Estimating operative disease prevalence in a low-income country: Results of a nationwide population survey in Rwanda

Robin T. Petroze, MD,[a,b] Reinou S. Groen, MD,[c,d] Francine Niyonkuru, MD,[b] Melissa Mallory, MD,[e] Edmond Ntaganda, MD,[b] Shahrzad Joharifard, MD,[f] Thomas M. Guterbock, PhD,[g] Adam L. Kushner, MD, MPH,[d,h] Patrick Kyamanywa, MD, MPH,[b] *and* **J. Forrest Calland, MD,[a]**
Charlottesville, VA, Butare, Rwanda, Baltimore, MD, New York, NY, Boston, MA and Vancouver, BC, Canada

Background. *Operative disease is estimated to contribute to 11% of the global burden of disease, but no studies have correlated this figure to operative burden at the community level. We describe a survey tool that evaluates population-based prevalence of operative conditions and its first full-country implementation in Rwanda.*
Methods. *The Surgeons OverSeas Assessment of Surgical Need (SOSAS) survey tool is a cross-sectional, cluster-based population survey designed to measure conditions that may necessitate an operative consultation or intervention. Household surveys in Rwanda were conducted in October 2011 in 52 clusters nationwide. Data were population-weighted and analyzed with the use of descriptive statistics.*
Results. *A total of 1626 households (3175 individuals) were sampled with a 99% response rate. 41.2% (95% confidence interval [95 CI%] 38.8–43.6%) of the population has had at least one operative condition during their lifetime, 14.8% (95% CI 13.3–16.5%) had an operative condition during the previous 12 months, and 6.4% (95% CI 5.6–7.3%) of the population were determined to have a current operative condition. A total of 55.3% of the current operative need was found in female respondents and 40.3% in children younger than 15 years of age. A total of 32.9% of household deaths in the previous year may have been related to operative conditions, and 55.0% of responding households lacked funds for transport to the nearest hospital providing general practitioner operative services.*
Conclusion. *The SOSAS survey tool provides important insight into the burden of operative disease in the community. Our results show a high need for operative care, which has important implications for the global operative community as well as for local health system strengthening in Rwanda. (Surgery 2012;■:■-■.)*

From the Department of Surgery,[a] University of Virginia School of Medicine, Charlottesville, VA; Faculty of Medicine,[b] National University of Rwanda, Butare, Rwanda; Department of Gynecology and Obstetrics,[c] Johns Hopkins Hospital, Baltimore, MD; Surgeons OverSeas (SOS),[d] New York, NY; Department of Surgery,[e] Brigham and Women's Hospital, Boston, MA; Department of Surgery,[f] University of British Columbia, Vancouver, BC, Canada; Center for Survey Research & Department of Public Health Sciences,[g] University of Virginia, Charlottesville, VA; and Department of International Health,[h] Johns Hopkins Bloomberg School of Public Health, Baltimore, MD

Surgeons OverSeas (SOS) provided the survey tool, technical assistance, and funding for the logistical execution of the data collection, including the salaries of the interviewers and field supervisor. The UVA Department of Surgery provided funding for statistical analysis and consultative assistance with study design.

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Reprint requests: Robin T. Petroze, MD, Department of Surgery, University of Virginia, P.O. Box 800300, Charlottesville, VA 22908. E-mail: rtp3z@virginia.edu.

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Although operative care is an essential component of health care, the global health community traditionally has not seen it as a priority. This may be attributable to the unfamiliarity of operative care within public health, concerns about cost-effectiveness, and the absence of the surgeon's involvement in health care planning.[1] Operative disease is estimated crudely to contribute to at least 11% of the global burden of disease, but no studies have correlated this figure to operative burden at the community level; current figures delineating operative burden are made on the basis of extrapolation of limited global data and estimations of disease incidence on the basis of hospital-level data.[2-4]

Rwanda is a land-locked country in sub-Saharan Africa with a population of 10.7 million.[5] The 1994 genocide decimated the socioeconomic, educational, and health care infrastructure of the country, exacerbating the country's existing problems with poverty and poor health care. However, Rwanda's subsequent aggressive development and health policies during the past decade have stimulated broad progress in both the economic and the health sectors.[6]

The Demographic and Health Surveys (DHS) are the most comprehensive sources in developing countries for population-based health statistics.[7] The 2010 DHS survey in Rwanda noted significant decreases in maternal and infant rates of mortality as compared with previous surveys, as well as an increase in the use of antenatal care and childhood immunizations.[5] The Maternal Mortality Ratio (maternal deaths per 100,000 live births) in Rwanda, for example, decreased to 340 in 2010 from 750 in 2005; to compare with more-developed countries, the 2010 Maternal Mortality Ratio for the United States was 21.[8] The DHS does not, however, include questions on operatively treatable conditions, which is not surprising because funding for operative development is severely lacking among international funding agencies.[9,10]

In a comprehensive national assessment of hospital-level capacity for emergency and essential operative care in Rwanda, researchers found deficiencies in operative infrastructure, personnel, and training, with numbers of available operating theatres and surgeons well below international standards.[11] Given these scarcities, the true burden of operative disease can likely only be assessed by extending evaluations beyond the hospital level to the community level.

The Surgeons OverSeas Assessment of Surgical Need (SOSAS) survey tool was developed to provide the missing data on operative need in low- and middle-income countries by establishing a standardized, duplicable survey tool to quantify the prevalence of operatively treatable conditions in resource-limited settings.[12] It is hoped that the data arising from SOSAS surveys will oblige global funds, nongovernmental organizations, and local health ministries to allocate increased resources to providing operative care, thereby strengthening health systems, saving lives, and reducing the burden of human suffering as the result of untreated operative disease. The SOSAS survey tool was developed for open-source access and is available at www.surgeonsoverseas.org.[13] Our study in Rwanda represents the first full-country survey to be conducted.

METHODS

Survey design. The SOSAS survey tool is modeled on DHS surveys as well as the WHO Guidelines for Conducting Community Surveys for Injuries and Violence. A research group comprising 46 international surgeons and public health experts provided input during the SOSAS development project. Designed for direct computer-based entry, a functional pilot of the study evaluating the ease and utility of use on iPad tablets was conducted in Sierra Leone in August 2011.[13] Local adaptations were made on the basis of population-based surveys of musculoskeletal impairment in Rwanda.[14,15]

The first section of the survey gathers household demographics, including a listing of all members of the household and information regarding timing and distance to health facilities, from a household representative. Household representatives also are asked to report the total number of deaths occurring in the household within the previous 12 months as well as the proximal cause of each death.

The second section of the SOSAS questionnaire is organized by anatomic area to measure a wide spectrum of proxy conditions that may necessitate operative consultation or intervention. The individuals who complete this section respond only regarding their own health. These conditions are meant to serve as representative of common conditions that can be easily described in the common language and identified by a nonmedical provider. For the purposes of this study, an operative condition is defined as a self-reported wound, burn, mass, congenital or acquired physical deformity, or operation in the anatomic areas defined in the survey: face/head/neck, chest/breast, back, abdomen, groin/genitalia, or extremities. For each anatomic area, survey questions seek to identify congenital, acquired, malignant, or injury-related conditions. Further questions investigate the timing of conditions and perceived barriers to care.

SOSAS was designed in English, translated to the local language of Kinyarwanda, and back-translated into English to ensure fidelity; French and English translations were available to interviewers for cross-referencing purposes during interviewing. Before we began to collect data, cognitive interviewing of the tool in English and Kinyarwanda occurred with nonmedical subjects.

Sampling. SOSAS is a cross-sectional, cluster-based population survey.[16,17] Because a nationwide population census has not been performed since the restructuring of administrative units in Rwanda

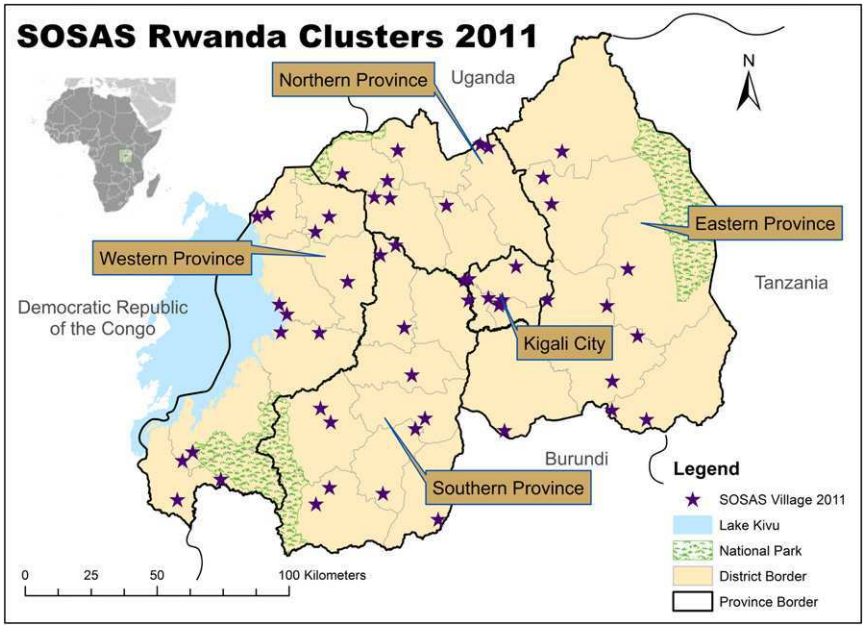

Fig 1. SOSAS Rwanda clusters, October 2011.

in 2006, our sample design used the 2012 census preparatory frame, as used for the 2010 Rwanda DHS. Each of the nation's 30 officially defined districts formed a sampling stratum. Two-stage sampling to select 50 clusters, as defined at the village level, was done such that the probability of cluster choice was proportional to the district population size.[16-18] For each cluster, a village was chosen at random from the census list of villages within a district. One alternate village per district was also identified. Three alternate villages (1 substitute and 2 additional due to inadequate available households in a given cluster) were used for a total of 52 sampled clusters. In each sampled village, interviewers began at a centralized location and sampled every third household with the goal of sampling 30 households per village. At each household, they interviewed a household representative regarding overall demographics of the household, access to care, and household deaths. With the household representative, the interviewer created a listing of the ages and sexes of all members of the household. To select the individuals who would complete the full survey regarding specific operative conditions, a random number generator was used to select a maximum of 2 individuals per household.

Study population. Household members were defined as anyone who was a usual resident of the household or who slept in the household the night before the survey. All sexes and ages were eligible for inclusion with information provided by a parent/guardian for children. Informed consent was obtained from all participants. Participants were excluded if they were absent from the sampled household after three documented visits from the interviewer.

Data collection. Ten interviewers were competitively recruited and trained during a 5-day period. Data collection took place during a 1-month period (October 2011) in 52 clusters nationwide. Interviewers were assigned across regions so that interviewer effects in the final result would be minimized. District medical officers, district administrators, and village chiefs were contacted before initiating household visits in each cluster. 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).

During the first week of data collection, interviewers submitted their iPads to the principal investigator and data supervisor for daily data download with biweekly or weekly download for each of the sampling periods thereafter. Embedded time stamps in the program and geographic tracking of interviewers in the field using the "Find my iPad app" were used to monitor for fraud. Interviewers underwent direct observation in the field, and a field supervisor revisited 12 of 52 clusters to validate data collection at approximately 5% of households.

Statistical analysis. The collected data were analyzed using Statistical Package for Social Sciences, version 19 (IBM Corp, Armonk, NY). Variance estimation took into account the stratification of the sample at the district level, the clustered sampling of households in 52 clusters, and the selection of only two individuals per household regardless of household size. Design weights were applied to adjust each district to its correct proportion of the population, and to correctly represent the percentage of individuals residing in households of different sizes (from 1-person to 13-person households). The design weights were scaled to bring the case count up to 10.7 million persons, matching the 2011 population projection.[19]

Analysis of the weighted data revealed that younger adults, especially younger males, were underrepresented among those who were interviewed (or interviewed by proxy); elders and children were correspondingly overrepresented in the interviews. These patterns probably reflect which persons were at home during the field period in each village. Poststratification weights were applied that bring the distribution by age and sex for the results on the basis of individuals into full alignment with the national results of the 2010 DHS. No poststratification weights were needed for household-level results.

The percentages and population-count estimates presented here were derived from the complex sampling frequencies and crosstabulation procedures in SPSS, which provide estimates of sampling errors, confidence intervals, and tests of independence that are corrected for the design effects from the stratified, clustered design, and from weighting.

Ethical considerations. Ethical approval was provided by the University of Virginia Institutional Review Board and the Rwandan National Ethics Committee. The hospital director at the nearest hospital was contacted before survey implementation in each cluster to facilitate referral of serious health problems that were detected by interviewers. Approval to engage in a nationwide household survey was obtained from the Rwandan National Institute of Statistics, which also provided critical input in sample selection. Results were presented to the Rwandan Ministry of Health, the Rwandan National Institute of Statistics, and the Rwanda Surgical Society before publication.

RESULTS

Demographics. Figure 1 shows the location of the 52 sampled clusters based upon GPS coordinates taken at the index household. A total of 1626 households were sampled with a 99% response rate. A household representative completed the first section of the survey regarding overall household demographics, access to medical care, and household deaths. Table I summarizes the demographics of the survey. The mean household size was 4.67 individuals with 59.9% having a female household representative. Each household listed the age and sex of all household members; this included a total of 7547 individuals, representing a population breakdown of 52.7% female and 44.0% younger than 15 years of age.

Access to operative care was found to be a consistent challenge, with 55.0% of responding households lacking the funds required for transport to the closest district hospital (general practitioner operative services) and 77.0% lacking funds for travel to referral hospitals (specialist operative services). A total of 70.4% of responding households reported greater than 2 hours' travel time for transport to the nearest operative services.

Table I. Demographics, SOSAS Rwanda

Demographics	*Estimate (SE)*
Household	
Mean household size	4.67 (0.04)
Sex of household representative	
Male	40.1% (1.1%)
Female	59.9% (1.1%)
Mean age of household members	21.9 (0.18)
Sex of household members	
Male	47.0% (0.7%)
Female	53.0% (0.7%)
Village location*	
Rural	93.1% (2.7%)
Urban	6.9% (2.1%)
Individual demographics (for adults 15–59 y)†	
Education level	
None	23.2% (1.2%)
Primary school	62.0% (1.5%)
Secondary school	13.1% (1.7%)
Literacy	71.3% (1.7%)
Occupation	
Agriculture	68.8% (2.9%)
Student	12.6% (1.4%)
Unemployed	9.2% (1.0%)
Skilled employee	3.8% (0.7%)
Unskilled employee	3.4% (0.5%)
Self-employed/small business	1.9% (0.6%)

*Rural/urban differentiation not available from NISR as administrative restructuring since 2002 census; report here by consensus of local PI and interviewers.
†Individual demographics are taken from the individual response section of the SOSAS questionnaire.
NISR, National Institute of Statistics of Rwanda; *PI*, principal investigator; *SOSAS*, Surgeons OverSeas Assessment of Surgical Need.

Table II. Prevalence of operative conditions at the community level

	Estimate, %	*95% confidence interval, %*	*Estimate (no. people)*	*95% confidence interval (no. people)*
Operative condition now	6.4	5.6–7.3	675,456	583,016–767,897
Operative condition in previous 12 months	14.8	13.3–16.5	1,568,268	1,393,707–1,742,829
Lifetime operative condition	41.2	38.8–43.6	4,359,980	4,081,975–4,637,984

Prevalence of operative conditions in the community. A total of 3175 individuals were randomly assigned from the household list (maximum 2 per household) to complete the full survey regarding their own health conditions. Table II details the overall prevalence of operative conditions in the community. If an interviewee identified a condition, we asked if he or she had sought or would like to seek medical care. If the answer was no, we asked why. Those individuals who responded "no need" were excluded from the calculations of operative need. A total of 41.2% of the population has had at least one operative condition during their lifetime, 14.8% had an operative condition during the previous 12 months, and 6.4% of the population was determined to have a current operative condition. For all identified potential operative conditions, 5.9% underwent a major operation. Of these 155 operations, 48 were cesarean deliveries.

The 2 main reasons cited by interview subjects for not seeking care were (1) no skilled doctor or nurse available and (2) no money available for health care. A condition was defined to be disabling if the interviewee reported significant shame, inability to work as they had previously, needing help with daily activities, or needing help with transportation. For all operative conditions reported, 34.3% were associated with a disability, and 58.0% of individuals with at least one identified condition had some type of disability.

Table III illustrates in greater detail the current operative need. The prevalence figures reported here are percentages of the total population. Univariate χ^2 analysis showed significant differences in current operative need by age and geographic region. Not unexpectedly, older individuals were more likely to report current operative problems. However, the prevalence in the young population, particularly in the student and young adult working population was greater than 6%. Regionally, the Southern Province evinced the greatest level of current operative need. Supplementary Table I further details the anatomic breakdown of the current operative need.

Figure 2 describes the characteristics of the 6.4% of the population currently in need of operative care, broken down by sex, age, location, and geographic region. A total of 55.3% of the current operative need is in female patients, with 40.3% of the need being in children younger than 15 years of age. In fact, greater than 80% of the current operative conditions in Rwanda occur in individuals younger than 45 years of age. The need is primarily rural with the Southern Province comprising the greatest-need region. Similar results are seen on evaluating the previous year and lifetime operative need by sex, age group, location, and province (Supplementary Figs 1 and 2).

Figure 3 shows the breakdown by anatomic location of the identified operative conditions currently in need of care. Extremity conditions were the most prevalent (36%), closely followed by conditions of the face, head, and neck (which includes eye conditions; 28%).

Household deaths. Household representatives reported a total of 77 household deaths within the previous year, with 49.4% of reported household deaths occurring in children younger than 5 years of age. A total of 32.9% of the total deaths may have come as a result of operatively treatable conditions, as detailed in Figure 4. Of these, abdominal pain/distention (10%) and mass/growth (10%) were the most common causes of death.

DISCUSSION

This study represents the first implementation of a nationwide survey to document the prevalence of operative conditions at the community level. A total of 6.4% of the study sample—corresponding to an estimated 675,000 Rwandans—were determined to currently need operative care, with nearly 15%—an estimated 1.6 million Rwandans—reporting an operative condition within the previous year.

The results of this survey have important implications for the global operative community, and, more importantly, to health system strengthening in Rwanda. Regional differences seen in this study can be further analyzed in conjunction with hospital-level epidemiologic data to develop

Table III. Characteristics of current operative need

Characteristic	*Prevalence (SE)*	P *value*
Age		
0–4 y	4.9% (0.6%)	.050*
5–14 y	6.3% (0.5%)	
15–29 y	6.9% (0.7%)	
30–44 y	5.2% (1.4%)	
45–59 y	9.6% (0.8%)	
60 + y	7.1% (1.0%)	
Gender		
Male	6.1% (0.6%)	.444
Female	6.6% (0.5%)	
Location		
Rural	6.6% (0.4%)	.339
Urban	4.0% (2.0%)	
Region		
Kigali	4.6% (1.1%)	.001*
South	9.5% (0.6%)	
West	5.1% (0.8%)	
North	7.6% (1.6%)	
East	4.2% (0.5%)	

*Significance indicated at $P \leq .05$.

interventions to improve access to operative care. The current estimate of operative need—6.4% of the population—is twice the HIV prevalence in Rwanda, estimated at 3.0% by DHS 2010.[1] In fact, the overall HIV prevalence in Rwanda has not changed since the previous DHS survey, perhaps highlighting effective public health initiatives and a shift towards noncommunicable disease burden in the community. Because the majority of funding for public health initiatives is directed at communicable diseases, with an increasing focus on chronic, noncommunicable diseases, it is imperative to channel funding and attention for initiatives to address the operative burden. A small proportion of the identified operative conditions (5.9%) underwent operative intervention. At the individual level, interview subjects identified several barriers to accessing care for their specific conditions, with a lack of providers and lack of money predominating. The challenges to accessing operative care identified at the household level, with 55% of households stating they did not have funds to travel to the nearest facility that offers operative services, provide further insight into issues of operative access and highlights potential areas for health system strengthening.

Operative conditions lead to substantial morbidity and mortality in the Rwandan community, with 41.2% of the sample population reporting an operative condition in their lifetime, which extrapolates to more than 4.5 million current Rwandan citizens. Our findings demonstrate the possibility that >30% of household deaths in the previous year may have been attributable to operatively treatable conditions. Alarmingly, the population represented in these estimates is relatively young, with nearly 80% of the lifetime operative conditions (and well >80% of the operative conditions in the previous year) noted in individuals younger than 45 years of age. A student and working population afflicted with operative disease and disability in the face of insufficient access to care carries significant economic implications as the country strives to move beyond poverty. The young population carrying this operative burden differs from the older population in the Western/Northern world; this may further hint at a future health care crisis as the Rwandan population ages and noncommunicable diseases, including potential operative conditions such as cancer, overtake the infectious disease burden.[20-22]

This study further demonstrates the usability of the SOSAS survey instrument in the field. The organization of the survey script by anatomic area anecdotally seemed to assist respondents in recalling previous operative conditions. The challenge in relying on operative recall in a population with limited access to operative care, however, is that, although recall bias may affect reported time frame of incidents, we believe it likely underestimates the true operative need to a significant degree due to poor access and information about operative conditions. On the other hand, results derived from recall can certainly provide a baseline with regard to breadth of conditions and barriers to accessing care when conditions are identified.

The benefits and drawbacks of using iPads for computer-assisted personal interview have been previously documented during the functional pilot of the SOSAS survey.[13] Our survey had similar findings: interviewers had little trouble familiarizing themselves with the technology and found the iPads easy to use in the field. Direct data entry limited errors in recording data and allowed for early analysis. We further believe that the use of embedded time stamps and tracking of interviewer movements through the 3G network helped to limit fraud during data collection.

The main limitation of this survey is in the definition of operative conditions and case-finding at the household level. Thus, the identified conditions serve as proxies in estimating operative disease prevalence. All operative conditions identified in our study were self-reported by respondents (who have inadequate access to operative care) to interviewers with medical knowledge but without operative expertise or

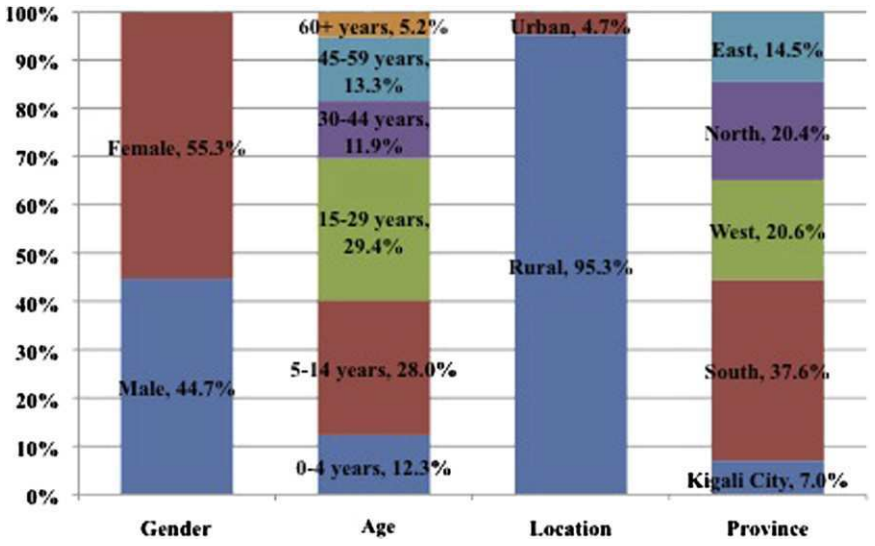

Fig 2. Breakdown of current operative need.

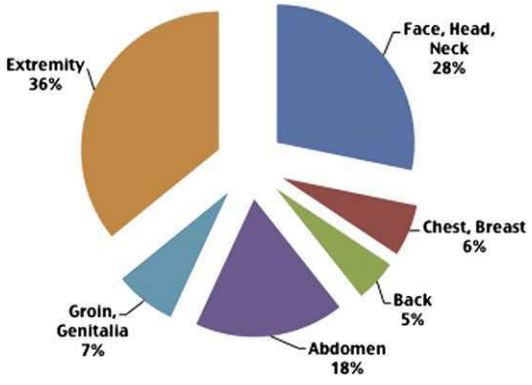

Fig 3. Anatomic breakdown of current operative need.

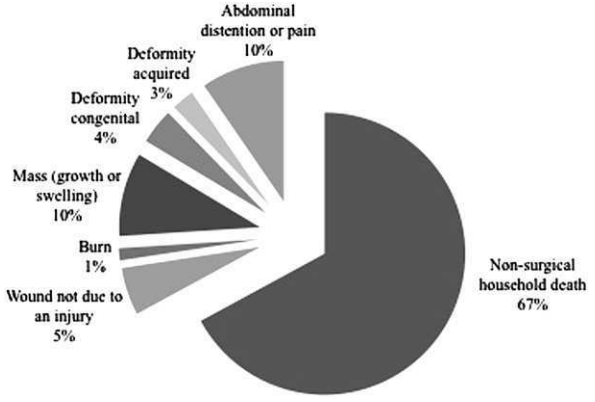

Fig 4. Potentially operatively treatable household deaths.

sophistication. This may overestimate some conditions such as a neck mass that could be a Burkitt's lymphoma requiring chemotherapy, not operative intervention, but we would argue that an operative consultation may still be warranted in this case. Alternatively, this survey does not identify such conditions as intra-abdominal cancers or early breast cancers that could be amenable to operation. For this reason, we believe our estimates of operative need in Rwanda are likely an underestimation of the true prevalence of operative conditions. Furthermore, the suspected prevalence of operative conditions before death (32.9%) highlights that the 6.4% estimate of current operative need does not adequately represent severe operative conditions truly in need of care now such as severe injuries, cancers, and abdominal emergencies.

A further limitation is that we did not validate our results in the community with physical examinations by trained surgeons or additional diagnostics such as one might see in similar projects that address the incidence and prevalence of infectious diseases such as HIV or malaria. This may limit the universality of the SOSAS findings. Although the validation of the survey tool with physical examination, laboratory, and/or radiographic diagnostics may provide insight, validation is limited by surgeon shortage in the community, funding for operative research in resource-limited settings, and ethical considerations in performing physical examinations in a community-members' household. Furthermore, the benefit of this study is to provide community-level estimates—to identify reasonable proxies for operative disease. Ideally, as operative capacity and access improves, operative

conditions can be reliably assessed and treated at health facilities, providing more accurate numbers of the prevalence of operative disease.

We think that the SOSAS survey tool provides important insight into the burden of operative disease and that the results should serve as a guide to highlight needs and stimulate further research. What is clear from these results is that operative conditions are a significant burden in the community and in a relatively young population. The results further highlight the issue of access—the operative needs of the community are simply not being met by the current operative capacity in the country.

In Conclusion, the results of SOSAS Rwanda can hopefully be used in Rwanda to geographically characterize specific categories of operative need at the community level, so as to plan hospital-level care. There is no gold standard for evaluation of operative need at the community level, but we would recommend the use of SOSAS widely to create a baseline in low- and middle-income countries. By providing a deeper representation of operative need than is currently available through hospital-based surveys and statistical modeling, these results can ultimately lead to improvements in operative services worldwide by highlighting the importance of operative capacity building through infrastructure and training and emphasizing the need to improve operative access in horizontal health system–strengthening approaches.

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