Estimating pediatric surgical need in developing countries: a household survey in Rwanda

Robin T. Petroze, J. Forrest Calland, Francine Niyonkuru, Reinou S. Groen, Patrick Kyamanywa, Yue Li, Thomas M. Guterbock, Bradley M. Rodgers, Sara K. Rasmussen

Purpose: Surgical services for children are often absent in resource-limited settings. Identifying the prevalence of surgical disease at the community level is important for developing evidence-based pediatric surgical services and training. We hypothesize that the untreated surgical conditions in the pediatric population are largely uncharacterized and that such burden is significant and poorly understood. Furthermore, no such data exist at the population level to describe this population.

Methods: We conducted a nationwide cross-sectional cluster-based population survey to estimate the magnitude of surgical disease in Rwanda. Conducted as a verbal questionnaire, questions included representative congenital, acquired, malignant and injury-related conditions. Pediatric responses were analyzed using descriptive statistics and univariate analysis.

Results: A total of 1626 households (3175 individuals) were sampled with a 99% response rate; 51.1% of all individuals surveyed were younger than age 18. An estimated 50.5% of the total current surgical need occurs in children. Of all Rwandan children, 6.3% (95% CI 5.4%–7.4%), an estimated 341,164 individuals, were identified to have a potentially treatable surgical condition at the time of the interview. The geographic distribution of surgical conditions significantly differed between adults and children (p < 0.001).

Conclusions: The results emphasize the magnitude of the pediatric surgery need as well as the need for improved education and resources. This may be useful in developing a collaborative local training program.

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their maximum potential impact. Yet, Rwanda has a shortage of healthcare professionals with only 5.5 physicians per 100,000 persons and 0.15 general surgeons per 100,000 persons [11]. This is in stark contrast with the recommended minimum of general surgeons per capita in the United States of 6 per 100,000 persons [12]. In the United States in 2006, there was one pediatric surgeon for every 108,305 children [13]. The ratio in Rwanda is startlingly smaller. There is one expatriate pediatric surgeon practicing in Rwanda for 5.6 million children [14] and no established pediatric surgical training program. Several academic surgical programs in the United States have partnered with the Rwandan government and training institutions to improve surgical training in Rwanda, including physicians, nurses, and ancillary services [15]. In order to influence the development of pediatric surgical training in Rwanda, this study examines the pediatric respondents of a cross-sectional national population survey to describe the prevalence and characteristics of the likely pediatric surgical need [16]. Given the shortage of surgical caregivers and resources in Rwanda, we hypothesize that there is significant untreated surgical need in the pediatric population and that ongoing collaborative training efforts should have a specific focus in the pediatric population.

1. Methods

1.1. Survey design

The Surgeons Overseas Assessment of Surgical Need (SOSAS) tool is a cross-sectional, cluster-based population survey for use in resource-limited settings. Survey development has been previously described, and the survey tool is available online at www.surgeonsoverseas.org [16–19]. All surveys were conducted as verbal questionnaires in the native language (Kinyarwanda) with a trained interviewer and utilized direct computer entry of data on iPads. The first part of the survey asks a household representative basic demographic information. The household representative answers questions regarding access to care, such as how long it takes them to reach the closest health clinic, district hospital, or referral hospital and if they can afford to do so. The household representative is also asked to report the total number and suspected cause of deaths that occurred in the household within the previous 12 months. All members of the household are listed in the demographic section, and two individuals are randomly selected to complete the detailed survey. The individual portion of the SOSAS survey seeks to identify potential congenital, acquired, malignant, or injury-related surgical conditions that began in any of three timeframes: current, during the past twelve months, or at any point during their lifetime. Questions are asked in each of six defined anatomic areas: face/head/neck, chest/breast, back, abdomen, groin/genitalia, or extremities. A potential surgical condition is defined as a self-reported wound, burn, mass, congenital or acquired physical deformity or prior operation. For example, a participant might be asked, “Have you ever had a wound, burn, mass, deformity, or an operation on your face, head, or neck?” For each category, descriptions of common conditions, such as a goiter or cleft lip are given as examples. For the purposes of this paper, pediatric surgical care is defined as a multifaceted system of care that is adequately equipped to provide the needed interventions in the pediatric population. An individual skilled in providing the procedures is one facet of this complex system.

1.2. Sampling

Clusters were defined at the imidugudu, or village, level, which is the smallest administrative unit in Rwanda. We utilized the list of 14,837 villages from the National Institute of Statistics of Rwanda (NISR) and population weighted it according to the 2012 census preparatory frame [20]. We selected 52 clusters through two-stage sampling, where the probability of cluster choice was proportional to the regional population. All 30 districts in all 5 regions were represented in the survey. Fig. 1 depicts the location of the sampled clusters.

Once entering a cluster, interviewers sampled every third household from a central location, with a goal of 30 households in each cluster. At the household level, interviewers took the list of all household members, which was recorded in descending level of age, and used a random number generator on the iPad to select the two interview subjects.

1.3. Study population

Anyone who was a usual resident of the household or who slept in the household the night before the survey was listed as a household member. For the purposes of this study, pediatric patients were identified as all individuals younger than the age of 18. Our analysis used WHO age brackets within the pediatric population.

1.4. Data collection

Ten Rwandan student interviewers were trained and completed data collection over a one-month period (October 2011) [16]. Students first contacted district medical officers or administrators and village chiefs before initiating household visits in each cluster. Parents or guardians provided answers for young children. Interviews were conducted in the native language of Kinyarwanda. Surveys were programmed in FileMaker Pro 11.0v2 (FileMaker Inc., Santa Clara, CA) and uploaded to 3G iPads (iPad 1, Apple Inc., Cupertino, CA) equipped with FileMaker Go 1.1 (FileMaker Inc., Santa Clara, CA).

The study investigator monitored interviewers with frequent download of data and geographic tracking on the iPads. A field supervisor revisited 5% of households (12 of 52 clusters) to validate data collection.

1.5. Statistical analysis

The data were abstracted from the electronic database and analyzed using Statistical Package for Social Sciences (SPSS), version 19 (IBM Corp., Armonk, NY). Estimates are population weighted to the most recent Rwandan population projection [10,14]. Data were also weighted by age and gender so that distribution was similar to the most recent nationwide population survey, the 2010 Demographic and Health Survey (DHS) [10]. Results from the pediatric population, defined utilizing WHO age brackets of 0–4, 5–9, 10–14, and 15–17, were abstracted and analyzed using univariate chi-squared analysis.

<table>
<thead>
<tr>
<th>Table 1</th>
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<tbody>
<tr>
<td>Maternal and child health indicators in Rwanda: comparison to USA.</td>
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<td></td>
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<tr>
<td>Rwandan United States</td>
</tr>
<tr>
<td>Life expectancy at birth (years)</td>
</tr>
<tr>
<td>Infant mortality rate (per 1000 live births)*</td>
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<tr>
<td>Neonatal mortality rate (per 1000 live births)**</td>
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<tr>
<td>Under-5 mortality rate (per 1000 live births)</td>
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<tr>
<td>Fertility rate, total (births per woman)</td>
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<tr>
<td>Maternal mortality ratio (per 100,000 live births)**</td>
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<td>Measles immunization (% of children aged 12–23 months)</td>
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<tr>
<td>30 47 55 76 77 78 129 106 59 8 7 7 47 42 29 5 5 4 254 177 91 10 9 8 6 6 5 2 2 2 1000 840 340 12 14 21 84 74 82 88 91 92</td>
</tr>
</tbody>
</table>

(Source World Bank databank) [9].

* IMR defined as deaths during first year of life proportional to live births.

** NNMNR defined as deaths during first month of life proportional to live births.

*** MMR uses the modeled estimate, as found in the World Bank database.
2. Results

2.1. Demographics

Results for the full population sampled have been previously published [16]. Interviewers surveyed 1626 households with a 99% response rate. The mean age of the 7547 individuals accounted as members of the selected households was 21.9 years. A total of 3175 individuals were randomly assigned to complete the full survey, with 51.1% being younger than age 18, and 31.6% younger than the age of 9 years.

Further stratification by gender, geographic region and urban or rural location is shown in Table 2. There was a 1:1 male to female ratio. As the cluster selection intended, there was representative distribution across regions. More than 90% of the respondents were from rural locations. This further supports the study as representative of the Rwandan population, where only 10% of the population reside in an urban setting.

2.2. Prevalence of surgical conditions

The occurrence of surgical conditions in the community was estimated as beginning at three timeframes. The current prevalence of surgical need was defined as a condition identified at the time of interview that might require surgical consultation or intervention. The overall prevalence of surgical conditions in the past 12 months and the cumulative incidence of lifetime surgical conditions were further estimated. The full study (all ages) found that 41.2% of the population reported at least one surgical condition during their lifetime, 14.8% reported a surgical condition during the previous 12 months, and 6.4% reported a current surgical condition [16].

Table 3 details the percentage of this total surgical need attributable to the pediatric population; 50.5% of the current surgical need, 50.6% of surgical conditions over the past 12 months, and 35.5% of lifetime conditions identified in the survey were reported in children. Prevalence results are further detailed as an estimate of the current population. Based on these results, more than 341,000 Rwandan children are currently estimated to be in need of surgical evaluation. Importantly, these data do not take into account the possibility that a household member may have died of a surgical condition, as only living members of a household were included.

Table 4 reports the estimated prevalence of surgical conditions in the Rwandan pediatric population compared to that of adults. For clarification purposes, Table 3 describes the pediatric surgical need as a proportion of the total surgical need whereas Table 4 describes surgical need as a proportion of the total population. Because the
denominators are different, the effect of the complex population weighting creates small differences in the 95% CI population estimates. As shown in Table 4, the differences in cross-sectional and 12-month prevalence are not statistically different.

Of 746 potentially-treatable conditions identified, 114 (15.3%) were present at birth. Congenital extremity conditions were the most common, accounting for 60.5% of all congenital conditions and 25.3% of all extremity conditions. For the other anatomic areas, the percentages of all conditions that were present at birth were: 6.8% (face, head, and neck); 15.2% (chest, breast); 6.2% (back); 7.8% (groin – suggesting inguinal hernias). For the abdomen, 18.8% of all conditions were present at birth, with 8.0% being soft masses (suggesting umbilical hernias).

Table 5 demonstrates the distribution of surgical conditions by anatomic area. For face/head/neck, extremity, and overall conditions were present at birth, with 8.0% being soft masses (suggesting umbilical hernias).

Finally, for the purpose of this study, potential surgical causes of death were identified as a mass, a wound, abdominal distention, a trauma, or a history of operation in the week prior to death. For pediatric deaths, 26% (n = 12) were identified as possible conditions that may have benefited from an operation. The reported deaths included 1 wound not owing to injury, 1 burn, 3 masses, 2 congenital deformities, 1 acquired deformity, 4 abdominal distension and pain, and 34 “other” conditions, presumably nonsurgical. In total, 8.7% (n = 4) underwent a major procedure prior to death. A major procedure was defined as one requiring anesthesia. 70% (n = 32) sought healthcare in the week before death. Reported infant deaths (n = 22) included 23% (n = 5) that may have been surgically treatable.

3. Discussion

Little is known about the burden of surgical diseases in the pediatric population in LMIC, and healthcare professionals trained in pediatric surgery are scarce [4]. Our study represents a novel population-level estimate of surgical disease prevalence in the pediatric population. This analysis was undertaken as part of an underlying effort to initiate a pediatric surgical training program in Rwanda and is only the first step in defining the epidemiology of pediatric surgical disease in Rwanda. If the identification of a potentially-treatable surgical condition during the interview serves as a proxy “marker” for surgical need, the data are compelling. The results suggest that the prevalence of pediatric surgical disease in Rwanda is at least as great as the surgical disease in adults, and, therefore, capacity building efforts in pediatric surgical care are needed as much as those for adult general surgery.

Throughout the African continent, dire shortages in pediatric surgical services have been observed; the number of pediatric surgeons per million persons ranges from 0.06 in Malawi to 1.5 in Egypt, with 90% of pediatric surgeons practicing in urban tertiary care facilities [4]. Training programs are variable throughout Africa, with multiple programs existing in Egypt, South Africa, and Nigeria and single programs existing in several other countries [21,22].

Limited data on surgical conditions exist in the pediatric population in Africa despite being a significant – and growing – portion of the population. Population growth in Africa far exceeds that in North America and Europe, so the problem becomes one of global importance. Sub-Saharan Africa has the highest fertility (5.2 births per female) and youngest population in the world (43% of the

2.3. Death data

Nearly 60% (46/77) of the total household deaths reported in the survey were in pediatric patients. 30% (n = 22) were in the first year of life, and 50% (n = 38) occurred in younger than the age of 5. For the purpose of this study, potential surgical causes of death were
population is younger than the age of 15) [5]. Disparities in health outcomes for children around the world are profound. While only 1% of all deaths in high-income countries are in children younger than the age of 15, 46% of deaths in Africa are in children younger than 15 [23]. A hospital-based survey in southwestern Uganda found an annual surgical rate of 180 operations per 100,000 children younger than age 15; this was only 3% of the operative volume in children in the United Kingdom over the same period [24]. There is a great disparity in injury mortality worldwide, with 95% of injury-related deaths in children occurring in LMIC [25]. Additionally, many children in LMIC have surgical conditions complicated by malnutrition, parasitic infections, or tropical infectious diseases, including HIV [26–28].

A prospective study of pediatric admissions to a national referral hospital in The Gambia found that surgical admissions constituted 11.3% of pediatric admissions, with injuries, congenital anomalies, and surgical infections constituting 90% of these admissions [29]. The World Health Organization (WHO) estimates that 10% of neonatal deaths in LMIC are owing to congenital anomalies [30]. Our survey reveals a high prevalence of conditions present since birth (15.3%), potentially representing correctable defects that result in significant long-term morbidity.

Global advances towards the Millennium Development Goals are a noble beginning, but with neonatal and infant mortality owing to infectious disease decreasing, addressing the surgical needs of the pediatric population is imperative. If congenital and neonatal surgical conditions are not further addressed, progress in reducing neonatal and infant mortality is limited. The global reductions in under-five mortality have not been seen in neonatal mortality; more than 40% of under-five deaths now occur in the neonatal period [8,30,31].

We attempted to define the magnitude of deaths from undressed surgical conditions by asking households for details about anyone who died in the previous year. While the numbers are interesting to consider, there is some potential incongruence with known causes of childhood mortality worldwide. For instance, the survey did not positively identify victims who died of polytrauma (except for one burn), which is one of the leading causes of pediatric deaths in LMIC [25]. Additionally, while “abdominal distension” in the week prior to death cannot conclusively be considered a death with a surgical condition, it is notable that a number of respondents reported this. The reported number of deaths may be too small to accurately extrapolate to real population numbers, and the question itself may be fraught with cultural or recall bias. However, it does point to a potential area of impact on mortality if pediatric surgical care was adequately available. Since >50% of deaths occurred in a health facility, an important next step will be a retrospective review of patient charts to objectively identify cause of death. This represents a possible point of validation for the survey, as well as a way to further define the surgical conditions leading to death in pediatric patients in LMIC.

Issues in pediatric healthcare continue to be prioritized by the Rwandan Ministry of Health. To support the large unmet need for pediatric healthcare practitioners, the Rwandan government has placed an emphasis on funding postgraduate medical education training positions in pediatric fields. The results of this survey indicate that addressing the breadth of surgical problems encountered in Rwandan pediatric patients will require broad-based training, with estimates that 341,000 children may currently be in need of surgical evaluation in Rwanda. Certainly, pediatric surgical training must keep pace with the adult and general surgery training initiatives that are ongoing. Continuous improvements in infrastructure and resource allocation must also take into account the distinct needs of pediatric patients, as well as further epidemiologic studies to more concretely build upon the findings of this study [32].

The SOSAS survey serves as a practical first step in collecting data to inform resource utilization and training for pediatric surgical care in Rwanda. Yet, there are several limitations that must be acknowledged. While we observed as much methodological and statistical rigor as was possible, the SOSAS survey has yet to be externally validated. In order to conduct a nationwide overview, our time allotment with the student interviewers and budget did not allow for physician exam as a validation step, and we acknowledge this would be an important next step. We were able to successfully monitor the students using geotracking and revisited 5% of households to verify survey results.

Although the study reveals estimates, the precision is flawed owing to limitations such as relying on interview data rather than physical exam and potential recall bias. The 6.3% of the pediatric population with a current surgical condition may be an underestimation, as 14.7% of respondent children had a surgical

<table>
<thead>
<tr>
<th>Location</th>
<th>Characteristic</th>
<th>Pediatric (&lt;18 years) (%)</th>
<th>Adult (18 years +) (%)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urban</td>
<td>Male</td>
<td>48.0 (41.4–54.7)</td>
<td>41.4 (35.2–48.0)</td>
<td>0.168</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>52.0 (45.3–58.6)</td>
<td>58.6 (52.0–64.8)</td>
<td></td>
</tr>
<tr>
<td>Rural</td>
<td>Kigali City</td>
<td>6.8 (3.3–13.6)</td>
<td>7.1 (6.1–8.2)</td>
<td>&lt;0.001*</td>
</tr>
<tr>
<td></td>
<td>South</td>
<td>29.0 (24.2–34.2)</td>
<td>46.3 (39.6–53.1)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>West</td>
<td>24.2 (17.9–32.0)</td>
<td>16.9 (13.1–21.5)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>North</td>
<td>18.8 (12.5–27.1)</td>
<td>22.1 (14.3–32.4)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>East</td>
<td>21.2 (16.7–26.7)</td>
<td>7.6 (6.3–9.1)</td>
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</tbody>
</table>

* Indicates statistical significance, p < 0.05 (Pearson chi-square).
condition within the previous twelve months; the discrepancy cannot be explained by having undergone surgery. The same discrepancy was seen in the adult population. While this represents a potential study flaw, it does allow us to compare the pediatric population to the adult population, highlighting that surgical need is different between the two demographics. This is very useful in advocating for more specialized pediatric surgical services and training.

One possible explanation for the time disparities in prevalence estimates is that conditions have started 12 months ago did not receive surgical care but healed with or without a disability. Examples include fractures or burns. Because of the self-reporting nature of the study, these may not have been reported as “new” conditions as they were no longer acute at the time of the survey. Indeed, to the other extent,inguinoscrotal pathology is significantly lacking in our estimates, which may be a selection bias secondary to interviewee perception of disability, translation, or interviewer training. During the first few days of the study, review by the supervising staff found very few conditions in the inguinoscrotal region identified. Our field supervisor directly observed interviewers in the field early in the study and specifically targeted training for correct probing of inguinoscrotal questions. Still, the lack of inguinoscrotal pathology identified in our survey is discordant with the known literature and would be an important directed study for follow-up [29,33]. This follow-up study would ideally provide clinic or district hospital level prospective or retrospective data to compare to the population estimates.

Importantly, the results of this study begin to define the impact that the paucity of pediatric surgical care is having on the population of Rwanda. These data are crucial to orient the development of formalized pediatric surgery training, as well as development of appropriate, multidisciplinary pediatric surgical care. It is easily understood that implementation of high quality pediatric surgical care will only be accomplished in the context of systems-wide improvement. Additionally, task shifting and the development of team-based services like nursing and anesthesia are likely to be required. The data from this survey help to describe the needs of the pediatric population but are only the first steps in informing the development of a local, self-sustaining training program.

4. Conclusion

As the global health population makes significant progress in addressing neonatal and childhood mortality related to infectious disease, the impact of surgically-treatable disease and long-term disability must be addressed. Identifying surgical need and barriers to care at the community level is useful for creating the baseline for developing a locally evidence-based training program to address surgical needs in the pediatric population.

Acknowledgments

Ethical Approval: This study was conducted in full collaboration with the Faculty of Medicine at the University of Rwanda, Butare, Rwanda. This study was approved by the University of Virginia Institutional Review Board for the Behavioral Sciences #2011-0261-00, the Rwanda National Ethics Committee #006/RNCEC, 2011, and the Rwanda National Institute of Statistics #893/2011/10/NISR.

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