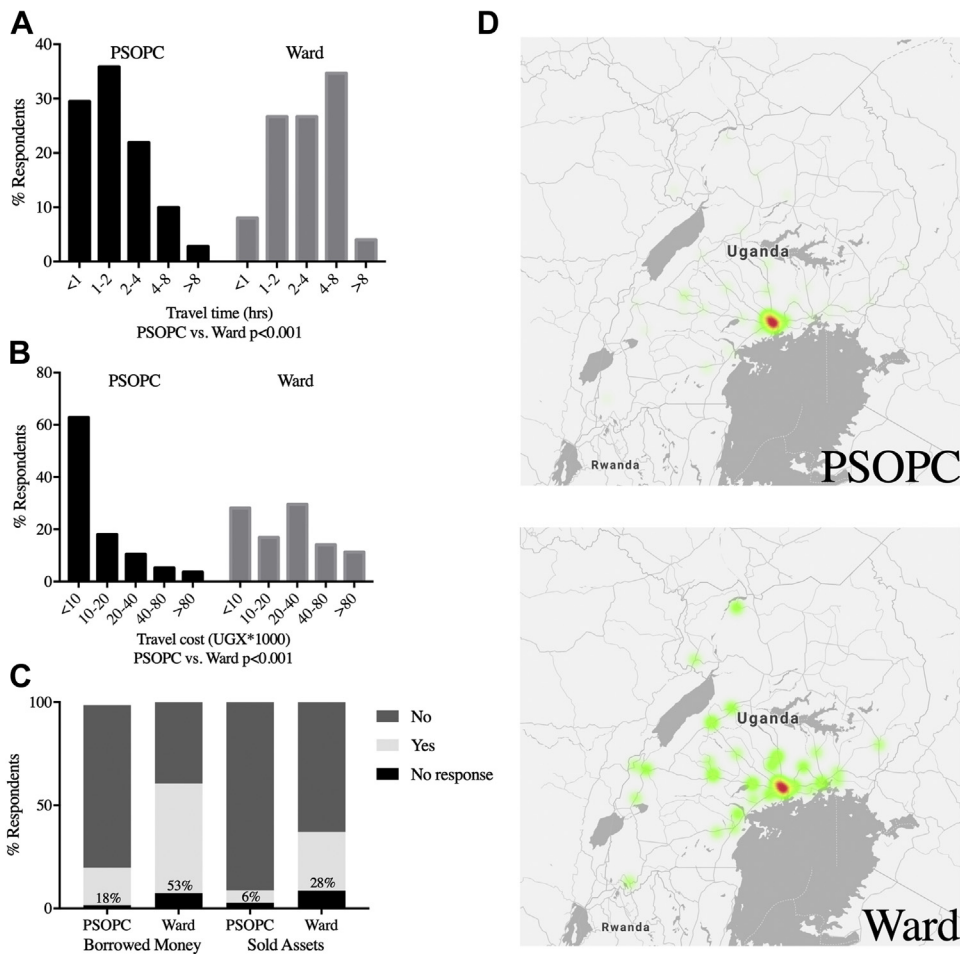
cost of 20,000 UGX (range 0-320,000 UGX) and median travel time of 2.5 h (for both cost and time,  $P < 0.001$  versus PSOPC patients; [Figure](#)). A majority of these families (53%) borrowed money for transportation, and 28.4% sold something they own ([Figure](#)). Differences in resources used between patients presenting to the PSOPC and ward are illustrated in [Figure](#).

The majority of PSOPC patients (75.4%) came from two surrounding districts, Kampala (46.9%) and Wakiso (28.5%), whereas only 28% of ward patients came from those two districts. The remainder of patients came from 43 districts (see [Maps](#), [Figure](#)). When asked what they had sold, the 16 (6.1% of total) PSOPC and 23 (28% of total) ward respondents cited crops, livestock, and material goods ranging from shoes to a boat, as well as land ([Supplemental Table 2](#)).

### Discussion

This pilot study sought to understand the barriers to accessing definitive treatment for pediatric surgical conditions through the “three delays” model<sup>4</sup>: (1) decision to seek care; (2) reaching appropriate healthcare facility; (3) receiving definitive care. The PSOPC was chosen as the primary study site as children with longstanding often nonacute conditions present to the PSOPC, whereas acute presenting patients with surgical problems often present directly to the ward.<sup>8</sup>

To estimate the first delay, patients identified when and by whom the patient’s condition was first noted and how long ago they first sought care. The majority of conditions were



**Figure – Differential demographics in PSOPC and ward patients. Distribution of travel time (A) and travel cost (B) for patients surveyed in the PSOPC and Ward. For both time and cost,  $P < 0.001$  for ward versus PSOPC patients. Patients in PSOPC and ward reporting necessity to borrow money or sell assets to reach the PSOPC (C). Visual representation of districts from where patients who arrived to PSOPC and ward came (D). (Color version of figure is available online.)**

**Table 4 – Summary.**

First delay	Second delay	Third delay
Increase in deliveries with trained birth attendants	Community transportation and ambulances	Infrastructure development
Community education regarding common conditions and early intervention	Insurance schemes	Providing services for elective pediatric surgery at district and regional hospitals
	Referral system among regional and district hospitals to tertiary facility	Training pediatric surgeons and anesthesiologists

identified by parents and secondarily by medical providers. Several studies have reported the benefit of investing in training community members and medical providers to improve maternal and neonatal outcomes.<sup>9,10</sup> Continued investment in training community providers, as well as encouragement of delivery with a trained birth attendant, may contribute to increased identification and referrals from rural areas to the appropriate healthcare facilities (Table 4).

The second delay was defined as reaching the appropriate healthcare facility, Mulago PSOPC, and admission to the ward for definitive treatment. A majority of patients visit other healthcare facilities, with one-third reporting multiple visits, before reaching Mulago. Delays in the healthcare system from the time of recognizing a medical issue contribute to impaired delivery of care. This is further exacerbated by the significant economic burden families face in accessing a health facility. Patients arriving at Mulago Hospital spend significant money, time, and often borrow or sell assets with each visit to reach the healthcare facility. Anecdotally, patients who are admitted directly to the ward on days other than clinic day tend to come from further away or with surgical emergencies. Our data reflect this, in that patients admitted directly to the ward travel significantly longer and expend significantly more to reach the hospital. In addition, they bear a larger burden of cost (median cost triple of PSOPC patients to reach the hospital), with >82% borrowing or selling to reach the hospital. A significant burden that was not studied here is reallocation of money within a family, for example, using school costs for their children to pay for their travel. For patients presenting to the PSOPC, attaining sufficient funds to travel was often cited as a contributor to delay to traveling to the hospital, consistent with findings on delays to accessing the other referral center for pediatric surgical care in Mbarara, Uganda.<sup>11</sup>

As there are a limited number of pediatric surgery providers in the country, continued investment in streamlining referrals among healthcare facilities for these conditions on the first presentation to a healthcare facility can contribute to more rapid referrals for appropriate care. Further facilitating arrival to appropriate hospitals could be achieved via community transportation initiatives or ambulance systems (Table 4). While arrival at the hospital represents a significant barrier to receiving care, they represent just the initial phase of costs associated with each health episode or interaction with the healthcare facility for each child. Included in the Lancet Commission on Global Surgery (LCoGS) 2030 goals was 100% financial risk protection against impoverishing expenditure from costs for surgical and anesthesia care.<sup>12,13</sup> The World Bank has included the risk of catastrophic expenditure for surgical care in its list of World Development Indicators.<sup>14</sup>

This metric is defined as spending >10% of annual household expenditure. More than 8% of patients presenting to PSOPC and 22% of patients presenting to the ward spent >2.5% of the gross domestic product per capita to travel to and from the hospital for the current effort to seek health care. For most of the patients presenting to the PSOPC, they would have to make the journey several times before receiving definitive care for their condition. Accounting for hospital costs including imaging, laboratories, supplies, and basic nutrition needs once receiving care, it is not far off to reach the threshold of 10% of gross domestic product per capita to define catastrophic health expenditure and leave these patients impoverished. These costs certainly affect those coming from further away most as they come from more impoverished regions and additionally must bear increased transport costs to reach a tertiary center and incur further costs with longer hospital stays once they reach the health facility. Surgical care remains of low to moderate priority on the national health agenda for Uganda.<sup>15</sup> However, strategies to address hospital costs, either via insurance schemes or community initiatives to protect against financial catastrophe, can combat the risk of impoverishment.

The scarcity of trained providers delays in accessing a healthcare facility before referral to a tertiary center for patients from distant districts, reflects a significant number of patients are not reaching the facilities where they would receive definitive care despite high estimates of need for surgical treatment for children in low-income countries.<sup>16,17</sup> Eighty-five percent of children in low-income countries are likely to require treatment for a surgical condition by the age of 15 y.<sup>18</sup> A national survey found that service delivery remains well below the recommendations to meet predicted surgical need, unchanged from what was reported a decade ago, and far from the Lancet Commission on Global Surgery goal of 5000 procedures per 100,000 people per year.<sup>19,20</sup> In some regions of the country, no pediatric surgery is being performed; in other regions, procedures are performed by medical officers. In regions with pediatric surgical cases are documented, the rate represents <5% the rate in high-income countries.<sup>21</sup>

The third delay—receiving definitive care once admitted to the Ward—is evident in the minority (10%) of patients admitted to the ward for care over the study period. Because of the limited capacity of the Ward, preventing admission, and high number of urgent operative cases (i.e., traumas, abdominal emergencies in older children, and neonatal cases) displacing elective cases, a plurality of patients electively admitted for surgery from the PSOPC were discharged from the unit without surgical care—the definitive treatment for

their condition. Data from the Mulago PSOPC reflect common conditions treated on an elective basis in pediatric surgery departments rather than emergencies. However, elective cases are often moved to accommodate children with surgical emergencies presenting to the Ward.<sup>22</sup> A retrospective study inclusive of the period analyzed here found that Mulago's surgical case burden is by majority emergent and urgent cases, 61.7% and 11.7%, respectively, often displacing scheduled elective cases.<sup>23</sup> The growing backlog evident at the PSOPC reflects an ongoing need to invest in infrastructure to more effectively manage referrals and also expand the roles of treatment teams (Table 4).

The backlog grows with every emergency that reaches the Ward, thereby displacing a nonurgent surgery. We analyzed a subset of our data that included patients awaiting herniotomy, orchiopexy, and second and third surgeries (e.g., pull-through and colostomy closures) for ARMs. Patients were aware of problem 9–18 mo ahead of presenting for treatment. Delays in accessing and receiving completion surgeries for multistage procedures have a significant socioeconomic impact on families who often travel long distances for long-awaited surgeries, and their care is further delayed by the growing backlog.<sup>24,25</sup> For patients traveling long distances to receive care, length of stay correlates with their distance, further contributing to the burden of cost on a family to receive treatment.<sup>8</sup> In the most recent edition of the *Disease Control Priorities*, guidelines for time priorities are assigned to interventions according to severity.<sup>6</sup> Among these guidelines is the optimal resources for children's surgery recommendation that elective surgeries be pursued after 1 y of age at the regional hospital level.<sup>26</sup> Establishment of surgical care at regional and district level centers for elective surgery for common conditions in infants after 1 y of age could significantly offload the volume of elective procedures at tertiary centers and allow of significant reallocation of resources toward urgently presenting cases.

Such proposals are further elaborated in the guidelines set forth by optimal resources for children's surgery report by the Global Initiative for Children's Surgery.<sup>26</sup> Recommendations for training, physical resources, and quality and safety are given for each level including health center, first-level hospital, as well as second, third, and national levels of referral hospitals for children's surgical care. In our own work, we have partnered with organizations to build and equip operating rooms in Kampala and now Mbarara to address the backlog in Uganda.<sup>27</sup> Methods to address the delays include continued investment in building operating rooms, increasing community awareness for surgical conditions and engagement of rural providers and mechanisms to facilitate transport via ambulances or financing through insurance schemes or community resource sharing. Each of these can help to reduce the delays via awareness and availability to local regional or district hospitals capable of offering elective surgical procedures for common conditions.

Limitations of this study include limited duration of the study during a period when the hospital was undergoing significant renovations, impacting care. Of note, our group has an ongoing longitudinal database, which has shown no seasonal variation in problems with which patients present.<sup>28</sup> This study provided the opportunity to perform a more in-

depth evaluation of patient care during a short segment of time. Challenges in longitudinally tracking patients due to limited records contributed to limitations in verifying patient-reported data, for example, number of prior visits to PSOPC. The use of informal interpreters for survey administration in a minority of patients and differences in linguistic diversity between PSOPC and ward patients may have affected survey results. At the time of this study, the capacity of the ward was 25 beds, and we sought to capture the baseline function and delays in delivery of care ahead of planned renovations of the hospital. The current capacity remains 12 beds due to renovations. Specialty pediatric surgeons in Uganda operate in Mbarara and Kampala (Mulago Hospital).

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## Conclusions

A minority of pediatric patients presenting to the PSOPC receive surgery at their first presentation to the PSOPC. Patients admitted directly to the ward have significantly higher burden of cost and come from significantly farther away than those presenting to the PSOPC. Delays in care and limited resources contribute to a significant backlog of care. A significant number of patients are at risk for catastrophic health expenditure. Intervention aimed at each level of delay associated with seeking care—identification of the problem, reaching the appropriate facility, and receipt of definitive care—are needed to address significant delays in accessing and receiving definitive care. Infrastructure and capacity development are necessary for improvement in pediatric surgical care.

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Authors' contributions: N.K. and A.G.-F. are the primary authors and share co-authorship as first author. They were involved with all steps of the study including the design, execution, analysis, and the article drafting of the study. A.N. was essential to the conception and execution of the study, especially via survey administration and record keeping. M.C. contributed to the editing of the article. P.K., A.M., and J.S. were essential in establishing a system through which surveys were administered and provided critical feedback in regards to data interpretation. D.O. is the senior author, who supervised each component of the study, including study design and reviewed the results and article of the study.

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## Disclosure

The authors declare they have no conflicts of interest.

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## Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.jss.2019.03.058>.

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