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From Procedure to Poverty: Out-of-Pocket and Catastrophic Expenditure for Pediatric Surgery in Uganda

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ABSTRACT

Background: Financial protection from catastrophic health care expenditure (CHE) and patient out-of-pocket (OOP) spending are key indicators for sustainable surgical delivery. We aimed to calculate these metrics for a hospital stay requiring surgery in Uganda's pediatric population.
Methods: A survey was administered to family members of postoperative patients in the pediatric surgical ward at Mulago Hospital. Cost categories included direct medical costs, direct nonmedical costs, indirect costs, plus money borrowed and items sold to pay for the hospital stay. CHE was defined as spending greater than 10% of annual household expenditure. Costs were reported in Ugandan shillings and US dollars.
Results: One hundred and thirty-two patient families were surveyed between November 2016 and April 2017. Median direct costs were $27.55 (IQR 18.73-183.69) for diagnostics, $18.36 (IQR 9.52-41.33) for medications, $26.63 (IQR 9.19-45.92) for transportation, and $32.60 (IQR 12.85-64.29) for food and lodging. Forty-four percent of respondents were employed, and median indirect cost from productivity loss was $95.52 (IQR 55.10-243.38). Eighteen percent (16/87) borrowed money, and 9% (8/87) sold possessions to pay for the hospital stay. Total median OOP cost for patient families per hospital stay was $150.62 (IQR 65.21-339.82). Sixteen percent (21/132) of families incurred CHE from direct costs, and the proportion rose to 27% (32/132) when indirect cost was included.
Conclusions: Although pediatric surgical services in Uganda are formally provided for free by the public sector, families accrue substantial OOP expenditure and almost a third of households incur CHE for a pediatric surgical procedure. This study suggests that broader financial protection must be established to meet Sustainable Development Goal targets.

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Background

Out-of-pocket (OOP) expenditure is the payment made directly by the patient receiving a health service. Catastrophic health care expenditure (CHE) is defined as OOP health care spending of more than 10% of a patient's annual household expenditure[1] or 40% of annual household expenditure after food expenses.[2] A comprehensive health care system provides both quality health care delivery and financial protection, though policies often fail to address the latter objective.[3] Financial risk protection from OOP spending is a key indicator of successful health care delivery as concluded by the Lancet Commission of Global Surgery[4] and the World Bank[5] and was incorporated into the Sustainable Developmental Goals[6] and the third edition of Disease Control Priorities.[7] However, studies suggest that 81.3 million people fall into financial catastrophe from surgical spending each year, and about half the world's population is at risk for CHE should they require surgery.[2,8]

Financial insecurity from CHE can lead to bankruptcy, and the burden rests heavily on the poor, with 90% occurring in low-income countries (LICs).[8] This disparity is caused by available health care services that require compensation, inadequate payer resources, and lack of health insurance.[9] Several OOP spending studies have recently been published on noncommunicable diseases in sub-Saharan Africa, where 8.7%-20% of patients experience catastrophic expenditure.[10-12] To date, however, little is known about the OOP spending of surgical patients in LICs, and even fewer are focused on pediatric surgical patients.

Half of Uganda's population of 41 million people in 2016 is under the age of 18 years, and the country's fertility rate is one of the highest in the world with 44 births per 1000 people.[13] A recent nationwide household survey estimated that 14% of Uganda's pediatric population will have a surgically treatable condition in their lifetime.[14] In 2016, gross domestic product per capita in Uganda was USD 1819, which was 3% of the gross domestic product per capita in the United States at USD 57,638,[15] and approximately 31% of adult patients incur CHE as a result of surgery.[16] However, no study has looked into the financial burden of pediatric patients, which comprises a large demographic. Our study seeks to capture the OOP spending and CHE of families of pediatric patients who underwent surgery in one of two pediatric surgical facilities in Uganda.

Methods

Study setting and sampling

Mulago Hospital was chosen as the study site as the national public referral hospital, and one of two facilities providing specialized treatment for pediatric surgical disease in the country. The ward cared for approximately 450 postoperative cases directly transferred from the pediatric operating room between 2015 and 2016. Mulago Hospital offers health care services, bed space, and a daily meal freely for patients, so OOP spending should theoretically be minimized. Medical supplies are distributed by the government via the National Medical Store, which frequently experiences shortages and does not hold certain medications that are commonly prescribed in the pediatric surgical ward. As a result, the patients resort to purchasing certain medications OOP from privately owned pharmacies, as there were no public means of access. Furthermore, although Mulago Hospital provides basic hematologic laboratory tests, more expensive diagnostic imaging is paid for by the patient's family. Patients also usually pay for transportation, food, and lodging.

Data collection

Institutional review board approval was granted by both Yale University and Mulago Hospital. A prospective survey administered to the patients' families determined OOP expenditure. Survey respondents were selected from a convenience sample of family members taking care of patients admitted to the pediatric surgical inpatient ward for surgical procedures. Internal validity was maintained by having the same ward nurses collect data for the entire study period. Verbal consent was obtained by a survey collector, and signed consent was waived as no personal identifiers were collected. From November 2016 to April 2017, bilingual ward nurses verbally translated English electronic questionnaires to family members. Inclusion criteria included guardian(s) who accompanied the child to the hospital, with preference given to the patient's parent. Questionnaires were administered postoperatively after the family had purchased postoperative medications and were close to being discharged, according to the physician's clinical judgment. Families whose patients were transferred to another department or admitted in the ward for nonoperative management were excluded from our study.

Survey instrument

Query categories of family OOP spending for a single hospital stay for surgery were divided into direct and indirect costs. Direct costs included 4 categories: (1) transportation (projected round trip to and from the hospital), (2) diagnostic tests, (3) medications, and (4) food and lodging. Indirect cost included the fifth cost category of lost productivity in the form of missed wages.

Survey questions were structured around previously validated tools including the Labor and Health Short Form Questionnaire and Household Consumer Expenditure Survey.[17-19] Demographic information gathered included the age, sex, home province, dates of admission, surgery and discharge, surgical diagnosis and intervention, and number of family members present to care for the child. The survey instrument was piloted over a week by two nurses administering the survey tool to patient families and other health care providers in the ward to confirm accurate understanding, with question format refined over multiple iterations. The pilot responses were not included in the final analysis.

Participants were also asked to estimate the total amount spent on the entire hospital admission (total estimated cost), and this value was compared with the sum of the five cost

query categories in the survey (total calculated cost). Monetary values were reported in the local currency of Ugandan shillings (UGX) and converted to US dollars (USD) using purchasing power parity (1 USD [in 2015] = 1088 UGX).

Statistical analysis

Statistical analysis was performed with R and Excel for each study parameter, stratified by the cost category and surgical disease. Interquartile ranges (IQRs) were reported with median values. Proportion of catastrophic expenditure was determined by comparing total calculated expenditure to the median household expenditure in Uganda in 2013, which was 244,444 UGX or 3113 USD, as reported by the most recent Ugandan Bureau of Statistics.[20]

Results

Study population demographics

In the span of 6 mo, between November 2016 and April 2017, 132 respondents participated in the OOP spending questionnaire. The patient's average age of presentation was 2.17 y. All respondent families were from Uganda, distributed across 34 provinces throughout the country. In the following section, "*n*" is the number of patient families, which could refer to one or more members per family unit. The most common home district was Wakiso (30.2%, $n = 35$), followed by the capital city of Kampala (17.2%, $n = 20$), where the Naguru operating room was situated (Fig. 1). Most respondents were mothers of the patient.

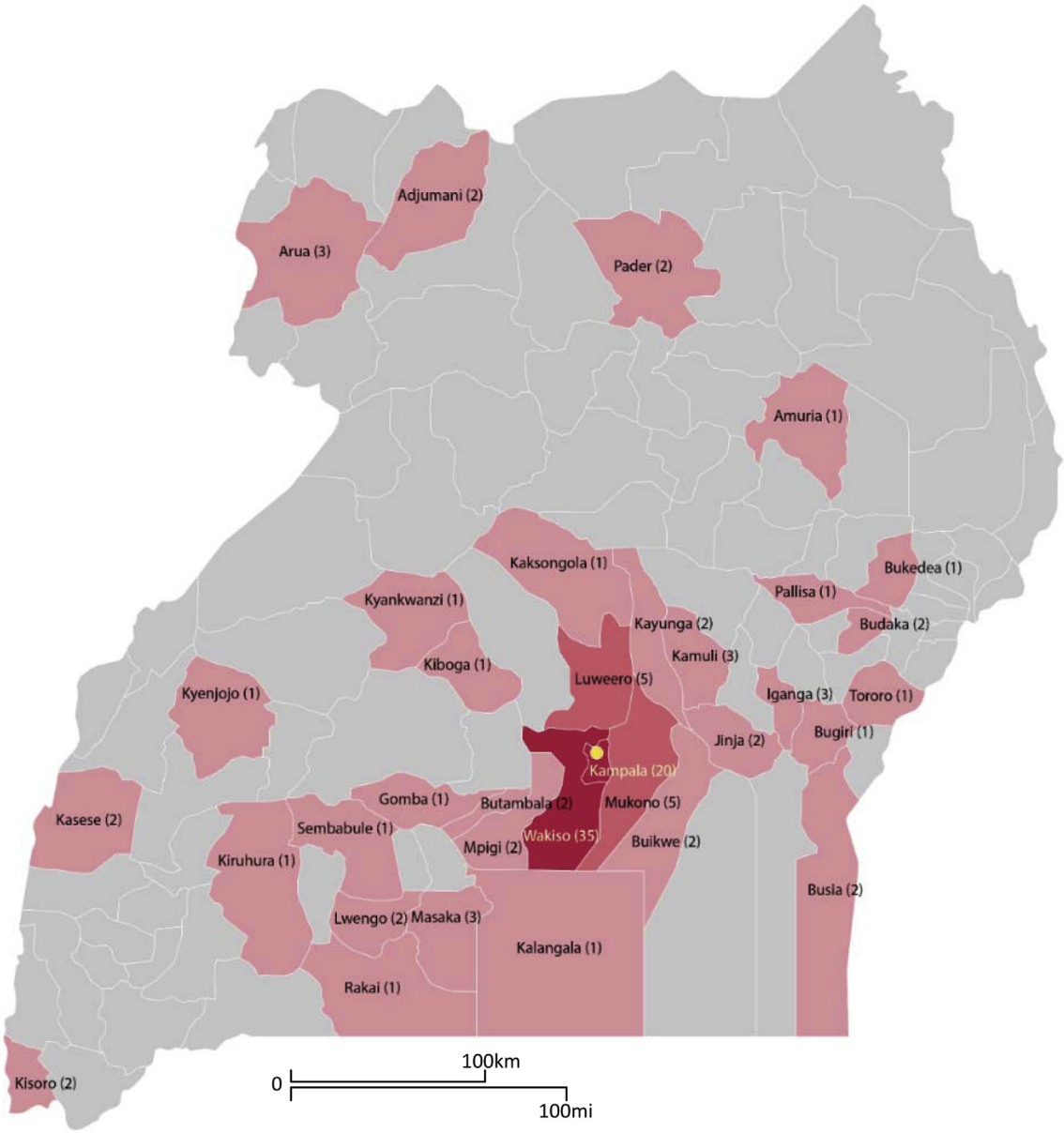

Fig. 1 – Respondents originated from 34 districts of Uganda. The yellow circle indicates the location of the Mulago Hospital pediatric surgical ward, in the district of the capital city of Kampala. (Color version of figure is available online.)

The median inpatient waiting preoperative period was 4 d, with the longest wait to surgery at 33 d. The median length of stay was 7 d, with the longest admission at 39 d. Reasons for delay ranged from personnel, lack of operating room space mostly due to overwhelming burden of emergent cases, and equipment supply shortage (e.g., depleted oxygen tanks). Fourteen patients underwent ambulatory hernia repairs that did not require overnight admission. All patients had family members present during the entire duration of the hospitalization, and most patients had one relative at bedside (57%, $n = 75$).

Indirect costs of productivity loss

Most family members were not employed (56%, $n = 74$). Of the patients who were accompanied by working relatives (44%, $n = 58$), 84% ($n = 49$) had one working family member at bedside, whereas 7% ($n = 9$) had two working relatives. Farmers and vendors earned the least at a daily wage of 3000-10,000 UGX (<1 USD). Highest wages were held by businesspersons who earned up to 100,000 UGX (30 USD) per day. The working relatives' missed days of work accounted for the cost of productivity loss. Of the 58 patients who had working members at bedside, the median cost of productivity loss per household was $95.52 (IQR 55.10-243.38) or 104,000 UGX (IQR 60,000-265,000).

Closely related to productivity losses was the proportion of families that needed to take out a loan or sell possessions to pay for hospitalization costs. Eighty-seven families agreed to respond to this portion of the survey. Eighteen percent ($n = 16$) of families borrowed money from their family or friends, at a median value of $59.70 per household (IQR 33.29-126.28) or 65,000 UGX (IQR 36,250-137.500). Nine percent ($n = 8$) of families sold household items, with possessions ranging from livestock to furniture, at a median value of $64.29 (IQR 64.29-257.16) or 70,000 UGX (IQR 16,250-280,000).

Transportation costs

Taxi was by far the most common form of transport, used by 61% ($n = 88$) of patient families, distantly followed by boda-boda, or local motorcycle for hire (Fig. 2). From Wakiso, transit time to and from the hospital was under an hour, and most patient families did not need to travel for more than a day. The maximum cost of 400,000 UGX or $367.38 spent by two patients: one who came by an ambulance from the Kyankwanzi province and another who traveled by a private car from the province of Iganga. The median transportation cost was $26.63 per family (IQR 9.18-45.92) or 29,000 UGX (IQR 50,000-10,000).

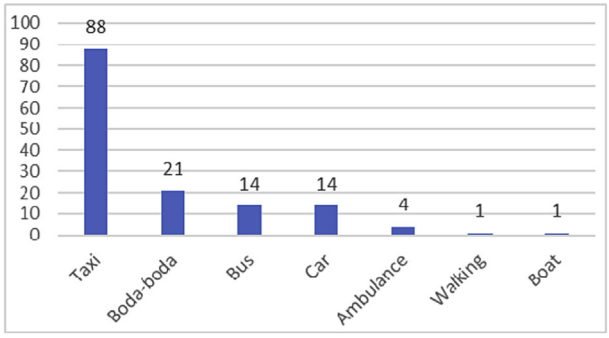

Fig. 2 – Histogram depicting mode of patient transportation. Y-axis indicates frequency of respondents. (Color version of figure is available online.)

Diagnostic imaging costs

A little more than half of the respondents had some financial expense from diagnostics (51%, $n = 67$). Plain films and ultrasonography were the most common imaging tests purchased (Fig. 3). The maximum amount spent on diagnostics per family was $688.83, which was the cost of an MRI study. The median cost of diagnostics per family was $27.55 (IQR 18.37-183.69) or 30,000 UGX (IQR 20,000-200,000).

Medication costs

Thirty-six percent ($n = 48$) of patient families in the 6-month period purchased medications from a private pharmacy, most frequently from the pharmacy located next to the hospital. Rectal acetaminophen, intravenous dextrose, and intravenous metronidazole were the most common drugs purchased. The median medication cost per household when all respondents were included was $18.36 (IQR 9.52-41.33) or 20,000 UGX (10,125-45,000).

Lodging costs

Food and lodging expenses were reported as a daily estimate from the respondents multiplied by the days of inpatient stay leading up to surgery, as discharge dates were not consistently recorded. This value served as a conservative measure of the total lodging costs because it underestimated the postoperative inpatient days were not included. Median daily lodging cost was $9.18 or 10,000 UGX. Median total lodging cost for the hospital stay was $32.60 (IQR 12.86-32.60) or 35,500 UGX (IQR 14,000-70,000).

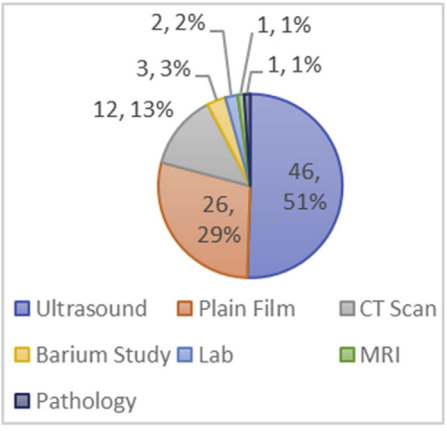

Fig. 3 – Distribution of diagnostic tests by type. (Color version of figure is available online.)

Total costs

Total estimated cost per household reported by the family members for a single hospital stay was a median of $91.85 (IQR 45.92-183.69) or 100,000 UGX (IQR 50,000-200,000). Total calculated cost per patient family was significantly higher ($P < 0.001$) at a median of $150.62 (IQR 65.21-339.82) or 164,000 UGX (IQR 71,000-370,000). Because the indirect cost of productivity loss was not traditionally counted toward OOP costs, the total calculated cost including only direct costs (and excluding productivity loss) came to a median of $102.87 (IQR 47.76-221.80) or 112,000 UGX (IQR 52,000-241,500), which was still higher than the total estimated cost ($P = 0.005$).

When total calculated costs were stratified by surgical condition, choledochal cyst treatment accrued the most OOP costs regardless of whether the indirect cost of productivity loss was included or excluded. Tumors and sacrococcygeal teratomas were also expensive for patient families, costing more than $200 per visit in direct costs only. When indirect costs were included to the total (direct plus indirect) cost, colostomy closure became much more expensive for families, second only to choledochal cyst (Fig. 4).

Catastrophic health care expenditure

In Uganda, the average annual consumption expenditure per household in 2013 was UGX 244,400 or USD 3113 in 2015 US dollars, after adjusting for inflation rate and currency. Based on survey results, 36 of 132 respondents or 27% of households incurred CHE, defined as spending more than 10% of the average annual household expenditure. When productivity loss was excluded from the total calculated cost, 21 respondents or 16% of households incurred CHE. In other words, 16%-27% of households spent enough OOP to place them at risk of falling into poverty in the setting of inadequate financial protection, as stated by the World Health Organization. Figure 5 shows the breakdown of total expenditure of the sum of OOP costs for a hospital visit requiring an operation in the pediatric surgical ward. Notably, the indirect cost from productivity loss comprised the largest proportion of all OOP spending.

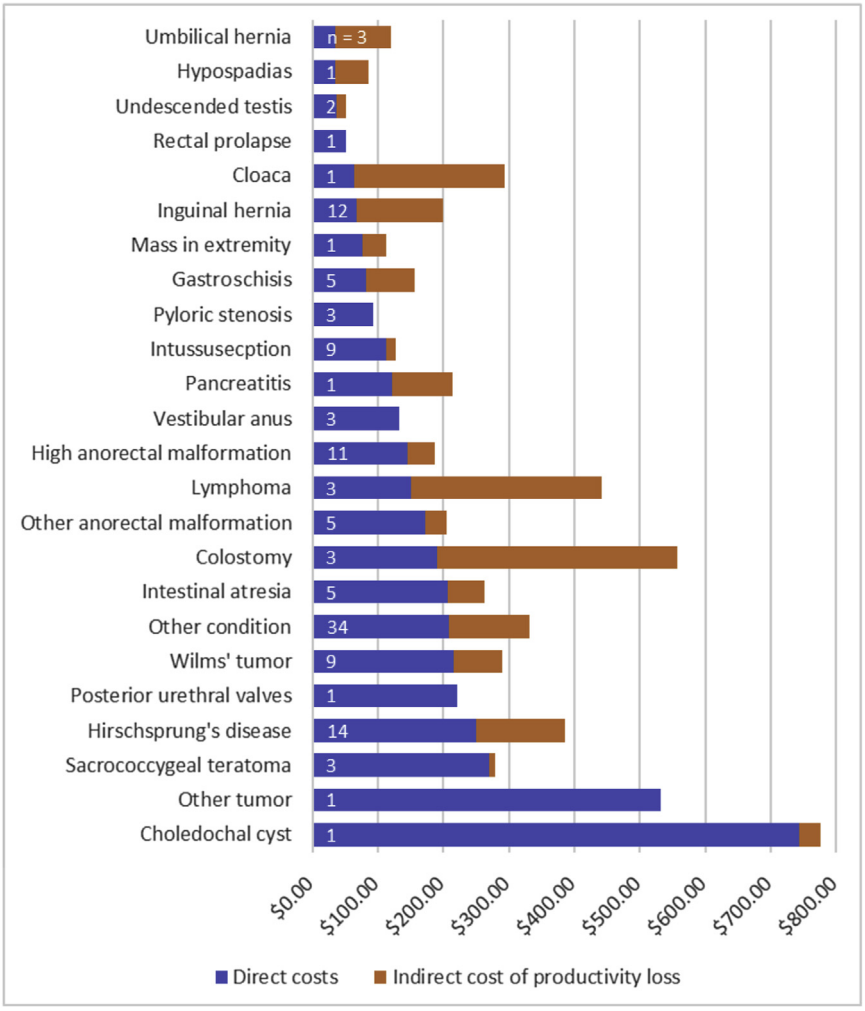

Fig. 4 – Total calculated costs by patient condition, including or excluding the indirect cost of productivity loss. Sample frequency (*n*) of each condition is labeled at the end of each bar. Conditions are sorted by direct costs. (Color version of figure is available online.)

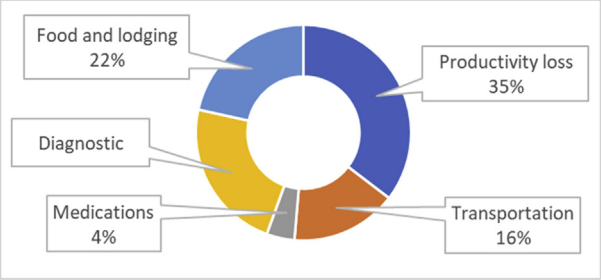

Fig. 5 – Proportion of the total OOP costs for an inpatient stay in each cost category. (Color version of figure is available online.)

Discussion

The overall median OOP cost for patient families was 164,000 UGX or 150.62 USD per family per hospital stay and consisted of five cost categories: transportation, food and lodging, diagnostics, medications, and productivity loss (as an indirect cost). When looking at condition-specific spending, diseases that accrued the most financial burden were choledochal cysts, tumors, and sacrococcygeal teratomas, which could allude to the complexity of these diseases. When productivity loss was included, colostomy closure was most financially burdensome to patients' families. This could be because families of colostomy patients were waiting for a nonemergent operation and may stay in the ward for many days before receiving definitive treatment.

Our patients' families OOP costs were derived mainly from productivity loss (33%) and to a lesser extent food and lodging, although a little less than half the family members were employed. The low employment rate could reflect the country's working demographics and the distinction between employment and work, as 43.2% of the working age population (16-64 y) are subsistence farmers and do not earn a solid for-profit income.[20] The true productivity loss was probably larger due to the missed opportunity to harvest crops, which our study could not quantify. Nevertheless, productivity loss consisted of a substantial proportion of OOP expenditure, and it would be prudent to include the indirect cost of forfeited wages in future OOP spending studies. One study reported the proportion of jobs lost due to surgery but did not convert this into monetary value.[16]

At least 16% of households incurred CHE from direct medical and nonmedical costs. When indirect cost from productivity loss was included, the proportion of households incurring CHE rose to 27%. Both percentages were unexpectedly high considering Mulago Hospital provides operative facilities and certain ancillary services (patient beds, one daily meal) free of charge. Financial protection from CHE is a key indicator in the Lancet Commission on Global Surgery and the Disease Control Priorities project, which sets the target to protect 100% of OOP surgical costs by 2030. Individuals who suffer from CHE reside predominantly in sub-Saharan Africa and southeast Asia,[4,8,21] and a disproportionate burden of the cost falls on indigent patients, as the world's poorest patients were 61 times more likely to suffer from CHE compared with the richest patients.[4]

To date, this is the first report of OOP spending from the patient's perspective in a pediatric surgical setting in an LIC. A study of Rwandan adult patients with peritonitis requiring surgery reported similar numbers, with 28% of patients incurring catastrophic health expenditure when nonmedical expenses were included.[22] The study did not however look at the cost of productivity loss from missed days of work. Our CHE percentage was also slightly lower than a previously reported 31% of Ugandan households incurring CHE in a rural regional referral hospital for all surgical and obstetric procedures.[16] However, high CHE prevalence was not isolated to LICs and could also occur in subgroups in high-income countries, as one recent simulation study in America cited a striking 70%-90% risk of CHE in the uninsured population.[23]

Difference in hospital location may have accounted for the lower rate of CHE in our study, as Mulago Hospital is situated centrally in the capital city of Kampala and could attract families with higher income living in urban areas. Families that did not have the funds to transport their child to the national referral hospital from distant rural communities could not take part in the survey, whereas a rural regional referral hospital may be more accessible to these patients. The Lancet Commission CHE simulation study demonstrated this positive correlation between accessibility and higher percentage of CHE, showing a higher proportion of patients in low-middle income countries experienced CHE compared to that of LICs, presumably because a higher number of patients had access to a hospital to pay for health care services.[4,8]

In addition, economic insecurity is only one component of the burden that patient families must shoulder. Surgical treatment for anorectal malformations and Hirschsprung's disease involves creating a diverting ostomy to gain temporary symptomatic control, but significant backlog delays definitive corrective surgery and ostomy reversal. Once the patient is discharged, the responsibility of ostomy care is placed solely on the family. This poses substantial time and caregiver burden on the parents who can often span years before the ostomy is reversed.[24]

A significant difference was also observed between perceived and calculated total costs, as patients consistently underestimated their OOP spending. This was especially apparent when productivity loss was included in the total calculated cost. This underestimation could indicate unawareness of the financial burden that surgery posed for the patient's family, which could contribute to the caregiver's insufficient preparation to handle the child's health care expenses.

Eighteen percent of families had to borrow money, and 9% sold household items to pay for their child's surgical care. These transactions were also observed in a regional referral hospital of Uganda, albeit at a higher percentage of 53% and 21%, respectively.[16] Another OOP spending study at a district hospital in India showed that 47.2% of the poorest 20% of patients borrowed money to pay for surgical care, although the prevalence of catastrophic expenditure was much lower at 5.6%.[25] The recurring theme of loaning and pawning suggests that these families struggle to pay for their surgical costs and need to find temporary coverage that may put them in debt.

Efforts to alleviate OOP spending could target the most expensive cost categories. Examples include minimizing productivity loss by introducing more in-house staff, providing patients with more in-hospital food, and gaining access to in-hospital diagnostic imaging. Social insurance or other means of risk pooling is also a necessary step to establish solid financial protection. One cost-effectiveness study in Ethiopia modeled scenarios to include universal health care coverage, travel vouchers, and task-sharing and showed that impoverishment is fully averted only when patients have these combined services at their disposal and no longer face costs of accessing care.[26] Increased surgical capacity through workforce and infrastructure expansion may also lower the backlog of surgeries and is a focus of our research collaboration. The construction of the pediatric operating room for the patients of this study was funded by the ARCHIE Foundation, now renamed KidsOR, a charity dedicated to building surgical facilities for children in low-middle income countries, alleviating the backlog and delays of care. By meeting surgical demand and reducing length of stay, the surgeries will be less costly to participating families by reducing productivity loss, lodging expenses, and caretaker burden.[27,28]

Limitations

Collection of OOP spending costs was limited by survey setting, as questions had to be simple and nonsensitive so that families felt comfortable answering them in the busy pediatric surgical ward. The anonymous survey relied on participants' memories to remember items they purchased, which may be subject to recall bias as we had no way of verifying the responses. This margin of error was minimized because the survey components were drawn from previously validated surveys, and the questions coincided with the inpatient stay so that the family's knowledge of their hospital expenditure should be current. We also did not survey patients during the summer months and therefore were not able to account for seasonal changes in patient demographics and OOP spending.

Our focus on cost data for a pediatric patient's hospital encounter omitted cost of trips that other family members may have made to visit the patient and were not present at time of survey. The family members who we surveyed were at bedside served as the patient's primary caregivers for the entire inpatient encounter and seldom traveled back and forth from home. Furthermore, the survey did not collect data on subsequent costs of discharge medications, follow-up clinic visits, or home care, as we only included expenses for a single hospital admission. A related study looked at the backlog and investment of postoperative care by family members of pediatric patients with ostomies, who need to have daily ostomy care and frequent diaper changes from family caregivers.[24] These limitations taken together suggest that this study underestimates the true cost of an inpatient surgery for patients' families caring for their child.

Potentially sensitive topics waived included informal payments made to receive care, and the possibility of job loss due to hospital stay, though the opportunity cost based on the productivity loss from days of work missed, served as a proxy. We also did not ask about monthly patient income, as a significant proportion of participants did not have a steady monthly wage or were unemployed. Furthermore, we could not calculate the respondents' household annual expenditure as we could not reliably ask participants for estimates on the families' spending in the last year. We instead used the average annual expenditure obtained from a national census.

Conclusions

Our OOP cost analysis showed that financial protection for pediatric patients undergoing surgery in Uganda was not adequate, as at least 16% of these families were subjected to CHE. There is a critical need to alleviate these OOP costs to sustainably provide surgical care indiscriminately to all wealth demographics. Further efforts to pool system-wide resources and increase financial risk protection are warranted and would require sustained collaboration with the Ugandan Ministry of Health and the public hospital system in Uganda.

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Authors' contributions: A.Y. is the primary author and was involved with all steps of the study including the conception, execution, analysis, and the manuscript drafting of the study. M.C. contributed greatly in the study design, Yale IRB approval, and the editing of the manuscript. N.K. submitted the Makerere IRB approval and catalyzed the collaboration between the Yale and Makerere research teams. P.K., A.M., and J.S. were integral in setting up the infrastructure needed for survey administration on the ground and assisted in the writing and editing of the manuscript. D.O. is the senior author, overseeing all components of the study and internally reviewed the finalized manuscript.

Disclosures

All authors have no conflicts of interest.

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