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# Nationally Representative Household Survey of Surgery and Mortality in Sierra Leone

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#### Abstract

*Background* There is limited evidence to characterize the burden of unmet need of surgical diseases in low- and middle-income countries. The purpose of this study was to determine rate of deaths attributable to a surgical condition and reasons for not seeking surgical care in Sierra Leone. *Methods* The Surgeons OverSeas Assessment of Surgical Need (SOSAS) is a survey tool developed collaboratively to be used for cross-sectional data collection of the prevalence of surgical conditions in any country. A population-weighted cluster-sample household survey was conducted throughout Sierra Leone in 2012 using the SOSAS survey tool.

*Results* Total of 1,840 households (11,870 individuals) were sampled, yielding a 98.3 % response rate. Overall, there were 709 total deaths reported (6.0 %). The mean age at death was  $36.4 \pm 30.1$  years: 330 (46.6 %) were female. Most deaths occurred at home (58.1 % vs. 34.1 % in

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hospitals). Of the 709 deaths, 237 (33.4 %) were associated with conditions included in our predefined surgical disease category. Abdominal distension/pain was the most commonly associated surgical condition (13.9 %) followed by perinatal bleeding/illness (6.0 %). Among the 237 with surgical conditions, 51 (21.9 %) did not seek medical care, most commonly because of a lack of money (35.3 %) or inability to provide timely care (37.3 %).

*Conclusions* A large proportion of deaths in Sierra Leone was associated with surgical conditions, the majority of which did not undergo surgical intervention. Our results indicate that to remove barriers to effective surgical care in Sierra Leone policymakers should first focus on relieving financial burdens and increasing access to timely surgical care.

# Introduction

Measurement of the global burden of surgical diseases is the first crucial step toward effective implementation of surgical services and optimization of access to surgical care [1]. Although analyses using existing data suggest a significant

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global burden of surgical diseases, precise estimates are limited owing to the lack of representative databases needed for such purposes. The Disease Control Priorities Project, which is frequently referenced, reported that surgical disease is responsible for as much as 11 % of the global burden of disease [1]. This was not based on actual data but solely on the consensus of 18 surgeons estimating the proportion of each disease that would require surgery among those diseases listed on the World Health Organization's Global Burden of Disease study. Another study gathered surgical volume data from 56 countries with available information and reported that around 234.2 million major surgical procedures are undertaken every year worldwide [2]. They found a significant imbalance in surgical procedures performed, with only 3.5 % of surgical procedures occurring in lower income countries when they accounted for nearly 34.8 % of the global population.

Limited data or estimates exist to describe the volume of individuals with surgical diseases who did not undergo surgical procedures (population with unmet need) [3]. One approach would be to estimate avoidable deaths for patients with unmet surgical needs, which is difficult in countries without an organized system of vital statistics and death certificate data. Current figures of causes of death in such countries come from estimates, extrapolations, and consensus [4]. Sierra Leone is one such country whose mortality estimates are extrapolated from those of neighboring countries. The estimated life expectancy at birth in Sierra Leone is only 47.8 years among an estimated population totaling about 6 million, ranking them as the lowest life expectancy of the 187 nations listed in the United Nations Development Index (http://hdrstats.undp.org/en/ countries/profiles/SLE.html). This prompted an urgent need to collect and analyze data on mortality for those with unmet surgical need in Sierra Leone. The Surgeons Over-Seas (SOS) Assessment of Surgical Need (SOSAS) is a household survey based on a two-stage, probability proportional to size cluster sampling design that was executed in Sierra Leone in February 2012 [5]. We reported our overall finding recently describing the large proportion of unmet surgical need [5]. The survey also contained important information focusing on issues related specifically to those family members who died during the year leading up to the survey. In this article, we look at the mortality data in detail and describe those deaths that may have been associated with a surgical condition. We also evaluate the reasons for not seeking health care.

#### Materials and methods

This study was approved by the Sierra Leone Ministry of Health and Sanitation (MoHS) and ethical approval was obtained from the Ethics and Scientific Review Committee of Sierra Leone and the Research Ethics Committee of the Royal Tropical Institute in Amsterdam, The Netherlands.

#### Data source/survey tool

The SOSAS was developed collaboratively by a 46-member international research group of experts to be used for cross-sectional epidemiologic data collection to determine the prevalence of surgical conditions in a society [5, 6]. The survey was administered by the members of the Faculty of Nursing, medical students from the College of Medicine and Allied Health Sciences (COMAHS), and professional enumerators from Statistics Sierra Leone (SSL). They were trained over a 1-week period regarding the survey content along with interview strategies and data collection techniques. Data collection was randomly screened on a daily basis by the field supervisors for immediate feedback to the enumerators. Data were amended in case of inconsistencies only after clarification of the enumerators. If clarification was not possible, the inconsistent data were noted as missing data.

# Sampling technique

This cross-sectional cluster-sample household survey used randomly assigned clusters using methods similar to previous studies [7–9]. The assignments were stratified to represent all 14 districts in Sierra Leone and comprise representative proportions of households from rural and urban areas. The probability of being chosen as a cluster was proportional to the population size. The sample was self-weighted because the number of households per cluster was consistent. A sample of 25 households per cluster was selected from 75 clusters, yielding a targeted 1,875 households. In each cluster, 25 households were randomly selected using the published methods for areas where household listings are not available [8, 9], which involves first structure count (house count) of the enumeration area and random assignment of the structures with a random calculator [5].

# Data

The SOSAS survey tool contains numerous data points to assess the prevalence of surgical conditions. The household representative was asked to enumerate any household member(s) who passed away during the 12 months prior to the interview. Eight categories of questions related to the household member's death were analyzed. They included the age, sex, pregnancy at death, associated conditions just prior to death, location of their death, whether health care was sought and/or received, and reasons for not receiving surgical care (eAppendix).

Surgical disease was defined as conditions that were present less than a week before the household member had died. The terms were defined in words that could be understood by those not familiar with medical terminology. These categories included injury, wound not due to an injury, bleeding or ill around childbirth, mass (growth or swelling), deformity congenital, deformity acquired, abdominal distension or pain, or none of the above (eAppendix). The injury category was further categorized according to the type of injury: car/truck/bus crash, motorcycle crash, pedestrian/bicycle crash, gunshot/firearm, stab/slash/cut/crush, bite or animal attack, fall, open fire/explosion, hot liquid/hot object. There was a question about deaths occurring in the perinatal period defined as deaths occurring during delivery or within 6 weeks of the household member's death.

Access to care was defined as the provision/receipt of health care prior to death. Questions were asked about whether the deceased had visited a health care facility prior to death and specifically whether he/she received care from a physician/nurse or from a traditional healer/witch doctor/ bone setter. If the household member did seek medical care, surgical interventions were specified. It was defined as none/no surgical care, major procedure (defined as a procedure requiring regional or general anesthesia), or minor procedure (defined as application of dressings, wound care, care of punctures, suturing, and incision and drainage). Conversely, if the deceased either did not seek medical care or did not receive surgical care after having sought medical care, the reasons were documented. The potential responses were predefined as no money for health care, no transportation, no time (person died before arrangements), fear/no trust, no availability of facility/ personnel/equipment, or no need (condition is not surgical).

# Analysis

Demographics of deaths were summarized using frequency distributions for categoric variables, and means and standard deviations for continuous variables. STATA version 11 was used for all analyses (STATA, College Station, TX, USA).

# Results

Of the targeted 1,875 households, 1,840 households had complete data for analysis, yielding a 98.3 % response rate. The mean household size was  $6.44 \pm 3.53$  members (range of 1–32), yielding a total population of 11,870 surveyed. Altogether, 61 % were from rural locations. A total of 575 households (31.3 %) reported at least one household death

during the last 12 months. Overall, 709 total deaths reported [6.0 % (709/11,870)]. Multiple deaths included 78 households with two deaths, 22 households with three deaths, and 4 households with four deaths, totaling 104 households with more than one death during the past 12 months.

Characteristics of the deceased household members

The mean age at death was  $36.4 \pm 30.1$  years, and 330 (46.6 %) were female. A higher proportion of reported deaths were from rural areas (59.0 %), and most deaths occurred at home (58.1 vs. 34.1 % deaths in hospitals) (Table 1).

The majority of deaths occurred in those between the ages of 0 and <5 years and those > 65 years (Table 2). Most respondents stated "none of the above," indicating that they may not have known what the cause of death was or it was not surgery-specific. Overall, 237 deaths (33.4 %) were associated with conditions that were included in our defined surgical disease category. Abdominal distension/ pain was the most commonly associated condition (13.9 %) followed by perinatal bleeding/illness (6.0 %), injury (5.8 %), mass (3.0 %), and acquired deformity (2.6 %) (Table 3). Abdominal distension or pain was the first or second leading problem across all age groups except in patients <1 year of age. Injury (n = 5) and congenital deformity (n = 5) were the most commonly reported reasons for death in the children <1 year old. In the age group 1-4 years, injury and an abdominal mass were the second most common. Bleeding or ill around childbirth was the leading problem in age groups 15-24 years and 25-34 years, and it was the second leading problem in the age group 35-44 years (abdominal distenson/pain was first). In those over age 45, injury was the second highest reported problem.

For injury-related deaths (n = 41), a fall was the most common injury category (30.8 %) followed by a bite or animal attack (20.5 %), motor vehicle crash (20.5 %), motorcycle crash (12.2 %), stab/cut/crush injury (7.3 %), and open fire/explosion injury (2.4 %). There were no reported gunshot/firearm injuries. Of the female population of all ages, 53 (16.1 %) deaths were within the definition of a maternal death (i.e., death while pregnant or within 6 weeks after delivery). Also, 40 of the 53 deaths (75.5 %) were categorized as bleeding/illness around childbirth.

Barriers to and reasons for not receiving surgical care

A total of 555 (78.3 %) sought health care from a health facility or doctor/nurse before they died, and 222 (31.8 %) went to a traditional healer. Of those who sought health care, 77.1 % received no surgical treatment, 18.0 %

underwent a minor procedure, and 4.7 % underwent a major procedure (Table 4). Of those who reported a condition in the predefined surgical categories (n = 237), 51

 Table 1
 General overview of the demographics of the 709 reported deaths

| Parameter  | Data <sup>a</sup> |
|--|-------------------|
| Age (years), mean $\pm$ SD   | $36.7 \pm 30.3$   |
| Female sex   | 330 (46.6 %)      |
| Rural residence  | 418 (59.0 %)      |
| Place of death   |                   |
| Hospital   | 242 (34.4 %)      |
| Home   | 412 (58.6 %)      |
| Elsewhere  | 49 (7.0 %)        |
| Deaths from conditions that may have<br>benefited from surgical intervention | 237 (33.4 %)      |
| Surgical death <sup>b</sup>  | 179 (25.2 %)      |

<sup>a</sup> Missing data: five cases had missing age information, one had missing sex information, and five had missing place of death information

<sup>b</sup> Defined as due to one of the predefined conditions that may have benefited from surgical intervention and excluding those who had "no need" for surgical intervention

Table 2 Age distribution of the reported deaths

| Frequency (no.) | Percentage (95 % CI)   |  |  |
|-----------------|--|--|--|
| 86              | 12.2 (8.6–15.8)  |  |  |
| 92              | 13.0 (10.215.9)  |  |  |
| 44              | 6.2 (4.7–7.8)  |  |  |
| 67              | 9.5 (6.5–12.4)   |  |  |
| 67              | 9.5 (7.0–12.0)   |  |  |
| 56              | 7.9 (6.39.6)   |  |  |
| 70              | 9.9 (7.7–12.1)   |  |  |
| 51              | 7.2 (5.3–9.2)  |  |  |
| 173             | 24.5 (21.1-27.9)   |  |  |
|                 | Frequency (no.)<br>86<br>92<br>44<br>67<br>67<br>56<br>70<br>51<br>173 |  |  |

There were three cases with missing age information

CI confidence interval

| Table 3         Number of associated |
|--------------------------------------|
| conditions observed by other         |
| household members 1 week             |
| before death: total and stratified   |
| by age                               |

One case missing age information for "Injury," four cases missing "Bleeding or ill around childbirth" information, and one case missing "Abdominal distension or pain" information (21.9 %) did not seek medical care (Table 5). The two most common reasons for not seeking medical care were lack of money (18/51, 35.3 %) and not enough time (person died before arrangements to receive surgical care) (19/ 51, 37.3 %) (Table 5). Of those who sought medical care with these potential surgical conditions (n = 116), 52 (44.8 %) were assessed to have no need for surgical intervention. Reasons for not receiving surgical care in this group included lack of funding (33.3 %), inability to provide timely care (13.2 %), and no availability of surgical care (7.9 %) (Table 5).

# Discussion

The biggest barrier to accurate estimation of surgical diseases and other conditions is the lack of appropriate databases in low-income countries. Contini estimated that one-third to one-half of the world's population have no access to basic surgical care [10]. In our study, we found that approximately 25 % of all reported deaths in this sample might have benefited from surgical interventions. Of the surgical disease categories assessed, abdominal distension/pain was the most common condition (98/237) associated with deaths followed by perinatal complications, and injury with fall accounted for most of the injury-related deaths (>30 %). Most household members sought medical care prior to death (555/709, 78.3 %). However, nearly 22 % of those who died with associated surgical conditions did not seek medical care, primarily because of insufficient funds or missed opportunity to receive timely surgical care prior to death. Among those with a surgical condition who sought medical help, we found that only about 45 % were assessed to have no need for surgical intervention. The rest of the population could not receive surgical care because of a lack of funding (31.9 %), missed opportunity for timely surgical care (12.9 %), no availability of resources (8.6 %), lack of transportation (0.9 %), or fear/lack of trust (0.9 %).

| Associated conditions             | Total (%)  | Birth to 4<br>years (%) | 5–14 years<br>(%) | 15–64 years<br>(%) | ≥65 years<br>(%) |
|-----------------------------------|------------|-------------------------|-------------------|--------------------|------------------|
| Injury                            | 41 (5.8)   | 8 (4.6)                 | 0                 | 29 (9.4)           | 3 (1.7)          |
| Wound not due to injury           | 10 (1.4)   | 0                       | 0                 | 7 (2.3)            | 3 (1.7)          |
| Bleeding or ill around childbirth | 42 (6.0)   | 0                       | 1 (2.3)           | 37 (12.0)          | 0                |
| Mass                              | 21 (3.0)   | 3 (1.7)                 | 1 (2.3)           | 10 (3.3)           | 7 (4.0)          |
| Deformity                         |            |                         |                   |                    |                  |
| Congenital                        | 7 (1.0)    | 6 (3.5)                 | 0                 | 0                  | 1 (0.6)          |
| Acquired                          | 18 (2.6)   | 3 (1.7)                 | 1 (2.3)           | 6 (2.0)            | 8 (4.6)          |
| Abdominal distension or pain      | 98 (13.9)  | 8 (4.6)                 | 8 (18.6)          | 57 (18.5)          | 24 (13.8)        |
| None of the above                 | 467 (66.3) | 145 (83.8)              | 32 (74.4)         | 162 (52.6)         | 128 (73.6)       |

With growing recognition of surgical intervention being a crucial component of health services and improving health outcomes in low-income countries [11-14], it has become important now more than ever to define the burden of surgical diseases. The volume of major surgery has been estimated at 187 million to 281 million cases per year [2]. This translates into one operation for every 25 humans per year. An earlier (1980s) population-based survey of surgical care in Pakistan documented similar findings [15]. It estimated that the rate of operations was equivalent to only 1.5-9.0 % of the rate in Western countries. The rates of surgical procedures in African countries during the 1990s were estimated to be 20 times lower than that of the Western countries and varied across the country [16]. These studies indicated a severe "unmet need" of their surgical conditions in these countries. Sierra Leone ranks 180 of 187 nations in the United Nations Development Index (http://hdrstats.undp.org/en/countries/profiles/SLE. html) and belongs in the category of one of the poorest countries. Our analysis estimated that around 33 % of the deceased population had had conditions that might have benefited from a surgical intervention. Only 29 % of those with possible surgical conditions underwent procedures. To our knowledge, ours is the first study to evaluate both those who do and those who do not undergo surgery when the need is present. This is vital information for countries with limited access to care or limited or no death registration.

Determining the actual cause of death with a postmortem examination or verification with clinical notes would be ideal and needs to be incorporated into monitoring and evaluation systems of hospital care [17]. However, only 34.4 % of the deaths in the sample were in hospitals, and 31 % of those were related to a surgical condition. Evaluation of deaths that occur outside of health care facilities can provide useful insights and opportunities for health care systems to begin to react. One study from India dealt with this limitation by performing verbal autopsies in households with a death in areas randomly selected that were representative of all India [18]. Using this method, they were able to estimate that there were >550,000 cancer deaths in India. It was also able to identify tobacco use and early detection and treatment as two sectors that can reduce cancer deaths. Similar research efforts are needed in other low-income countries because

 Table 5
 Reasons/barriers for not receiving surgical care among those with conditions that may require surgery

| Reason for/<br>barrier to<br>receiving<br>surgical care | Did not seek<br>medical care<br>$(n = 51^{a}, \%)$ | Sought health care<br>but received no<br>surgical treatment<br>$(n = 116^{a}, \%)$ | Total<br>( <i>n</i> = 168 <sup>a</sup> ,<br>%) |
|---|--|--|--|
| No money  | 18 (35.3)  | 38 (33.3)  | 56 (33.9)                                      |
| No<br>transportation                                    | 3 (5.9)  | 1 (0.9)  | 4 (2.4)  |
| No time<br>(person died<br>before<br>arrangements)      | 19 (37.3)  | 15 (13.2)  | 34 (20.6)                                      |
| Fear/lack of trust                                      | 0  | 1 (0.9)  | 1 (0.6)  |
| Not available<br>(facility/<br>personnel/<br>equipment) | 3 (5.9)  | 9 (7.9)  | 12 (7.3)                                       |
| No need   | 8 (15.7)   | 50 (43.9)  | 58 (35.2)                                      |

Among the total 237 patients, 69 (29.1 %) underwent a procedure (22 major and 47 minor procedures), leaving 168 who did not receive surgical care. Note that the reasons/barriers to surgical care are stratified by the subjects: those who did not seek medical care and those who sought health care but received no surgical care

<sup>a</sup> There were 138 deaths of patients with missing information on reasons for not receiving surgical care. There was one case of death with missing information on reasons for not receiving surgical care among those who did not seek medical care and two cases of deaths with missing information on reasons for not receiving surgical care among those who sought health care but received no surgical care

Table 4 Those who sought medical care before death and type of surgical care received

| e  |            | 51 0                 |                |                 |               |
|--|------------|----------------------|----------------|-----------------|---------------|
| Parameter                                    | Tota (%)   | Birth to 4 years (%) | 5-14 years (%) | 15-64 years (%) | ≥65 years (%) |
| Did not seek health care                     | 152 (21.4) | 36 (20.7)            | 10 (22.7)      | 65 (20.9)       | 41 (23.6)     |
| Sought health care                           | 555 (78.3) | 136 (78.2)           | 34 (77.3)      | 246 (79.1)      | 133 (76.4)    |
| Sought health care from traditional healer   | 222 (31.3) | 37 (21.3)            | 12 (27.3)      | 116 (37.3)      | 54 (31.0)     |
| Among those who sought health care $(n = 1)$ | 555)       |                      |                |                 |               |
| No surgical treatment                        | 429 (77.1) | 107 (78.7)           | 28 (82.4)      | 190 (77.1)      | 102 (76.7)    |
| Underwent a minor procedure <sup>a</sup>     | 100 (18.0) | 26 (19.1)            | 6 (17.7)       | 42 (17.1)       | 23 (17.3)     |
| Underwent a major procedure <sup>a</sup>     | 26 (4.7)   | 3 (2.2)              | 0              | 14 (5.7)        | 8 (6.0)       |
|  |            |                      |                |                 |               |

There were six cases of missing age information for those who "Sought health care" and three cases for those who "Sought health care from traditional healer." There were also two cases of missing age information for those receiving "No surgical treatment," three cases for those undergoing "a minor procedure," and one for those undergoing "a major procedure"

<sup>a</sup> Minor procedure is defined as one that includes dressing changes/wound care, punctures, suturing, and/or incision and drainage. Major procedure is defined as one that requires regional or general anesthesia

of the high proportion of the population having no access to surgical care.

Additional research should focus on defining the barriers to appropriate surgical care and the associated outcomes. Previous studies have demonstrated that the lack of surgical services is the key factor in not receiving quality surgical services, leading to poor outcomes. Mock et al. [19] observed a rate of 89 per 100,000 injury-related deaths in low- and middle-income countries compared to 51 per 100,000 in the high-income countries. Other studies have demonstrated a lower rate of cesarean sections in lowincome countries with higher rates of associated neonatal and maternal mortality [20, 21]. Studies demonstrating a lack of available surgical care in low-income countries [11, 12, 15] have concluded that the lack of availability is the reason for poor surgical outcomes in these countries. Although this may be true for emergent surgical conditions, it is not necessarily the case for elective/urgent surgical services. The barrier "no availability" (of surgical care) was only the third most common reason for not receiving appropriate surgical care in this survey. The most common barriers were financial restraints and missed opportunity to receive surgical care in a timely fashion. This may also represent the unavailability of surgical care in the rural areas of Sierra Leone-and therefore higher costs of traveling to available care (increased indirect costs).

There are limitations to this study apart from the limitation of the study design as described above. There are 14 languages used in Sierra Leone, which may have limited the interviewers' communications/data gathering for certain questions. Given the literacy rate of only 40 % in Sierra Leone, responders may have had a different perspective on the questions being asked. To address some of these limitations, all enumerators were provided background on the SOSAS tool and were trained over a 1-week period in interview strategies and data collection techniques. Also, data collection was screened on a daily random basis by the field supervisors for immediate feedback to the enumerators. This was a cross-sectional study and there may be associated recall bias by the responders. To make the survey understandable to the responders, the categories we created for surgical diseases may not be linked to a death from true surgical disease. This leads to a potential misclassification bias and also relies on the responder's perceptions of surgical conditions. To minimize the bias of the data collectors, they were sent out in teams with a medical supervisor who was available for clarification. The sample was designed as a nationally representative sample [8], and the reported total death rate of 60 per 1,000 population per year is almost three times higher than what has been previously reported [22]. This may be due to underreporting of deaths by the World Health Organization, especially in rural areas or to telescoping of tragic events by the family members who reported the death. Lastly, suboptimal surgical care should also include those who have had worse outcome from receiving surgical care (i.e., receipt of inappropriate surgical care). This could not be assessed with our survey.

### Conclusions

There was a high prevalence of surgical conditions associated with deaths in Sierra Leone. Less than one-third of the population seeking medical care with surgical conditions received surgical care. Lack of financing and missed opportunity for timely surgical care were the most common reasons for not receiving surgical care. Our findings should educate policymakers and help them plan intervention strategies, such as relieving financial burdens for patients needing surgical care and providing surgical clinics to facilitate timely surgical care to the districts. Such measures could improve the health of the Sierra Leone population by providing them access to surgical care.

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