Unmet Surgical Need in Malawi

Carlos Gomes Varela

Thesis for the degree of Philosophiae Doctor (PhD)
University of Bergen, Norway
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Scientific environment

The studies included in this thesis were carried out as a nation-wide survey in villages in Malawi. Data for all the four studies was collected using the Surgeons OverSeas Assessment of Surgical Need (SOSAS) tool installed on computer tablets – Apple iPad 2, in July and August 2016.

Medical students in their third year of medical studies conducted the data collection under daily supervision by the principal investigator.

During data collection, there was collaboration with another PhD candidate, Dr Leonard Banza, orthopaedic surgeon based at Kamuzu Central Hospital. Dr Banza was conducting another study that used another survey instrument focused on musculoskeletal impairment, but the two studies shared transport logistics. Other collaborations included two other PhD candidates. One was doing needs assessment on integrating ear and hearing care into primary health care and the other was assessing the quality of life after treating femur fractures with surgery as compared to those treated non-operatively. All four PhD candidates collaborated closely with Asgaut Viste and Sven Young from the Surgery Department at Haukeland University Hospital (HUH), and with Nyengo Mkandawire from the Malawi college of Medicine, as well as with numerous people at the Centre for International Health, and mostly coordinating with Bente Elizabeth Moen who provided support on technical aspects, course work and materials for data analysis and supervision. The other major collaboration involved in this thesis work was with Reinou Groen, from Johns Hopkins Hospital and Alaska Native Tribal Health Consortium. This collaboration involved the data collection materials, which enabled collection of the data analysed in the published papers.

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Summary

Introduction

Globally, and especially in sub-Saharan Africa, including Malawi, surgical conditions receive a low level of priority in national health systems. The burden of surgical diseases is not well documented and the reasons for which people still live with treatable conditions and disabilities or sometimes present late for care have also not been studied. There is also little information on surgical deaths from untreated conditions in both adults and children, including trauma, as well as potential barriers to obtaining surgical care..

Objectives

The aim of this thesis was therefore to describe the untreated surgical conditions, in both adults and children, the barriers to surgical health care, as well as to document information about deaths from surgical conditions in Malawi.

Methods

This thesis is based on four papers. All four involved data collected using the SOSAS tool, which is a questionnaire-based data collection tool for documenting household information in the communities. The tool had three sections, the first section capturing demographic data for the households; including number of occupants, ages, gender, location and type of household, and tribe. The next two sections were similar but involved interviewing two different people and asking about information relating to surgical conditions present for both adults and paediatric age groups, including injuries, associated disability from acquired or congenital disorders, transportation to health facility and location of death from different surgical conditions. The two household members interviewed, included the head of household and another random member within the household. Data collection was centrally organized by a project group, and performed by third year medical students from the University of Malawi, College of Medicine.

Data was collected as a national survey from the 28 districts in Malawi. The National Statistics Board helped us to identify the villages used in the study.

Results

We found that a third of the Malawian population were living with a surgical condition and were in need of a surgical consultation or treatment. These conditions were either congenital or the result of a traumatic or other non-traumatic condition. We also found that almost one fifth of the children with a surgical condition that could have been treated by surgery, instead remained with a disability that affected their daily lives.

In addition, we found that transportation poses a barrier to timely access to surgical health care. Transportation barriers included the lack of efficient public transportation, cost implications, and long travel distances to get to a health facility capable of offering care by either consultation or surgical procedures.

Other findings were that acute abdominal distention, body masses and trauma, contribute to surgical conditions that are highly associated with mortality in Malawian communities. We also noted that there are various reasons that lead to delays in obtaining formal health care, including initial consultations with traditional herbalists before going to the hospital.

Conclusion

Almost 6 million Malawian people, including an estimated 2 million children, are living with a condition that could be treated by either a surgical procedure or consultation. There are an estimated 1 million disabled children currently living with such surgically treatable conditions. The treatment of these conditions is hampered by transportation barriers. The transportation barriers have led to delays in obtaining timely surgical health care service, something that often leads to mortality. The common causes of these deaths are from injuries, but also other surgical emergencies. Most of these deaths occur outside a health facility environment.

List of original publications

The thesis is based on the following four interrelated papers. They are referred to in the text by their Roman number.

Paper I:

Carlos Varela, Sven Young, Reinou Groen, Leonard Banza, Nyengo C. Mkandawire, Asgaut Viste.

Untreated Surgical Conditions in Malawi:
A randomised cross-sectional nation-wide household survey.

Malawi Medical Journal 29 (3):231-236 Sept 2017.
Doi: 10.4314/mmj.v29i3.1

Pic 1: A woman with deformed little finger from injury

(Photo: C Varela)

Paper II:

Carlos Varela, Asgaut Viste, Sven Young ,Reinou S. Groen, Leonard Banza, Bip Nandi, Nyengo Mkandawire, Bente Elisabeth Moen

Paediatric Surgical Conditions in Malawi:

A cross-sectional nation-wide household survey.

In press: Accepted for publication in the Malawi Medical Journal

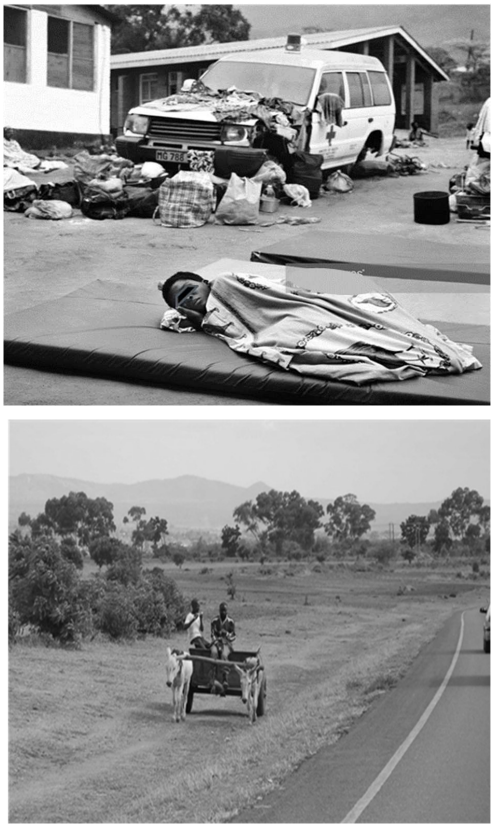
Pic 2: A young boy with a congenital right foot deformity: Paediatric untreated surgical condition) Right club foot

(Photo: C. Varela)

Paper III:

Carlos Varela , Sven Young, Nyengo Mkandawire, Reinou S. Groen, Leonard Banza, Asgaut Viste.

Transportation Barriers to Access Health Care for Surgical Conditions in Malawi. A cross-sectional nation-wide household survey.
BMC Public Health (2019) 19:264. doi.org/10.1186/s12889-019-6577-8



Pic 3: Non-functional ambulance posing a transportation barrier for a sick woman waiting to be transferred to a district hospital from a primary health centre – donkey cart (Photos: C. Varela and Asgaut Viste)

Paper IV:

Carlos Varela, Sven Young, Reinou S. Groen, Leonard Banza, Nyengo Mkandawire, Bente E. Moen and Asgaut Viste.

Deaths from Surgical Conditions in Malawi –
A randomised cross-sectional nation-wide household survey.

BMC Public Health (2020) 20:1456
doi.org/10.1186/s12889-020-09575-8

Pic 5: *Two coffins being prepared for a couple that died from traumatic injuries following a road traffic accident*

(Photo: C. Varela)

Abbreviations

CHAM: Christian Health Association of Malawi

CI: Confidence Interval

COSECSA: College of Surgeons of East, Central and Southern Africa

DALYs: Disability Adjusted Life years

DC: District commissioner

DHO: District Health Officer

DMO: District Medical Officer

EPH: Essential health Package - did not find this in the text?

GDP: Gross Domestic Product

LIC: Low Income countries

LMIC: Low and Middle Income countries

NGO: Non-Government Organisations

Norad: Norwegian Agency for Development

NORHED: Norwegian Programme for Capacity Development in Higher Education and Research for Development

OCO: Orthopaedic Clinical Officer

PHC: Primary Health Care

POP: Plaster of Paris

SOSAS: Surgeons Overseas Assessment of Surgical need

SPSS: Statistical Package for Social Scientists

SSA: Sub Sahara Africa

SV: Surgical Volume (The number of surgical procedures/operations per 100,000 people)

USD: United States Dollar

WHO: World Health Organisation

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1. Introduction

The motivation for writing this thesis was based on my interest in studying how many people in Malawi are living with a condition that could benefit from a surgical consultation or a surgical procedure. Based on my 10 years of surgical practice experience, I knew first hand that there are still many gaps in documentation concerning the impact of surgical diseases and conditions in Malawi. For example; how many children have a disability that would benefit from a surgical intervention, where are these people living and how can they get assistance? When they fall ill and want to seek health care, where and how do they do it? What are the transportation constraints preventing them from reaching hospitals in good time for assistance? How many of them die before they can get care, and what are the causes of these deaths and where do they occur? All these questions needed answers and my goal was to contribute with information that could help reduce suffering and deaths from surgical conditions.

Below I will present the overall background on the global burden of surgical diseases and traumas in Low- and Middle- Income Countries (LMIC). I will focus in particular on the situation in the sub-Saharan region and Malawi.

I will then present the health system in Malawi, and write briefly about the country's economic situation. Finally, I will elaborate on the surgical health service in Malawi, including trauma and mortality. In the discussion I will explain more about the burden of surgical disease in reference to untreated conditions in both adult and paediatric persons, associated disability, transportation barriers and mortality from untreated surgical conditions.

1.1 Global burden of surgical disease

Globally, almost five billion people have limited or no access to safe, affordable surgical and anaesthesia care if and when they need it. Access in LMIC is at its worst, with 9 of 10 people being unable to access basic surgical care [1]. Around 16,9 million people each year, die from conditions that require surgical care and most of

them are in LMICs [2, 3]. Each year 143 million additional surgical procedures are needed in LMICs to save lives and prevent disability [1]. Furthermore, the Covidsurg collaborative has shown that surgical care initiatives have been disrupted and it is estimated that more than 28 million surgeries will be cancelled or postponed worldwide due to the current COVID -19 pandemic [4].

Compared to low-income countries, high income countries have a 3 fold greater effectiveness at improving surgical care. This is documented in the Healthcare Access and Quality (HAQ) index [5]. In addition, the African Surgical Outcomes Study (ASOS) showed that the surgical volume (SV) is unacceptably low in Africa, i.e. few people receive surgery, with a median of 212 operations per 100 000 population. This value is 20 times lower than the level that is considered to indicate a crucial surgical volume per year of 5 000 operations per 100 000 people. Surgical volume is an indicator of met need for surgical care [3, 6].

Unmet surgical need is greatest in LMIC including sub-Saharan Africa. The Lancet Commission for Global Surgery showed that surgery is an important part of the health care system and that investing in surgical care and services in LMICs is affordable [6]. Surgery can save lives and provide better health, and this will promote economic growth. However, this is not possible in most LMIC as surgery in these countries is generally under prioritised [7]. There are many untreated surgical conditions in LMICs, and for many years these have gone unrecognised. The potential health profits from scaling up surgical services in LMICs are considerable, and could result in substantial socio-economic benefits. If safe and affordable surgical and anaesthesia care can be provided when needed, it may not only reduce premature deaths and disabilities, but in the long run it will boost economic development and increase social welfare.

At the *Lancet* Commission meeting on Global Surgery in January 2014, Jim Kim, World Bank President, stated that: “surgery is an indivisible and indispensable part of health care” that “can help millions of people have healthier and more productive lives” [1]. To help achieve this, one of the recommended policies is to scale up

financial investments and promote economic growth in LMICs in order to improve surgical and anaesthesia services to save lives [1]. This will improve public health and reduce disability and death.

The economic loss to the world economies between 2015 and 2030 is estimated at a staggering USD 12 trillion, if surgery and anaesthesia care needs are not addressed [6]. The 68th World Health Assembly (WHA) noted that many surgically treatable conditions are among the top 15 causes of physical disability globally. Diseases treatable by surgery represent 11% of the world's burden of diseases, with LMICs bearing the greatest burden [8]. Despite the challenges faced by limited resources including medical personnel and infrastructure, LMICs would do well to boost their investment in surgical health services as a way to improve outcomes in general [8]. There is increasing recognition that mortality and morbidity from surgically related conditions in LMIC could be reduced noticeably by scaling up basic life-saving surgical care.

Over 100 million people sustain traumatic injuries globally every year, and more than 5 million people die from these injuries. This is more deaths than HIV, malaria, and tuberculosis combined [9]. Significant proportions, almost 90%, occur in LMICs [10]. Many deaths are not reported to the government and thus information relating to national causes of death is limited and unreliable. In addition, many ill or injured persons never receive any formal medical care, so health system records represent an incomplete source of data [11, 12].

Though surgical conditions and injuries are increasingly being recognised as a growing global health problem, the burden of these conditions has not been adequately described in most of sub-Saharan Africa. Some low-income countries, however, have carried out national surveys to describe the situation in their country. Examples include Nepal, Sierra Leone, Rwanda and Uganda. In Sierra Leone, the prevalence of untreated surgical conditions among adults is 25%, while among children it is 17,6%, while in Uganda, Rwanda and Nepal its 11%, 6% and 11% respectively.[10, 13-19].

A study in Mozambique showed that 44,9% of the population has no timely access to surgical services, with more than 60% of the geographical districts lacking operating rooms and surgical care providers [20].

1.2 Surgical services need in Malawi

The need for surgical care is high in Malawi. With very few surgical providers, the system relies mostly on surgical service technicians, i.e: clinical officers working in the district hospitals. Referral centres i.e central hospitals, are situated only in the big cities of the country, which are far from the communities that need surgical care. These centres are also heavily congested with patients requiring surgery [21, 22].

In Malawi only 77% of the public service posts for health are currently filled, and there are only approximately 70 surgeons in total, nationwide (0,24 surgeons per 100 000). This is the lowest density of surgeons in the world [19]. Untreated surgical conditions and disabilities from these are widely spread in Malawian rural communities. As a response, basic surgical training for clinical officers has been introduced in the country to the level of a degree in general surgery to equip the providers with skills to provide basic surgical care and identify cases for referral to central hospitals [21, 23].

Many people in rural communities either present late, or do not present at all to the health facility due to transport problems, lack of funds, or lack of knowledge concerning the need to visit the health facility [24, 25]. In the rural areas of Malawi, transportation costs are high and vehicles are often not available for people with little financial resources to travel. Sometimes the hospital ambulances are not road worthy due to lack of maintenance, this reduces patient transportation possibilities to tertiary facilities. In addition, the roads become muddy and un-serviceable during the rainy season. It is also worth noting that even when patients can get themselves to a local health facility, they may end up disappointed because it may not have necessary equipment and drugs to treat their condition [22].

Primary health facilities including community hospitals and district hospitals in Malawi, have not met the surgical needs of the population they serve resulting in significant morbidity and mortality. Surgical conditions significantly affect mortality in Malawi.

Traumatic conditions also play an important role in surgical emergencies in Malawi. During a seven-year period there was an increase in injuries from 2 447 to 3 975 treated at a referral centre in Malawi, with the source of the trauma being predominantly road traffic accidents [26]. This correlated with a prevalence of 21,2% of surgically-related mortality due to injuries in Malawi [27]. Road traffic injuries, falls from heights, and assault are the most common causes of injury in Malawi resulting in hospital admissions. In terms of the body part affected, head injuries are commonly associated with trauma deaths. Mortality is high in elderly males who present with a lower level of consciousness on arrival at the hospital. Road traffic injuries are a global health scourge with an estimated 1,2 million deaths and 50 million nonfatal injuries per year. In Malawi road traffic injuries rank top as the overall cause of traumatic death [28, 29].

In Malawi there is limited information on children with surgical conditions and associated disability. A recent study on paediatric surgical conditions showed that almost one fourth of children living with a surgically correctable condition, and of these, two thirds are disabled. Apart from inadequate infrastructure for surgical services in Malawi, the number of paediatric surgical providers is also very low when compared to high income countries.

In summary, in Malawi there is a large potential to prevent the complications of surgically correctable condition, including disability and death, if there can be early enough presentation to health facilities that can provide good surgical health service [24].

1.3 Malawi health system

The health care system in Malawi has two main providers: Non-governmental facilities under Christian Health Association of Malawi (CHAM) and government facilities. CHAM is composed of church-managed health facilities, community hospitals and training colleges supported financially by the Malawi Government. The organisation has a network of 175 health facilities across the country and provides 37% of health services in the country. CHAM offers its services at a cost, while the government facilities offer free services [30-32].

The government health structure has a three-tiered network design of medical facilities in a hierarchy of services offered referred to as; primary health facilities or health centres, district hospitals, and central hospitals. The health centres, institutional clinics and other smaller private clinics are the primary health facilities. They are run by medical assistants and nurses and have no doctors. Health centres do not offer any form of surgical services, and medical supplies are often not available [33].

District hospital and community hospitals form the second tier. They cater to critical medical cases, which cannot be handled at the health centres. District hospitals are run by clinical officers, nurses and anaesthetic clinical officers. They often have one or two non-specialist medical doctors. These facilities are located centrally in each of Malawi`s 28 administrative districts. District hospitals can handle some surgical cases, including uncomplicated obstetric emergencies, and non-operative orthopaedic emergencies, but they cannot handle emergencies that require laparotomy or other major operative orthopaedic emergencies [34]. Another challenge at the secondary tier level is equipment shortages, such as radiologic equipment and other medical supplies. These institutions are headed by District Health Officers (DHO) and District Medical Officers (DMO), who are appointed after completing their internship training at the central hospitals for 18 months. These Officers are medical doctors with a Bachelor medical degree (MBBS).

Medical assistants have a certificate documenting completion of 2 years of clinical medical training, while clinical officers have a diploma documenting 3 years of

clinical medical training. Anaesthetic clinical officers are trained for 18 months and are certified in the provision of clinical anaesthesia. There are no specialist surgeons or anaesthesiologists to provide advanced surgical and anaesthetic care in the district hospitals [35, 36].

The top tier includes the tertiary centres referred to as central hospitals. These centres have more advanced technology; including diagnostic medical equipment and supplies, and medical personnel including different specialist doctors. There are four central hospitals in Malawi, located in the four major cities; Lilongwe, Blantyre, Mzuzu and Zomba. These are also teaching hospitals for undergraduate and post graduate medical bachelor degree and specialist training, nurse training and clinical officer training. Only two of the central hospitals have well equipped Intensive Care Units (ICU) to offer critical care services. These are Kamuzu Central Hospital, and Queen Elizabeth Central Hospital [37].

While CHAM and the community hospitals provide 37% of health services, government health facilities are responsible for 60% of the health service delivery, with a further 3% being provided by other private institutions and organisations.

Patients go to any of the government facilities when they need health service depending on their need and proximity to health facility. Most people live within 5 km of a health facility, usually a health centre. Patients from the health centres can be referred to district hospitals, while district hospitals, in turn, refer patients to a central hospital via district hospital ambulances.

Some CHAM and other private hospitals are run by specialist physicians, and can refer patients to a central hospital for multi-disciplinary specialist care.

FIGURE 1

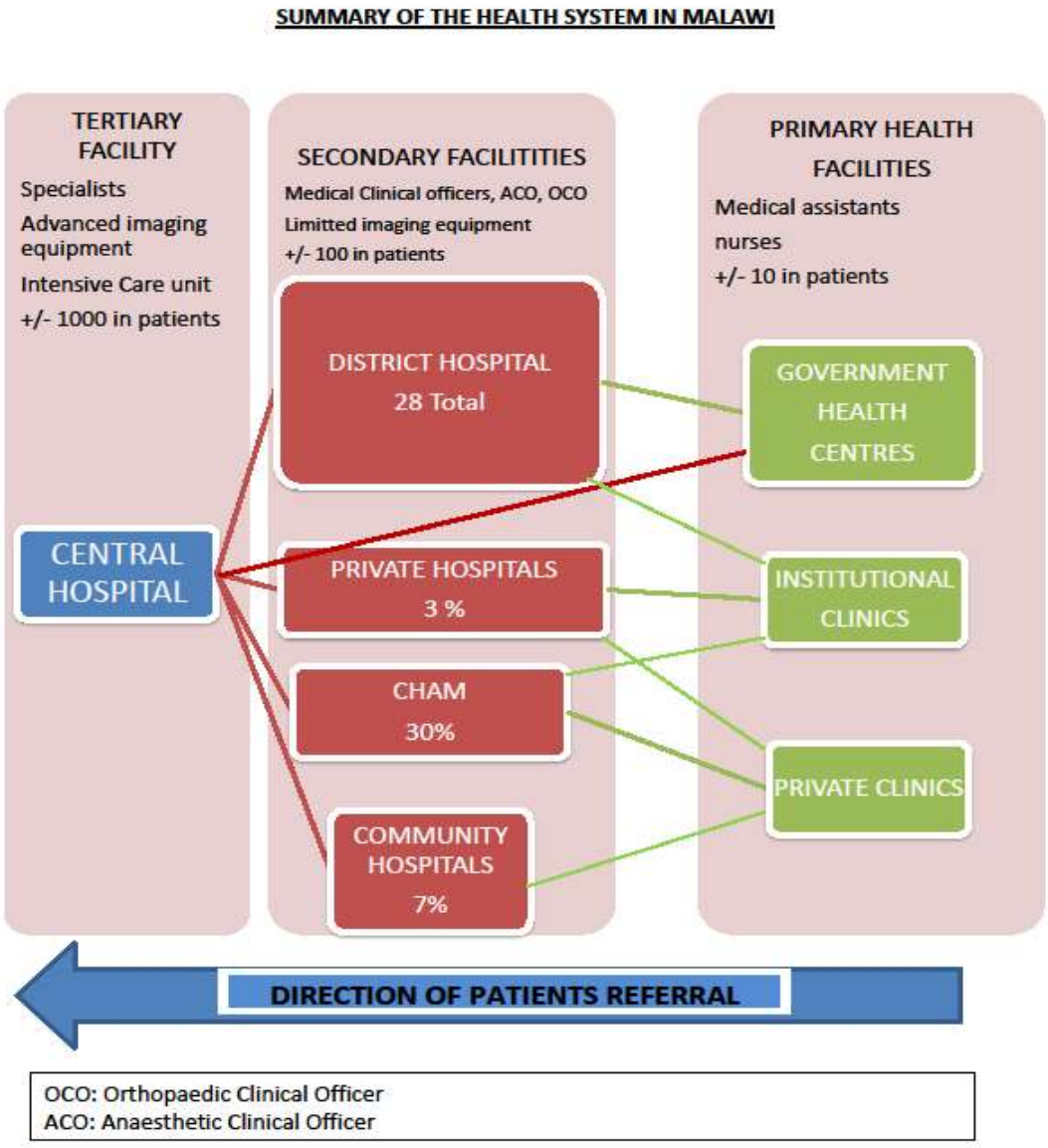


Fig 1: Tertiary centres/Central hospitals get referrals from secondary/district hospitals, which receives patients referred from primary-health centres

1.4 Surgery capacity building in Malawi

Malawi has very few trained surgeons across all the surgical disciplines. The training for surgeons in Malawi is provided by the University of Malawi College of Medicine, or under the umbrella of the College of Surgeons of East, Central and Southern Africa (COSECSA), which is a collaboration of 14 member countries. With a Malawian population of close to 18 million, there is a need for many surgeons, and meeting this need is challenging. There are approximately 70 surgeons across the country. There are about 900 doctors, total, in Malawi. Only 11% of these are specialised in different disciplines, and only 8% are surgeons. As there are very few surgical specialists in the country, most surgical care is provided by clinical officers who have undergone different specialist training programmes. General clinical officers have three years training across all four major disciplines of medical training (internal medicine, paediatrics, surgery, and obstetrics and gynaecology), while Orthopaedic clinical officers have 18 months of orthopaedic training. Anaesthetic clinical officers also have 18 months of clinical anaesthesia training [33, 38]. General clinical officers are deployed in different sections based on the human resource needs for the given hospital. This results in a competency a challenge because of the different levels of expertise each has, depending on their number of years of clinical experience. In some district hospitals, medical officers (DHOs and DMOs) are overwhelmed with administrative responsibilities, therefore most of the clinical work including surgical work is performed by the clinical officers.

Due to the human resource challenges for surgery and anaesthesia in Malawi, these non-physician surgical and anaesthetic providers mostly provide services in the district hospitals and some also work in the central hospitals [1, 33, 34, 38].

In order to increase the medical human resource capacity for Malawi, the Malawi College of Medicine has recently introduced a Bachelor degree that runs for four years. It offers training in surgery, orthopaedic, anaesthesia as well as some other fields of medicine.

Specialty	Available numbers
General surgeons (central hospitals only)	45
Orthopaedic surgeons (central hospitals only)	7
Paediatric surgeons (central hospitals only)	5
Dental surgeons (central hospitals only)	2
Neuro-surgeons (central hospitals only)	3
Plastic surgeons (central hospitals only)	4
Urology surgeons (central hospitals only)	1
Ear Nose and Throat surgeons (central hospitals only)	3
Total surgical specialists	**70**
Orthopaedic clinical officers (OCOs)	149
(District hospitals and central hospitals)	
Surgical clinical officers	
(district hospitals, community hospitals and central hospitals)	36

Table 1: Surgery workforce in Malawi [23, 25, 33, 39]

***0,38 Surgical specialists / 100 000 population** (70 surgeons for 18,4 million total population)*
***1,4 Surgical providers / 100 000 population** (255 surgical providers for 18,4 million total population)*

In comparison with other African countries in the COSECSA region, the surgical workforce in Malawi is considerably lower. Although there has been a small increase from 41 to 70 in the past 4 years (Table 1), the ratio per 100 000 populations remains the same, 0,41. The recent staffing increase has been due to the capacity building surgical training mostly supported by a NORHED program on capacity building and research. The number of surgeons is expected to continue to increase over the next 5 years through the continuation of the support from this capacity-building programme.

Country	Population	Surgeons	Ratio	Surgeons per 100 000
Burundi	10 395 931	19	547 154	0,18
Ethiopia	96 633 458	337	286 746	0,35
Kenya	45 010 056	543	82 891	1,21
Malawi	17 377 468	41	423 841	0,24
Mozambique	24 692 144	57	433 196	0,23
Rwanda	12 337 138	49	251 778	0,40
Tanzania	49 639 138	177	280,447	0,36
Uganda	35 918 915	259	138 683	0,72
Zambia	14 638 505	85	172 218	0,58
Zimbabwe	13 771 721	123	111 965	0,89
Total	320 414 474	1 690		
Regional surgeon :	**Population ratio**		189 594	
Regional surgeons per	**100 000 population**		0,53	

Table 2: Surgical workforce in east, central and southern African countries [25, 40]

There are 1 690 practicing surgeons in the COSECSA region, representing a ratio of 0,53 surgeons per 100 000 population. A majority of these surgeons (64%) practice in the main commercial cities of their countries, and just 9 % of the surgeons are

females. From this, we can extrapolate to see that the rural hospitals or district hospitals have, in general, a low surgical workforce [25].

Malawi is third lowest compared to other countries in the east, central and southern region of Africa (Table 2). It follows Mozambique and Burundi. The low number of qualified surgical experts definitely affects the surgical services for the country and therefore the low surgical volume.

In addition, there are very few female surgeons in the region including Malawi (Table 3) [25].

Country	Male		Female		Total
Burundi	19	100 %	0	0 %	19
Ethiopia	322	96 %	15	4 %	337
Kenya	499	92 %	44	8 %	543
Malawi	36	88 %	5	12 %	41
Mozambique	48	84 %	9	16 %	57
Rwanda	44	90 %	5	10 %	49
Tanzania	156	88 %	21	12 %	177
Uganda	228	88 %	31	12 %	259
Zambia	69	81 %	16	19 %	85
Zimbabwe	114	93 %	9	7 %	123
Total	1535	91 %	155	9 %	1690

Table 3: Gender distribution of surgeons in COSECSA region [25]

1.5 Economy and development in Malawi

Malawi is a low-income country. Its literacy rates are 73% and 59% for males and females respectively, above the age of 15 years [41]. The level of education achieved is 59% for primary education, 19% for secondary education and 1,4% for tertiary education. The population is 41% male and 59 % female, and has a combined life expectancy at birth of 64 years [24, 42]. The GDP per capita is one of the lowest in the world at $327 in 2018 [42]. The economy grew by 4,4% in 2019 from 3,5% in 2018 [43]. A large population of people in Malawi (pics 6 - 9) depend on subsistence agricultural farming (38%), and 30% of the population is unemployed.

Pic 6: A local subsistence farmer working in a maize field in Mchinji (Central region). Maize is the staple food for Malawi (Porridge meal) and people grow it for both personal consumption and selling for financial support.

Pic 7: Goat farming on a small-scale farm in Salima District (Central region). Animal farming is done for mostly selling of the meat product for financial support

Pic 8: Harvested maize crop being prepared for storage in Ntcheu District

(Photos (5-8): Carlos Varela)

The economy of Malawi is highly dependent on agriculture, which contributes 35% to the Gross Domestic Product (GDP). The projected GDP growth for 2020 was estimated to be 4,8% in September 2019 due to the expectation of a strong agriculture harvest [43]. The agriculture sector has two categories; These are the estate agriculture sector and a smallholder sector, with the latter accounting for 60% of the GDP due to agriculture [44].

Pic 9: Tea estate commercial farming in Luchenza district (Southern Malawi). Tea farming estates provide source of employment to the local people surrounding the tea farms. Most of the tea is produced for export purposes

(Photo: Carlos Varela)

Table 4	Malawi	SSA	(as at)
GDP			
GDP (current billions of US$)	6,3	1 529	2017 (Est.)
Exchange rate (per US$, end-period)	725		
Income			
GDP per capita (current US$)	327	1 582	2017 (est.)
GNI index (World Bank estimates)	46,1		
Population			
Population, total (millions)	18,1	1 033	2016
Population aged 65 and above (% of total)	3,4	3,1	2015
Life expectancy at birth, total (years)	64,0	59,0	2015
Education			
Literacy rate, adult females (% of females aged 15 and above)	59,0	53,0	2010
Literacy rate, adult males (% of males aged 15 and above)	73,0	69,2	2010
School enrolment primary (% net)	97,5	77,9	2014
School enrolment primary, female (% net)	95,3	75,8	2014
School enrolment primary, male (% gross)	1 440	102,0	2014

Table 4 cont.	Malawi	SSA	(as at)
Health			
Mortality rate, under 5 (per 1 000 live births)	64,0	83,2	2015
Mortality rate, infant (per 1 000 live births)	43,4	56,4	2015
Nurses and midwives (per 1 000 people)	0,3	1,1	2011
Maternal mortality ratio (national estimates, per 100 000 live births)	570,0		
Poverty			
Poverty headcount ratio at national poverty lines (% of population)	50,7		
Poverty headcount ratio at $1,90 a day (2011 PPP) (% of population)	70,9	41,0	2013
Poverty headcount ratio at $3,10 a day (2011 PPP) (% of population	87,6	65,0	2013
Public Expenditure			
Health expenditure, public (% of GDP)	6,0	2,3	2014
Current education expenditure, total (% of total expenditure in public institutions)	98,8	90,6	2010

Sources: IMF staff estimates. The World Bank WDI database, and Malawi authorities
[45]

Table 4: Malawi human development indicators – SSA comparison

**Department, I.M.F.A., Kenya: Request for a Three-Year Arrangement under the Extended Credit Facility-Staff Report; Press Release on the Executive Board Discussion; and Statement by the Executive Director for Kenya. 2011: International Monetary Fund (IMF)* [42, 45].

This poor economic situation affects the health sector. There are inadequate human resources, badly equipped health facilities and insufficient hospital supplies. The

surgical volume in Malawi fails to reach international standard levels. The indicators for development for Malawi are summarised in Table 4, where they are compared to the SSA region. Poverty head count is greater in Malawi than in other countries in the SSA region, but there is a slightly higher literacy level in this region. (Table 4)

2. RATIONALE FOR THE STUDY

Surgical disease is inadequately addressed globally, in LMICs and in sub-Sahara Africa in particular, including Malawi. Surgical emergencies contribute substantially to the global burden of disease. Despite efforts to reduce the global burden of disease, two billion people, namely those living below the poverty line in low- and middle-income countries, continue to lack access to surgical care [46]. Minutes and hours of delay before treatment to people requiring emergency or elective surgery have a profound impact on their ultimate potential disability and chances of survival. This may lead to loss of lives and high disability may affect productivity and low economic development due to DALYs to many people living in rural communities.

The rates of major surgical operations from countries with published data, range from 148 per 100 000 persons per year in LMICs to 23 369 per 100 000 persons per year in high-income countries. The situation may actually be worse in Malawi as there is a gap in data collected on surgery and unmet surgical needs [47].

Over the years in Malawi, clinical experience shows that the surgical volume (SV) is low, indicating that there are many people requiring surgical procedures across the country who are not getting access. There are also disabled people as a result of non-accessibility to surgical care. Most of the disabilities are in children who grow up in the communities, and only half of these disabled children are able to function independently from help from others. There are many barriers that prevent people from getting to facilities that can offer timely surgical interventions and prevent disability and loss of lives. Most of the deaths do not take place in a health care facility that provides surgical intervention services. In order to overcome these

experiences and improve on the general surgical care, there is need for reliable data about the situation.

This thesis is focused on describing the burden of surgical diseases among adults and children in Malawi. It is based on a study where data was collected detailing untreated surgical conditions as well as trauma, which are associated with poor outcome – disability and mortality, as well as on the transportation barriers that hinder timely presentation to health facilities in Malawi.

The information in this thesis fills a knowledge gap in Malawi and can be used to inform policy- and decision makers at the Malawian Ministry of Health, to improve Malawi's National Surgical, Anaesthesia, Obstetrics and Gynaecology Strategic Plan. It provides evidence to support capacity building in this area, such as strengthening of surgical services at district hospitals including training of surgery service providers, and for improving the referral system to help overcome the burden of disease and disability, thereby reducing deaths and disability from surgical conditions in the country.

3. STUDY AIMS AND OBJECTIVES

3.1 AIM OF THE STUDY

The main aim of this thesis was to obtain information about the surgical conditions in adults and children in the Malawian population.

3.2 SPECIFIC OBJECTIVES

-To estimate the burden of surgical diseases by quantifying the untreated adult and childrens surgical conditions including trauma and associated disability among children in Malawi. (Paper I and II)

-To investigate and describe factors affecting travel to health facilities for medical and surgical care through transportation barriers in Malawi (paper III)

-To outline the causes and place of deaths from surgical conditions in Malawi (paper IV)

4. METHODS

The organisation of the study included field work for data collection. This involved a team of data collectors that I personally was in charge of and supervised. We travelled through the entire country of Malawi, except one district, which is an island on the Lake Malawi. Mobility into the remote villages and communities was very challenging and in some places in included hiring push pedal bicycles or even motor cycle taxis because the roads were not passable by vehicles. The data collection was done in July and August of 2016. We worked every day and the collection lasted the entire day. In some circumstances we had to travel at night to find places for accommodation as the communities did not have private lodging places.

The major financial support for fuel, hiring of bicycles and accommodation as we travelled though the country was undertaken by the Norwegian government through the NORHED project on capacity building and research in Malawi, collaborating with the College of medicine, a medical school under University of Malawi.

4.1 STUDY DESIGN

This thesis builds on four publications. The study design for all of them employed multi-stage, clustered, probability sampling with systematic sampling of participants at the household level, and used the SOSAS tool for data collection. These publications were all cross-sectional studies, performed as part of a larger study, conducted at the national level.

Sample size was estimated based on the findings of the pilot study. This estimated the level of untreated surgical conditions to be 25%, based on the reports from other African countries that had carried out similar studies [10, 48, 49].

The pilot study was conducted in 2015 prior to the main survey. It was carried out in the rural environment of Lilongwe city, the capital of Malawi, with a population of approximately 3.2 million people.

The sample size was estimated to be 1487 households, and the sample size of individuals was estimated to be 2994. The actual number of visited households in the study ended up with 1487, and 2960 people were interviewed. Two to four households were randomly selected, and 2 household members were also randomly selected for interviews using computer generated random numbers assigned to household members depending on the number of individuals per household.

Paper title	Objective	Households Visited	Individuals interviewed (Analysed data)	Analytical techniques
1: Untreated surgical conditions in Malawi	To estimate the burden of surgical conditions in Malawi	1 487* Analysed 1 448 household (39 missing data)	2 960 interviewed Analysed data from 2 909 individuals (51 missing data)	Univariate statistics Multivariate statistics Pearson`s Chi-square test Mann-Whitney U test t-test
2: Paediatric surgical conditions in Malawi	To estimate the burden of surgical diseases and disability in Malawian children	1 487 (no missing data on children)	2 960 interviewed Analysed data from 510 children (255 alive and 255 deceased children	Descriptive statistics (Frequency and percentages)
3: Transportation barriers to access health care for surgical conditions in Malawi	To describe factors affecting access to surgical health care: Transportation, finances and travel time	1 487 Analysed 1479 households (8 dropped because of inadequate data	2 960 interviewed Analysed data from 2 958 individuals (2 missing data)	Univariate statistics Multivariate logistic regression Pearson`s Chi-square test t-test Mann-Whitney U test
4: Deaths from surgical conditions in Malawi	Outline the causes and location of deaths from surgical conditions in Malawi	1 487* Analysed 1479 households (8 dropped - missing data)	2 909 interviewed on household deaths (616 died) Analysed 558 (58 missing data)	Pearson`s Chi-square test

Table 5: Summary of the methods used for the papers included in this thesis

**Article print errors: errors were typos prior to submission for publication*

Paper 1 (Untreated surgical conditions in Malawi): Number of households is 1 480 instead of 1 487

Paper 4 (Deaths from surgical conditions in Malawi): Number of households is 1 497 instead of 1 487

4.2 DATA COLLECTION TOOL

Surgeons OverSeas (SOS), founded in 2007, is an organisation with a mission to save lives in developing countries by improving surgical care. SOS has three programme arms: Research, direct interventions and missions, and advocacy. SOS developed the tool Surgeons Overseas Assessment of Surgical Need (SOSAS) I used in my studies. The SOS vision is to decrease the deaths and disability from surgically treatable conditions to enable LMIC to approach the rates found in developed countries. It also aims to be recognised as a global leader in improving surgical care in developing countries. The mission statements are; SOS saves lives in developing countries by improving surgical care and achieves this through collaborative training, funding and research initiatives [*(SOS annual report 2014*) www.surgeonsoverseas.org].

A draft version of SOSAS was developed by combining elements of the World Health Organisation (WHO) guidelines for conducting community surveys on injuries and violence [50], demographic health surveys [51], and a survey on road traffic incidents [52]. It also included additional items on maternal, congenital, neoplastic, and infectious surgical conditions. SOSAS has been validated and used in other LMICs countries such as Sierra Leone, Nepal, India,[53] Uganda, Rwanda, Nigeria and Cameroon. It has been shown to be a useful tool for surveys [10, 13, 14, 16-18, 48, 49, 54-65].

In Malawi, a pilot study was followed by a national survey. The SOSAS tool used for data collection had two sections. The questionnaire was installed on I-Pads, Apple Inc. using File maker Pro 12.0v3. The first section captured information of type and location of the household, number of members per household, level of education, and the number of deaths that occurred in the household in the prior 12 months. The second section had two parts that were similar and that were used for two different people. These questions in this section captured individual information from these two people within one household concerning; the present symptoms; acquired or congenital, that could be treated by surgical consultation or operative procedure in adults and children, associated disability in children; the cause of death of the

household member (if the person died); location of the death occurrence; type of health care sought (Herbal, or health centre); type of health facility; the approximation of time it took them to travel to the health facility; as well as mode of transport. This questionnaire also captured information about the surgical symptoms that the patient had at the time of interview, including body region location, type of occupation, availability of funds and cost for travelling to health facility, and type of care received while at the health facility for their present condition. Inquiries about the loss of a family member focused only on the previous 12 months, and transport to health facility inquiry focused on the previous 6 months. Questions relating to the availability of financial resources for transportation and mode of transport were also for the previous 6 months for any family member who was unwell.

4.3 DATA COLLECTION

Pic 10: Data collectors backing up the information into a cloud data base

(Photo: Carlos Varela)

Data collection was done by medical students at the end of their third year block on their long break from medical training. It lasted for 8 weeks. There were 31 data collectors spread in two phases of 15 and 16 for the first and second phase respectively. Gender balance was equal for the data collectors. Upon arrival at each district, the district commissioners` (DC) office was approached and permission was sought and granted. Two representatives from the DC`s office accompanied the team for the direction and location of the identified randomised villages i.e. enumeration areas for the data collection. Some places were not reachable by vehicle due to terrain and poor access from roads, so hired motorbikes and pedal-push bicycle taxis were used by individual data collectors to reach the villages.

When the data collectors reached the villages, they asked for the village head-man`s house (Village chief), where they sought permission to go around visiting the households in the village for the interviews.

The questionnaire was translated into the local language, Chichewa. In some areas where there were people with unique languages or dialects, language translators were engaged to secure good communication and interpretation for the interviewer`s and interviewee`s understanding.

Two to four households were visited depending on the size of the village. In larger villages (with more than 10 households), 4 household were visited, while in smaller villages (less than 10 households) 2 households were visited. From the chief`s house, the data collectors used the "floor bottle spin technique" for randomly selecting the direction to start from. In smaller villages, the 3rd or 4th house was first chosen after the bottle spin direction, and then the process was repeated for the following household. In large villages, after the first and second households, a third and fourth household was subsequently selected in the same pattern and was visited for an interview. When they reached the household, the data collectors introduced themselves to the household head and obtained consent to proceed with the interviews.

Pic 11: Data collection by interviewing the head of the household (Female head in this case)

(Photo: Carlos Varela)

4.4 STUDY SITES

Data was collected from all the districts in Malawi except one, as it is an island on Lake Malawi and is difficult to reach. Malawi has three geographic regions; north, central and south, with 28 districts in total.

The national statistics office provided list of all the settlements in the country. There are 48 233 registered settlements according to the 2008 Malawi population and housing census [66]. Areas for data collection were selected using computer generated random numbers.

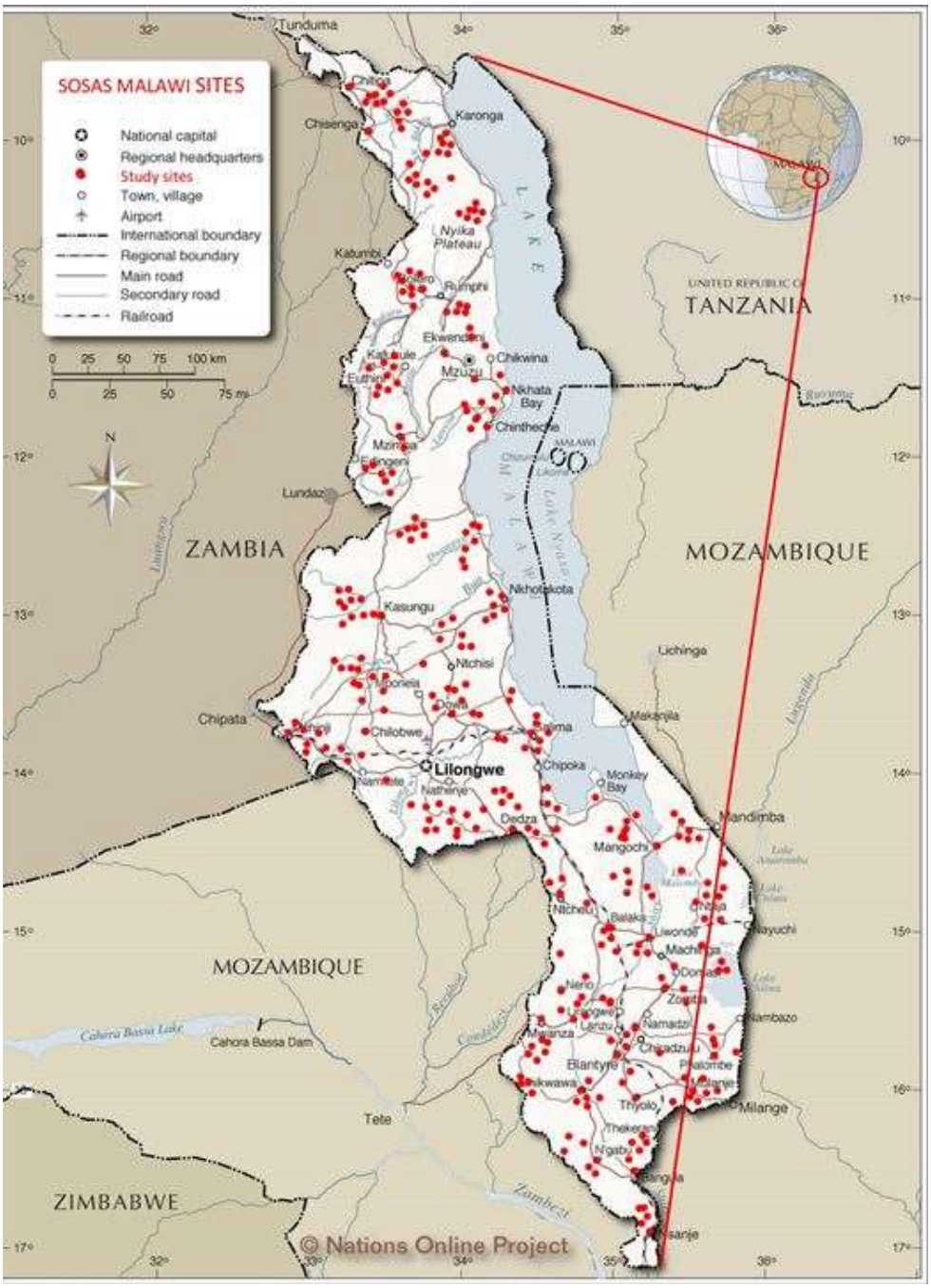


Fig 2: Red dots represent all the sites/enumeration areas visited for data collection (July – August 2016) [67, 68]

4.5 DATA MANAGEMENT AND ANALYSIS

Data was exported from the data collecting gadgets to an Excel data base every day for the entire data collection period. To ensure data security and quality, the data was backed up in cloud storage using a wireless internet connection. .

Data analysis was done using STATA and SPSS. Descriptive statistics with frequencies were calculated. Pearson`s Chi square tests, t-tests and Mann-Whitney U-tests were used for comparing groups. Associations were evaluated by Univariate and multivariate logistic regression models.

4.6 ETHICS

The study was approved by the Malawi College of Medicine Research Ethics Committee and the Norwegian Regional Research Ethics Committee. Consent and assent forms were translated into local languages and were used to ensure informed consent prior to the interviews.

5 RESULTS AND SUMMARIES OF PAPERS

5.1 Paper I:

Untreated Surgical Conditions in Malawi
A randomised cross-sectional nationwide household survey

Data were analysed from 1 448 households in Malawi, with 2 960 interviewed individuals. The findings showed that 35% of the interviewed people reported living with a condition that could be treated by either surgical consultation or surgical procedure. Among the health conditions described, having a solid mass (growth or swelling), was predominant (13,6%), and congenital birth defects and injury wounds were also very common, 4,3% and 11,5%, respectively. It also showed that 24% of the total deaths reported to having occurred in the preceding 12 months were associated with a surgical condition.

A woman with deformed 5th finger of left hand from injury (Cover page pic)
Surgery would have helped correction of the deformity hence contributed to restoring full functional capability of the hand

Of those who reported a surgical condition, only 3.1% had surgical intervention.

This study indicates that a third of the Malawian population is living with a surgically correctable condition. Urgent scale up of surgical services is needed to reduce this gap in Malawi's Public Health Plan.

5.2 Paper II:

Paediatric Surgical Conditions in Malawi
A cross-sectional nation-wide survey

The data set included information about 510 children, 255 of these were alive at the survey and 255 had died in the prior 12 months.

Living children

The information obtained from living children showed that 26,3% (67 children) were living with a surgically collectable condition, mainly conditions caused by injuries (13 of the 67). Traffic accidents were the cause of the injuries for eleven of the children. Two thirds of the children living with a surgical condition were disabled, with one third of them grossly disabled, and not able to function on their own without assistance.

An extrapolation from the findings of the study suggests that an estimated 2 million children are living with a surgically correctable condition in Malawi.

Cover page picture: A boy with club foot of the right leg
Surgery would have helped correction of the deformity hence improving the functional mobility of this boy

Children who had died

Out of the 255 children who had died the past 12 months, a surgical condition was the cause of death for 34 of them. Death was caused by congenital anomalies for 13 children and due to a mass/growth for 11 children.

5.3 Paper III

Transportation Barriers to Access Health Care for Surgical Conditions in Malawi.
A cross-sectional nation-wide household survey

The 2 448 participants (employable age group) in the study described three different types of transport to health facilities, including health centres, district hospitals and central hospitals.

This study showed that animal drawn carts were the most common form of transportation from home to health facilities, especially in the rural areas.

Cover page picture: Female patient waiting for transport to central hospital. An ambualance has broken down and this has for a long time affected travel for patients to get health care (Photo: Asgaut Viste)

Pic 12: Donkey pulled car transporting patient transporting a patient to a health facility – a xommon mode of transport in rural Malawi (Photo: Asgaut Viste)

Travel to district hospitals and referral hospitals was mostly by paid public transport, 31,5% and 43,4% respectively. Travel time to a central hospital was 1 – 2,5 hours.

The data showed a gender difference, whereby women tended to have lower financial resources for going to a hospital than men. Fifty nine percent of female and 39% of male heads of the households reported lacking financial resources to go to a hospital for care.

The most important study finding was that there were delays or cases of untimely presentation to health facilities that could provide surgical services.

5.4 Paper IV:

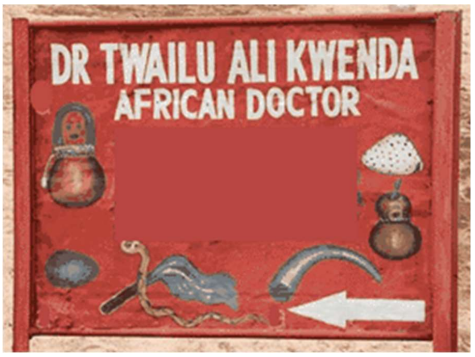
Deaths from Surgical Condition in Malawi
A randomised cross section nation-wide survey

Surgical conditions accounted for 26,9% of the deaths in 558 analysed people. Most of these deaths did not take place in a health facility. Body mass or swelling (24,3 %), trauma and acute abdominal distension (21,5 and 18% respectively) were the most common causes of death associated with surgically oriented symptoms.

Of these deaths, 55,3% occurred outside a healthy facility, and 12,9% of the persons with a possible surgical condition initially visited a traditional healer before their death occurred.

Out of the people who died, only 21,3% received surgical health care.
In this study, there were 12 women who died from complications associated with child birth.

Cover page picture: Died from road traffic accident.



P*ic13: Advert for traditional herbalist*

(Photo: Carlos Varela)

Delays in accessing care at a health facility were due to patients initially consulting a traditional herbalist.

6. DISCUSSION

6.1 MAIN FINDINGS

This study indicates that a third of the Malawian population is living with a surgical condition that could either be treated through a surgical consultation, or procedure. Many children who live with a surgical condition have a disability seriously affecting their daily lives. Transportation poses a barrier to timely access to surgical health care. A large proportion of deaths from possible surgical conditions occur outside a healthy facility.

6.1.1 Surgical conditions among adults

Surgical conditions represent a significant proportion of admissions in both high-income and LMIC hospitals [69, 70] . Many LMICs face multiple burdens of maternal diseases, neonatal and childhood diseases, non-communicable diseases, and trauma. Surgical care is essential for the management of many of these conditions. It represents an integral component of a functional health system. Surgically correctable conditions are highlighted as being a major contributor to the global burden of disease. Inaccessibility to surgical care has been shown to be a leading cause of death in the rural areas of LMICs, with most of the deaths occurring at home from acute abdominal conditions, obstetric complications, and trauma. In addition, the probability of death from non-communicable diseases is higher in low-income regions such as sub-Saharan Africa than in high-income regions such as those with established market economies [71-74]. The need for surgical services in LMICs is rising and will continue to rise substantially in the future. There is little documentation about the socio-economic effects of untreated surgical conditions, current levels of state of care, and potential strategies to scale-up surgical services.

In the present study we found that 35% of the analysed persons were living with an untreated surgical condition. This figure is much higher than that found in other low-income countries (Table 14). The Malawi figure is also higher than found in other LMICs studies with similar methods.

In Nepal, for example, the number of individuals requiring surgical care was 207 of the 2 695 surveyed individuals, 7,7% [18] in one study and 10% [54] in another study, where surgical care could have avoided 23% of the deaths. This study was a countrywide survey using the SOSAS tool and had a 97% response rate. This study looked at individuals, transportation access, and other reasons for not receiving surgical care. The reasons for not receiving surgical care were affordability, accessibility, and fear/no trust. In this study, only 15 out of 75 districts were sampled in the country and hence this might explain the low figure, as this method is likely to

give an underestimation of the actual proportion of individuals who did not receive surgical care [18].

In Sierra Leone, prior studies on untreated surgical conditions showed a prevalence of 25%, and death from surgical conditions was 25% respectively. This study also used the SOSAS tool, and was a cluster randomised, cross-sectional countrywide survey. The figures from this study are similar to the findings from our present study [75].

In Uganda another similar study, cross-sectional national-wide household survey using the SOSAS tool showed that 10,6% of the individuals reported a condition requiring a surgical consultation, and from the household deaths, 34,2% were associated with a surgically treatable symptom [17].

In Rwanda, the prevalence of untreated surgical conditions was 12%. The Rwandan study was a cross-sectional and sampled 30 villages, with 23 households. The same sampling methods were much similar to our Malawian study, but their study was only performed in a part of the country and this may have affected their results. Also the questions in the interview were different in the two studies. The difference may also be caused by a real difference in access to surgical care [76].

In all these studies from different LMICs such as Malawi, there was a range of 8% to 35% in the untreated surgical condition, while the range for the deaths from surgical conditions was narrower, 23% to 34%. The studies have similar reasons for inaccessibility to surgical care.

COUNTRY	Population	GDP/capita ($)	Untreated surgical conditions (Individuals living with a surgical condition)(%)	Mortality due to untreated surgical condition. (%)	**Ref.no**
Nepal	26,5 m	689	7,7	23	[49, 58]
Sierra Leone	6,3 m	808	25,0	25	[14, 75]
Uganda	34,6 m	726	10,6	34	[17, 65]
Rwanda	12,4 m	722	12,0	33	[57, 76]
Malawi	18,5 m	320	35,0	24	[68]

Table 6: Compared unmet surgical need and mortality in other African countries

Traumatic injuries account for 10% of mortality worldwide, but they are often ignored. They include 5 of the 25 leading causes of mortality (Road-traffic accidents, self-inflicted injuries, violence, drowning, and war) [74, 77-81]. In LMICs, such as those of south Asia and Africa, injury is one of the major causes of adult mortality and is a leading contributor to disability in most age groups. It accounts for 14% of all disability-adjusted life year (DALY) losses for the world`s population [11, 52, 82, 83]. The World Health Organisation and the World Bank projected that injury is most likely to account for 20% of all DALY losses for the world`s population in 2020, with road traffic accidents alone being the third-leading cause of DALY losses [82, 84, 85]. Road traffic, crash-related deaths, injury, and chronic disability continue to be a major burden worldwide for drivers, pedestrians and mass transit users in LMICs [72, 73, 86, 87].

An important health statistic is that around 5 billion people have no access to safe, affordable surgical care when they need it. Access is worst in LMICs, where 9 out of 10 people do not have access to basic surgical care [6]. In countries such as Malawi, injury often goes under-reported either because the data is not processed properly or because death occurs outside of any reporting agency. Statistical analyses in LMICs

suggest that every year there are 5 million injury-related deaths and another 30 million people who are rendered disabled [9, 88]. This means trauma ranks equal to AIDS, malaria and tuberculosis combined as a global health burden from a total morbidity perspective. This is the situation in Malawi where infectious diseases are more prioritised than non-communicable conditions, for instance trauma.

6.1.2 Surgical conditions among children

The burden of surgically treatable diseases in children is high. Up to 15% of children have a surgically treatable condition by age 15 in LMICs [89, 90].A study that considered data from LMICs reported that nearly 20% of children had surgical needs, and that 62% of these children had at least one unmet surgical need. This extrapolates to an estimated 3,7 million children in need of surgical care in this region [90]. In a study for paediatric surgical need, Sierra Leone, reported 27,5% children with at least one surgical condition, with corresponding figures for other LMIC countries as follows: Nepal 17,6%, Uganda 17,1%, and Rwanda 11,8% [90]. Our study in Malawi showed 26,3% of living children having a surgically treatable condition (Ref paper on children). Our findings are similar to the findings in Sierra Leone. All these studies used the SOSAS tool for their data collection.

Trauma does not spare children at all, and a surgical condition including injuries has left most children disabled from lack of surgery. It is estimated that close to 2 million children in Malawi have a surgical condition and one-third of them have a disability (Varla C et al in press).

The burden is severely underestimated and the backlog for surgical delay for treating children with surgical conditions is high. Scaling up paediatric surgical capacity in LMICs is highly recommended [91]. Care for children with surgical conditions should be incorporated into National Surgical, Obstetric and Anaesthesia Plans in low-resource countries [92].

6.1.3 Transportation barriers

In most LMICs, people seeking health care often have to pay indirectly or directly to the service provider. The indirect fees may have to do with transportation costs to the health service provider, while direct costs are the ones needed for the health service itself. The expenses are typically borne by the health service seeker and are not subsidised or reimbursed by the state or any insurance scheme due to the fact that most people do not belong to any such schemes [93-96].

This is also the situation in Malawi with many people not belonging to medical insurance schemes. Thus indirect and direct costs may be a sufficient deterrent to people who are unable to afford care even if they have compelling reasons to seek such care [97].

In Malawi another indirect cost is the potential lack of qualified medical personnel at local health facilities or community hospitals, making it necessary for patients travel even longer distances to obtain the surgical care, ensuing higher costs and longer delays in presenting for treatment [22]. The burden of surgical conditions in Malawi, as with other LMICs, is considerable and represents a sizable workload, coupled with poor remuneration and untimely emigration of surgeons and allied health professionals to other countries. This presents significant challenges to any improvements in the delivery of surgical health services.

Both communicable and non-communicable diseases including trauma contribute significantly to the current health problems in Malawi. A third of Malawian people in the rural areas are living with a surgically correctable condition [24]. There are a variety of reasons, including finances, transportation barriers, social and cultural barriers, stigma and traditional beliefs about disease processes, that are preventing people from seeking surgical care. Because of the long distances and other transportation barriers, some people seek health care from traditional herbalists, which further delays facility presentation [22, 67]. Primary Health Care (PHC) has prioritised addressing the great killers (malaria, pneumonia, diarrhoea, and HIV/AIDS complications) in both children and adults in Malawi. However surgically

treatable diseases and conditions such as trauma, surgical emergencies and obstetric complications are increasingly emerging as an integral and necessary part of public health and health system development worldwide and in Malawi specifically [98]. This needs to be included in the national PHC strategy. The numbers alone underline that surgical care is an intrinsic and vital part of public health. In Malawi, 26% of total deaths are associated with surgical care (or lack of appropriate surgical care), (45.9 % under the age of 18 and 33.9 % under the age of 5 years respectively [67]. In addition, trauma from road accidents also plays a major role as a cause of fatalities. With ever-increasing levels of road traffic, the number of accidents, and the seriousness of the accidents have multiplied in the last few years.

6.1.4 Improving surgical care in Malawi

The present study indicates that there are unmet surgical needs in the population of Malawi. The numbers of qualified health workers in Malawi is slowly increasing, but the growth rate seems insufficient to meet the demands of its growing population [99-101]. Twenty-five Sub-Saharan countries utilise non-physician clinicians to perform minor surgical procedures to fill in the gap in man-power [102-110]. Malawi is no exception. Here, most district hospitals do not have specialist surgeons. As a result, non-physician surgical providers (clinical officers and anaesthetic clinical officers) form the backbone of Malawi`s surgical and anaesthetic workforce. This is non-sustainable and these staff should receive qualified support and/or training. These non-physician surgical providers take care of the majority of patients requiring surgical services [35, 111, 112]. When Malawi's surgery training program was established, the data show that the adjusted injury-associated mortality decreased each year, indicating that the program probably improved trauma-associated outcomes in Malawi [23, 25, 38, 39, 113, 114]. District hospitals and community hospitals should be empowered with adequately trained personnel, infrastructure and resources in order to be capable of treating trauma and other surgical emergencies to reduce the deaths from surgical conditions. Most surgical procedures undertaken at

district hospitals include non-complicated hernias, obstetric procedures, and some emergency cases, which may not require sophisticated equipment. It is therefore feasible to establish minimal surgical services in rural areas of developing countries by utilising simple facilities, with basic equipment and on-job training of surgical service providers. This is really the only realistic possibility for providing surgical care to rural populations of the world's least developed countries at the primary or secondary health facility level [115-120].

Another challenge with the surgical workforce is the distribution of surgical providers. In Malawi, most trained surgeons are concentrated in central hospitals and specialist referral centres. These are inaccessible to patients who are unable or unwilling to travel due to travel distance or financial constraints [22, 95, 121]. This creates an imbalance of surgical services between urban centres and rural hospitals. It often results in patients reaching the facility at a relatively advanced state of the disease when the curative window has passed. For example, in Uganda 77% of patients with breast cancer presented at a referral centre with advanced stage compared with a much smaller fraction in high-income countries [122, 123].

In Malawi, because most experienced surgeons are located in referral centres leaving district hospitals without qualified surgeons, there is a skewed distribution that is seen in the number of referrals that are sent to the central hospitals for surgical care from district hospitals. For example, the majority of clinicians from district hospitals send patients requiring surgical procedures such as laparotomies for trauma, or abdominal emergencies, fracture management, and some obstetric surgical management.

Some facilities attempt to meet the demand for surgical services by establishing routine surgical camps conducted by teams from the referral centres. These camps have helped with surgical service provision and capacity building by training the rural hospital staff to be able to perform many of the most common procedures.

In Uganda, the surgical association (ASOU) conducted similar camps to alleviate the backlog of surgical diseases requiring surgical procedures at different facilities. They

trained local medical officers, clinical officers, and health care personnel during these camps [106].

6.2 METHOD DISCUSSION

6.2.1 Study design

This study was cross-sectional, including the whole country of Malawi. This design gives limitations in the results when it comes to causal conclusions but is sufficient to give a description of the situation of the country as a whole. This design was chosen to be able to have a survey of the whole country of Malawi, as I is hoped that the results can be applied o policy decisions affect he national health plans.

The randomisation processes in this study were performed systematically. This was possible as each district is organised under several major chiefs labelled as traditional authorities (TAs). The TAs are responsible for several village chiefs who report to them. In the study, randomisation of these districts TAs was performed and then the villages under these TAs were randomly chosen as well. From the randomised villages, households were then visited using another randomisation starting from the first house, which was the chief`s house. This random house selection was done by spinning a glass bottle on the floor to determine the direction of movement in the village. These methods make the study reliable and the results are likely representative of the country as a whole.

We had good coordination starting from the district commissioner/ district chief executive officer for each district that accepted and allowed us to collect data in their districts. Locating the villages was guided by the officers working at the district commissioner's offices, as they had better knowledge of the location of the villages. The task of moving into these villages was simplified for us as they shared their knowledge of the access routes to some very remote, difficult to access areas.

One of the challenges during data collection was the recall bias by the interviewees. Information was requested for the previous 12 month period. It was thus possible that some did not remember all the details. Also, some may have felt uncomfortable disclosing too much information about the loss of a family member. We do not know the extent to which this might have affected the study results.

One way to reduce information bias, especially on the cause of death, would be to have access to the death certificates of the deceased to ensure actual cause of death. In Malawi, this information is not readily available in the rural communities. We had to rely on verbal autopsy information, which may not be entirely accurate. In future studies we hope that the National Registration Bureau will be able to provide this information for the rural areas.

Though interpreters were used to bridge any language barriers, it is possible that there were misunderstandings because some surgical conditions bear different names in the different local languages, and these sometimes may mean totally different things in other languages.

6.2.2 Study population

One of the major strengths of this study was the sample size. It was large enough to well represent the population as the study fulfilled the requirement for the statistical sample size calculations made before the study started. Also, the response rate was high. Only 7 out of 1487 households refused to be interviewed. The people who refused claimed they did not see the relevance of being interviewed without getting any handouts in return. This number was very low, and is not likely to interfere much with the results of the study. Another advantage of the study was that sampling was distributed all over the country of Malawi, making it representative of the whole country. Most of the people who were interviewed were located in the rural areas where there is the largest unmet need for health services, including surgical services. Most Malawian people live with very limited resources in rural areas. Most of them

live on less than $1 US per day. [17]. The sample size and data collection area represented the country`s 28 districts well, except for the one district, which was not visited because of the transportation challenge involved, as it is an island on lake Malawi and only has a commercial ferry across the lake to the island once a week.

The timing of the interviews during this period was challenging. Most people in rural Malawi depend on subsistence farming, thus July and August are the months when the farmers are preparing the field for the next growing season. For non-agricultural households, it was appropriate to catch the people in the communities before they left their homes for their gardens. For farming households, however, as most people prefer to work in the farms from early in the morning, efforts were made to catch them either in their fields, or later in the day after they returned home. We solved this by being flexible with the availability of the people at the households. In some cases we had to wait for one household member to go and alert the household head if she/he was not far away.

Sometimes the head of the household was away doing routine business for example at the market selling farm products only leaving children at home. In this case the household was still interviewed, but we picked the next person in charge to interview. It is possible that this may have affected the results.

While being fairly comprehensive in terms of the kind of data we collected, we found that there was still some missing data from the records, and this did not affect the findings of the current studies. This could be discussed and modified for future use of this tool.

6.2.3 Study tool

The tool that was used for the data collection was standardised and had been validated in other LMICs, including Sierra Leone, Uganda, Nepal, Nigeria, and

Rwanda. We therefore expected that using this tool would have high validity for our studies in Malawi.

One of the challenges with the tool is that it does not include clinical examination for the diagnoses. It relies solely on verbal information and the data collection depends on the information given by the respondents. This may have reduced the quality of the information about the diagnoses and made it necessary for us to simplify the results to large diagnostic groupings.

The SOSAS tool has been modified in other studies by including a physical exam component, which is carried out by trained physician. These trained physicians also take a picture using the data-collecting gadget to increase the certainty of the diagnosis [124-127]. This modification should be used in our next study or in similar studies in Malawi to help increase the certainty of the pathologies involved. However, this means that experienced physicians need to be involved with the physical examination of the interviewees to ensure that the diagnoses are correct.

6.2.4 Ethics and consent

It was necessary to get ethical clearance from the research ethics committee as a requirement to conduct any study in the country and per requirements from the two involved universities; University of Bergen and University of Malawi. It was also important to obtain consent from the participants as the data collected was personal and involved emotional memories especially when enquiring about any departed relatives.

We used different consent forms including assent forms for the minors. The seven household heads that refused to participate did not give their consent. The different reasons included; they had no time because they had to rush for other priority events, they did not see the need because there was nothing materialistic in exchange for them offering information, and they were not willing because previous interviewers for other topics never brought feedback that had benefitted the community.

6.2.5 Data collectors

Strength of the study was the well-trained data collectors. These people were familiar with local expressions used by the populations for the symptoms and signs of medical conditions. The data collectors underwent 2 training sessions. First was for 5 days prior to the pilot study, and the second for a week prior to the main survey. This gave the data collectors' confidence in their work and also clarified and reinforced aspects that may not have been clarified enough during the pilot study.

However, as Malawi has many different local languages, there were some areas where the data collecting personnel did not know the language. We therefore assigned helpers from the DCs office to help with language interpretation in each district whenever this was necessary. This may have influenced the results when it comes to the different diagnoses described, but we are unable to assess this. We did the best we could do during this study.

7. IMPLICATIONS AND RECOMMENDATIONS

7.1 Malawi surgical care

Although we did not study the surgical care facilities, we feel it is appropriate to give some recommendations based on the results from this study. These include:

Most district hospitals and community hospitals (mostly run by CHAM) have an infrastructure for performing surgical procedures. However, these are largely not functional due to lack of equipment and / or human resources. Therefore, a scaling up of surgical services and increased provision of surgical service personnel and equipment for these community hospitals and district hospitals could help fill the gaps in human resources and operating room resources in surgical health care.

Training of paediatric surgeons should be promoted to boost the human resources that can treat children with surgical conditions, both congenital and acquired from traumatic injuries thereby helping to rehabilitate disabled children.

Scheduled routine surgical camps and surgical specialist outreach services including anaesthesiologists in all districts at National level, and on job training of medical personnel can also help boost the surgical human resource capacity building for surgical care.

Improving transportation and rural road infrastructure from local health facilities to district hospitals and central hospitals can help people from the communities access timely health care. In most health centres in the rural areas, public ambulances are not available or non-functional due to poor maintenance, therefore these primary health facilities should be empowered with good public ambulances to bring patients to district hospitals for further medical attention. Introduction of routine patient buses that can ferry patients from district hospitals to referral centres and vice-versa once a week could help financially handicapped patients access to surgical care at referral centres.

These recommendations are in supportive of the sustainable development goal number 3, which promotes good healthy lives and well-being for all nations around the world.

7.2 Future research

A future research question within surgical needs assessment in Malawi could focus on the availability of resources providing surgical services at the different levels of health services, including community hospitals, district hospitals and central hospitals.

We would also like to do a follow-up on the untreated surgical conditions and transportation barriers after the implementation of the National Surgery, Obstetrics

and Anaesthesiology Strategic Plan by policy makers. Such reports to the Malawi Ministry of Health would help to evaluate if there has been improvement in surgical service provision thereby providing focus to future efforts to improve surgical health care in Malawi.

The findings in our Malawi study can help in comparing findings in the neighbouring countries on surgical needs and help in implementing strategies for improving health services in the region.

8. CONCLUSIONS

The study indicates that 1/3 of the total Malawian population is living with a condition that needs surgical consultation or intervention. There are approximately 2 million children living with a surgically correctable condition, and almost one-third of these children are disabled.

Lack of suitable transportation, financial constraints, and long travel times to health facilities pose barriers to timely access to health care and surgical health care provision.

Most of the deaths from a surgical condition occur outside a health facility. A quarter of all these deaths are potentially avoidable with surgical intervention and surgical procedure. Trauma and abdominal conditions are common causes of deaths from surgical conditions.

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Original Research

Untreated surgical conditions in Malawi: A randomised cross-sectional nationwide household survey

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Abstract

Background

Non-communicable diseases, such as surgical conditions have received little attention from public health planners in low income countries (LIC) like Malawi. Though increasingly recognised as a growing global health problem, the burden of surgical pathologies and access to surgical care has not been adequately identified in many LIC. Information on the spectrum and burden of surgical disease in Malawi is important to uncover the unmet need for surgery and for planning of the National Health Service.

Methods

This was a multistage random cluster sampling national survey. Households were selected from clusters using probability proportional to size method. 1448 households and 2909 interviewees were analysed. The Surgeons Overseas Assessment of Surgical need (SOSAS) tool was used to collect data. This electronic tablet based questionnaire tool included general information and a dual personalised head to toe inquiry on surgical conditions. The general information included number of household members, and inquired on any death within the past twelve months, and if any of the deaths in the family had a suspected surgical condition leading to that death. Data was collected by specially trained third year medical students.

Findings

Out of 1480 selected households, 1448 (98%) agreed to participate, with 2909 interviewed individuals included in the study. The median household size was 6 individuals (range 1 – 47). Median age of interviewed persons was 35 years (range 0.25 – 104 years). 1027 out of 2909 (35%) of the interviewed people reported to be living with a condition requiring surgical consultation or intervention, whereas 146 of 616 (24%) of the total deaths reported to have occurred in the preceding 12 months were reported to have died from a surgically related condition. Most individuals did not seek health care due to lack of funds for transportation to the health facility. Only 3.1% of those that reported a surgical condition had surgical intervention.

Interpretation

There is a large unmet need for surgical care in Malawi. A third of the population is living with a condition needing surgical consultation or intervention, and a quarter of all deaths are potentially avoidable with surgery. Urgent scale up of surgical services and training are needed to reduce this huge gap in public health planning in the country.

Introduction

Non-communicable diseases, including many surgical conditions, have been neglected for a long time in public health planning in low income countries[1]. Though surgical diseases and injuries are increasingly being recognized as a growing global health problem[1], the burden of these conditions has not been adequately described in most of Sub Saharan Africa. Some low income countries, including some African nations, have however carried out national surveys to describe the situation in their country, such as Nepal, Sierra Leone, Rwanda and Uganda[1, 2, 3, 4, 5, 6,7].

Many surgical conditions can lead to avoidable death if there is delay in seeking health care. Conditions such as incarcerated or strangulated hernias, bowel obstruction, appendicitis, peritonitis, congenital anomalies and some tumours can be treated surgically if identified and referred to a surgical facility early enough. Unfortunately, many of these conditions are neglected in low income countries, especially in the rural communities. Traumatic injuries, if neglected, can also cause significant delay in recovery, permanent disability or death. This can have a profound negative effect on a family's social and economic situation and even the economic development of the whole country[17].

The lack of data on the burden of surgical diseases and injuries in Malawi is a threat to effective health sector planning, and can perpetuate the current under funding of surgical services. The aim of this study was to estimate the burden of surgical conditions in Malawi.

Methods

Setting

Malawi is a low income country in South Eastern Africa with a population of 16.8 Million[7], and one of the lowest GDP per capita in the world at USD 294 in 2016[13]. Only 77 % of public service posts for health personnel are filled, with approximately 40 surgeons in total, of which 20% are in the private sector. With the lowest density of surgeons in the World, Malawi has 0.24 surgeons per 100,000[16]. It is estimated that the number of facilities with adequate staff to implement the WHO defined Essential health package (EHP) is 9.2 % of the total number of health facilities[7]. Malawi is divided into North, Central and Southern regions, with the majority (80%, 12.5 million) of the population living in rural areas[14]. The Central and Southern regions are the most densely populated with 6.4 and 6.8 million respectively and the Northern region the least densely populated region[14].

There are a total of 28 districts in the country, with a total number of 48,233 registered settlements i.e.; villages and towns. The majority of these settlements are rural communities dependent on subsistence farming and small

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scale businesses. 27 districts are on the mainland, while 1 district is an island on Lake Malawi.

Study design

This was a cross sectional multi stage national survey. The sample size was estimated to be 1497 households from a pilot study that was carried out in rural areas of the capital city, Lilongwe which estimated the combined untreated surgical conditions to be at 25%. The pilot study preceded the main survey by 5 months to validate the use of the SOSAS tool. The sample size for the individuals was estimated at 2994 individuals (95% CI) with a design effect of 1.5, at a 25 % prevalence of unmet surgical need.

The National statistics office provided the data on settlement areas from the Malawi Census Board for 2008 national census records with 48,233 recorded settlements. All the 48,233 settlements were randomised through computer generated random numbers using an Excel application, selecting 55 settlements as potential enumeration areas from each district on the mainland for this survey. From the selected 55 settlements from each of the districts, 16 per district were selected using probability proportion to size for sampling. Two or four households were randomly selected in each settlement depending on size. Two households were selected in a settlement with less than 10 households, while 4 households were selected in larger settlements, with more than 10 households. The household randomisation was based on a floor bottle spin and picking the fifth house in the direction of spin. Two household members were selected and interviewed per household, by first interviewing the senior member present, and then selecting another member at random using random numbers based on number of members in the household. When a member of the household under the age of 6 years was randomly selected, the actual information was given by their guardian. The total number of included households was 1448, with a total of 2909 people interviewed.

Survey instrument

The Surgeons Overseas Assessment of Surgical need tool (SOSAS) was used to collect data[1,2]. This is a questionnaire-based tool with three components. The first component outlines the general household information and demographics. The second part is a personalised interview, with specific questions on symptoms and findings from head to toe, of the same person who gave the general information. The third component involved a random second household member who was also interviewed on any current surgical conditions from head to toe. The questionnaire was installed on a tablet computer (iPad 2, Apple Inc.), using File Maker Pro 12.0v3 (File maker inc.USA) software. This electronic tablet was also used to capture visible surgical pathologies for certainty. The questionnaire was translated into 2 local languages; Chichewa and Tumbuka prior to installation on the tablet. The collected data was exported from the tablets into an Excel (Microsoft 2010) data base at the end of each day in the field for the entire period of data collection.

Data Collection

Data collection was done by medical students who had just finished their 3rd year and underwent tool training for 5 days as a refresher of the training for the pilot study. They all underwent ten days of training on how to use the questionnaire and computer tablet prior to the pilot study. There were in total 32 trained data collectors, with 16 interviewers in the field at a time. The period for data collection was from 1st July to 30th August 2016, and was spilt into 2 phases. The first phase involved half of the data collectors covering all identified enumeration sites in the northern part of the Central Region and the whole of Northern Region. While the second phase involved coverage of the rest of Central region and the Southern Region of the country. In some of the enumeration areas people belonged to smaller population groups with unique languages or dialects. In this case translators were hired to secure good communication. Each data collector was covering 1 or 2 settlements per day to interview 2 or 4 household depending on the size of the settlement; therefore 32 – 64 households were interviewed each day in total. This was confirmed by checking the number of entries at the end of the day for each of the individual data collectors. Random checking of the data entry forms was done at the end of each day to reassure quality of the data.

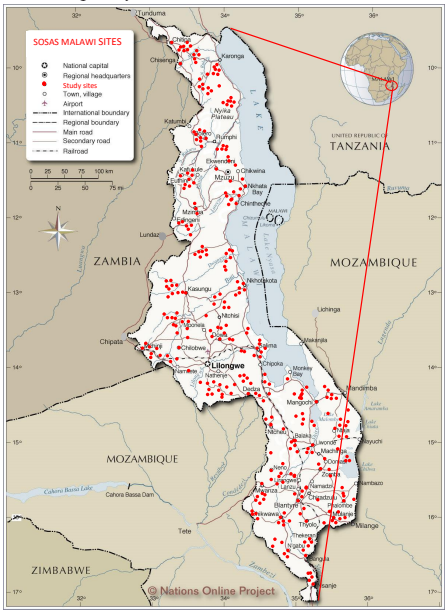

Fig 1 - Malawi map showing the areas from which the settlements were selected

Research ethics

The study was approved by the Malawi College of Medicine Research Ethics Committee (approval: P03/15/1696), and Norwegian Regional Research ethics committee (approval: 2016/1392/REK Vest). Consent and assent forms were translated into the local languages and used to seek informed consent prior to conducting the interviews.

Statistical analysis

Data analysis was done using STATA 13.1 (1985-2013 StataCorp LP, College Station, TX) and SPSS version 24. Analyses were done for univariate statistics and multivariate logistic regression model was also done to predict the untreated surgical conditions (Present surgical condition yes or no). Chi square tests were used for univariate associations for contingency tables. Normal distribution for data and skewness for data were checked by t-test and Mann-Whitney U test.

Funding

The authors got permission to use the SOSAS tool for no cost. The computer tablets were obtained with support from the Norhed programme for support of surgical training and research in Malawi (https://www.norad.no/en/front/funding/norhed/projects/capacity-building-in-postgraduate-surgical-training-and-research-in-malawi/) and were donated to the surgical department at KCH for use in further research. Costs for data collectors, fuel, meals and accommodation while travelling to the different areas throughout the country during data collection were covered by the same programme.

Results

The enumeration areas incorporated all the districts except for Likoma, which is an island where access is only by chartered plane or the once weekly ferry. Figure 1 shows the location of the areas from which the settlements were selected. This was provided by the national census board and was used for randomisation for the survey. The majority of households were rural (91%) while 9% were urban. The median number of household occupancy was 6 (Range 1 - 47) individuals, with a median age of 35 years (Range 0.25 – 104), (Table 1).

Out of the total targeted 1480 households, 1471 households consented and were included, representing 99% of the respondent households and 1448 were analysed data. 2909(98%) out of 2951 individuals consented and were analysed (Table 1). Data from 23 households were excluded due to entry missing values. Nine households refused to give consent for involvement, while 23 individuals refused to give consent, and 42 individuals had missing values on sex and age.

Table 1: Demographics SOSAS Malawi

	Estimates (%)
House hold data	
Location	
Rural	91.2
Urban	8.7
Median household size	6 (R 1-47)*
Respondents	99
Sex distribution	
Male	41
Females	59
Median age	35 (R 0.25-104)*
Individual data	
Respondents	98
Education level	
Non	19.8
Primary	59.2
Secondary	19.3
Tertiary	1.4
Graduate degree	0.2
Occupation	
Unemployed	30.8
House builder	7.3
Domestic helper	1.9
Farmer	38.2
Own business	15.9
Government employee	2.5
NGO employee	3.5
Table 1: Demographics SOSAS Malawi	n = 1448

There were 1039 (35.3%; 95% CI 33.8 – 38.6) reported surgical conditions in total (Table 2). In 140 individuals there was more than one complaint existing at the time of the interviews which accounted for the multiple presentation of conditions.

Table 2: Reported Surgical conditions requiring surgical consultation/surgery. n=2909

Condition	n	%
Wound (Injury related)	177	6.0
Wound (No- injury related)	116	4.0
Burn	45	1.5
Solid mass	258	8.8
Soft mass/reducible	140	4.8
Congenital deformity	124	4.3
Acquired deformity	107	3.7
Abdominal distension/mass	42	1.4
Urological complaints	14	0.5
Rectal bleed	16	0.5
Total	**1039**	35.5

1027 out of 2909 analysed individuals (35%: 95 % CI 32.6 – 37.4) confirmed having a mass, congenital birth defect, burn deformity or contracture, or other surgical condition at the time of interview, and indicated that they required a surgical consultation or intervention. Extrapolated to the population size of Malawi this gives an estimated 5.5 million people living with a surgical condition in Malawi at the time of this study.

By pathology, solid masses were predominant, followed by injury wounds and also congenital defects. See Table 2. By anatomic location, the predominant conditions were in the extremities, i.e. conditions of feet, legs, hands and arms followed by abdominal conditions, face, head and neck lesions. (Table 3)

Table 3: Anatomical location of condition requiring surgery

Anatomical region	n	%
Face/head/neck	240	8
Chest	81	3
Abdomen	261	9
Back	63	2
Groin/genitalia	81	3
Extremities	301	10
Total	**1027**	**35**
Table 3: Anatomical location of condition requiring surgery n = 2909		

597 households reported at least one death in the family in the previous year, with overall 616 reported deaths in the past 12 months. 146 (24%) out of 616 reported deaths were due to a surgically related condition (Table 2). Conditions assumed to be surgical in nature were; traumatic and non-traumatic wounds, abdominal distension, neck and other body swellings; Chest mass, Breast mass, groin mass, limb mass and other visible surface masses.

For multivariate analysis, the parameters used for comparison were, sex, current illness and illness in the past 12 months. Females were more likely to report or seek consultation than males (O.R 2.32 95% CI 2.1 – 2.6). Those that had recovered from the illness in the past 12 months were less likely to report an illness present at the current moment as having a sick health status (O.R 1.67 95% CI 1.21-1.93).

The crude death rate due to surgical disease was estimated at 67 per 1000 population per year (total household occupancy of 8644, 616 dead household members).

Discussion

This study uncovered a huge unmet burden of surgical disease and mortality in Malawi. The findings are comparable to those from other African countries, but, to our knowledge, at 35%, this is the highest reported prevalence of surgical disease in an African Country to date. The unmet need for surgical services in Malawi is evident. Many people are living with a condition needing surgical consultation or surgery. This study also found that 24 % of all deaths reported over the last year were due to a surgically treatable condition.

The SOSAS tool has been used in other Low income countries to estimate the burden of surgical disease and a comparison of the main findings from these countries can be found in Table 4. Our findings in Malawi were similar to those in Sierra Leone, where 25% of the population was found to have a surgical condition and 25% of mortality was estimated to be due to a surgical condition[1,2]. Malawi is a low income country with a GDP per capita of 294 and a population close to 17 million[13,14]. Although the Population of Malawi is three times that of Sierra Leone, with a GDP of almost a third of that of Sierra Leone, the estimated unmet need of the burden of surgical diseases is comparable in these two countries. These relatively similar findings of surgical burden and mortality from a surgical related cause when compared to other countries could be explained by similarities of the general healthcare set up and lack of adequate surgical care at the rural community level (Table 4). The crude death rate is also similar to that of Sierra Leone SOSAS survey, reflecting the inadequacy of health services in these countries. Mortality due to related untreated surgical disease is equally high in other countries that have conducted a SOSAS survey. In Rwanda, Uganda and Nepal, mortality due to a surgical disease was estimated to be even higher than in our study (table 4).

Table 4: Comparison of the situation in African countries

COUNTRY	Population	GDP/capita ($)	Untreated surgical conditions (%)	Mortality due to untreated surgical condition (%)
Malawi	16.8m	294	35	24
Sierra Leone	6.3 m	808	25	25
Uganda	34.6m	726	11	34
Rwanda	12.4m	722	6	33
Nepal	28.5m	689	10	23

It has been estimated that in 48 African countries, 288 million people are living with a surgically treatable condition, and that 5.6 million deaths could be averted by surgical intervention annually[9]. These extrapolated figures from three previous SOSAS studies demonstrate the clear need of surgical care scale up in the African region as a whole. It is high time surgical conditions become a main stream part of the global health discussion.

One of the main limitations of this survey is recall of events, especially deaths, in the household. If the family member died some months prior, the family member could not clearly disclose the cause and circumstances surrounding the death either due to recall effects or that culturally they are not comfortable discussing it. This could contribute to recall and information bias on data collection although the information was confirmed from the deceased person`s health passport book if available, or from the household head.

Another limitation could also be the reporting and description of the surgical condition. This was based on inquiry of the condition, and not examining the persons with their complaint. This would have required extra time, and more medically qualified enumerators, to conduct the physical examination on them. But realistically for a resource limited country like Malawi, it would not be feasible to get 30 medically qualified clinicians out for a 60 days' national survey and deprive the health facilities from service provision. Hence it was not possible within the timeframe and budget of this study. Some of the conditions, though interpreted as surgical, were not confirmed as such, and could have been wrongly classified. However, the opposite is also possible, and we do not think this is a major bias. Some congenital conditions, like cardiac septal defects, are not easily diagnosed without clinical examination. Some conditions like umbilical hernias or other body swellings are sometimes not considered as a problem, especially if some other family member has had a similar condition and it never caused any problem. So this required a lot of inquiry without actually examining the condition, otherwise it could be presented as a normal finding.

There are many other causes of mortality from communicable diseases, like Malaria, Tuberculosis and immune suppression related illnesses. Some of these conditions are not in isolation, but coexist with some surgical illness. Not all will require a surgical procedure for intervention, but even just a surgical consultation. This could either raise the incidence or vice versa if the diagnoses is missed.

Some surgical conditions are believed to be inherited and not harmful, like hernias and hydroceles. This could be one of the reasons the communities believe there is no need for them to seek health care from the facilities. Other communities believe the condition they have cannot be treated or even associate the condition with witchcraft. This may have been a contributing factor to not seeking health care for some.

Misunderstandings due to language could be another limitation. Malawi has 2 official languages; English and Chichewa, but many areas also have their own local languages. Though interpreters were engaged, some descriptions of medical conditions needed thorough explanation to understand what they were referring to. The questionnaire was only translated into 2 local languages, Chichewa for the central and the southern region, and Tumbuka, mostly spoken in the northern part of Malawi.

Some traumatic conditions are seasonal in Malawi, such as the high frequency of falls from trees in the mango season and collapsing houses during the rains, and therefore could

not be captured fully in this study conducted in the cold, dry ("winter") season. In winter, burns are more common due to people using fire in their houses to keep warm.

In the rural areas of Malawi, transportation costs are high for people with little cash income, and the roads often become muddy and un-serviceable during the rainy season. Many people in the rural communities either present late, or do not present at all to the health facility due to transport problems, lack of funds, or not knowing the need to visit the health facility[15]. Others get discouraged because the local health centre will not have the necessary equipment and drugs[10]. They would rather wait till they have sourced enough funds to enable them to visit a secondary level health facility, a district hospital, or even a tertiary centre, a central hospital, of which only 4 exist for the entire population of 16 million. These district hospitals and central hospitals are usually far from these rural communities, and also faced with inadequate supplies and inadequate human resource to offer the services[10,11,12]. These economic, social and geographical factors can all lead to delay in contacting the health system and explain why so many people are living with untreated surgical conditions.

Untreated surgical conditions are widespread in Malawian rural communities and there is a large potential to prevent the complications of such conditions if presentation to a health facility that can provide good surgical service is done early enough. With the knowledge of this, it could be sensible to promote community awareness of certain common pathologies that can be surgically treated. Alignment of funds for programs addressing surgical conditions by training health care workers to recognise, treat or refer surgical cases to the appropriate level of care in a timely manner could have a large impact. Surgical team visits could also be organised to rural areas by specialists from the central hospitals to make travel less of a barrier for the population in order to get health care. Strengthening of the surgical capacity in Malawi is urgently needed. With the severe resource limitations in Malawi, surgical service scale up can be most efficiently reached by sufficient support of the existing surgical training programmes in the main cities. Once a critical mass of surgeons has been trained, they can expand outreach services to district hospitals and rural health centres with the goal of also producing surgeons for the districts in the future.

Conclusion

This study has uncovered a huge unmet burden of surgical disease and mortality in Malawi. A third of the population is living with a surgically correctable condition, and one quarter of all reported deaths is potentially avoidable with surgery. Urgent scale up of surgical services and training programmes are needed to reduce this huge gap in public health service in the country.

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Original Research

Paediatric surgical conditions in Malawi - A cross-sectional nationwide household survey

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Abstract

Background

Untreated surgical conditions may lead to lifelong disability in children. Treating children with surgical conditions may reduce long-term effects of morbidity and disability. Unfortunately, low- and middle-income countries have limited resources for paediatric surgical care. Malawi, for example, has very few paediatric surgeons. There are also significantly inadequate infrastructures and personnel to treat these children. In order to strengthen resources that could provide such services, we need to begin by quantifying the need.

Aim

To estimate the approximate prevalence of surgical conditions among children in Malawi, to describe the anatomical locations and diagnoses of the conditions and the presence of injuries.

Methods

A cross-sectional, nationwide survey of surgical needs was performed in 28 of 29 districts of Malawi. Villages, households and household members were randomly selected. A total of 1487 households were visited and 2960 persons were interviewed. This paper is a sub analysis of the children in the dataset. Information was obtained from 255 living children and inquiry from household respondents for the 255 children who had died in the past year. The interviews were conducted by medical students over a 60-day period, and the validated SOSAS tool was used for data collection.

Results

There were 67 out of 255 (26.3%) total children living with a surgical condition at the time of the study, with most of the conditions located in the extremities. Half of the children lived with problems due to injuries. Traffic accidents were the most common cause. Two-thirds of the children living with a surgical condition had some kind of disability, and one-third of them were grossly disabled. There were 255 total deceased children, with 34 who died from a surgical condition. The most prevalent causes of death were congenital anomalies of the abdomen, groin and genital region.

Conclusion

An extrapolation of the 26% of children found to be living with a surgical condition indicates that there could be 2 million children living with a condition that needs surgical consultation or treatment in Malawi. Congenital anomalies cause significant numbers of deaths among Malawian children. Children living with surgical conditions had disorders in their extremities, causing severe disability. Many of these disorders could have been corrected by surgical care.

Key words; Prevalence, Surgical conditions, Children, Malawi, SOSAS

Introduction

Untreated surgical conditions in children may result in lifelong disability or death. In low- and middle-income countries (LMICs), there is a high burden of unmet surgical need in the paediatric population. A data analysis of numbers from four LMICs (Uganda, Sierra Leone, Rwanda and Nepal) using a validated Surgeons Overseas Assessment of Surgical Need (SOSAS) tool, showed that 19% of the children (0–18 years) had a surgical need and 62% of those children had one unmet surgical need[1]. The SOSAS tool was developed for population-based household surveys to assess surgical needs in LMICs.

There is a great need for improved access to surgery globally. LMICs, especially in sub-Saharan Africa (SSA), are the countries with the most limited access to health care resources[2, 3]. This region has a disproportionate unmet need for surgical care compared with other parts of the world. An estimate by the Disease Control Priorities Project, which determines priorities for disease control around the world[4], stated that 11% of the total burden of disease in LMICs was from surgically correctable conditions[5,6]. The treatment and care for children who have a surgical condition is underappreciated and inadequately funded in this region[7, 8]. A study carried out in Gambia showed that most surgical deaths in children were from burns, congenital anomalies

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and injuries[9]. There are very few paediatric surgeons in the SSA region as a whole. A study on the unmet need of paediatric surgery demonstrates this deficit[10]. In SSA, The number of regional surgeons per 100,000 people is 0.5 as compared to the USA where the number is 54.7/100,000[10]. Most countries in SSA have few paediatric surgery providers, including nurses, anaesthetists and surgeons. East and Central African countries such as Mozambique, Tanzania, Zambia, Zimbabwe and Malawi have between 3 and 8 paediatric surgeons nationwide. There is a need to train, employ and retain paediatric surgical teams[10].

Surgical teams in SSA are not only dealing with very poor socio-economic conditions and an overwhelming burden of disease, but also rare and advanced pathologies, which they must address without having much subspecialisation. In this region, infrastructure and the health care workforce are underdeveloped and fail to address the unmet paediatric surgery needs in this region[8]. A study on funding for paediatric surgery showed that paediatric operations are seldom performed in SSA[11] because of inadequate finances and the necessary out-of-pocket payments by a patient's family. There is also limited access to critical paediatric surgical procedures.

The literature on neonatal and paediatric surgery in SSA is limited. There are significant gaps in children's surgical care and strategies for children's surgery are absent from the national health plans. The National Health Strategic Plans for 47 independent countries do not have any sections on surgery for children[12], despite the fact that congenital anomalies are common surgical conditions in children and that these carry a high risk of neonatal death, life-long risk of disability and disproportionately increase the number of disability-adjusted life years (DALYs) lost[13].

In Uganda it is estimated that 55% of the country's surgical needs are attributed to the paediatric population. To address this, improved training of specialists in paediatric surgical care is required[14]. In Zambia a large proportion of the population does not have access to safe and timely surgical care owing to limited resources in hospitals providing surgical care[11]. In Somaliland there is a 12.2% prevalence of paediatric surgical conditions among all children. Only 23.7% of these had been surgically treated at the time of the survey[15].

Study significance

Our previous study in Malawi showed that the prevalence of untreated surgical conditions in the general population is 35%[16]. Just as in many other SSA countries, surgical care is a low health care priority in Malawi. Another study showed that paediatric surgical patients represented 18% of all surgical admissions at a referral hospital[17]. Also, 9.7% of all paediatric admissions at a central hospital in Malawi were related to accidents, burns and fractures from falls[3]. Malawi has only six paediatric surgeons working in the referral centres that offer paediatric surgery services[10,18]. This clearly demonstrates the inadequacy of paediatric surgery services in Malawi at a national level.

The World Health Assembly resolution WHA 68.15[19] recognises the importance of strengthening emergency and essential surgical care as a component of universal health care. Therefore, to plan for universal care strategies in Malawi, it is necessary to quantify and describe untreated paediatric surgical conditions among Malawian children at a national level. This information can be used to inform human resources and infrastructure planning for paediatric surgical services in Malawi. This study aimed to estimate the approximate prevalence of surgical conditions among children in Malawi, to describe the anatomical locations and diagnoses of the conditions and the presence of injuries. A secondary aim of the study was to describe the children's experiences when accessing surgical health care and the disability level of the children.

Materials and methods

This data is a part of a national population-based, cluster-randomised household survey of the prevalence of surgical conditions within the general population in Malawi. The detailed methodology has been previously described[16, 20, 21] and is summarised below. This analysis is focused on a subset of the data describing surgical conditions among children in Malawi.

Setting

Malawi is in Southern Africa and has a population of 18.4 million people[22-24]. The Gross National Income (GNI) per capita is $340 per annum (World Bank group, 2016)[23]. There are 9.8 million (51.6%) people below the age of 18 years in Malawi[24]. The country is divided into three geographic regions, and has 28 administrative districts. There are about 48,000 registered settlements, and the majority of people live in rural areas. Within the total population, 0.5 million people (3%) are infants under the age of 1 year, 2.6 million people (15%) under the age of 5 years, and 6.7 million people (37.2%) are aged between 5 and 17 years [23, 24] (Table 1).

Sampling and data collection

The original prevalence study carried out in 2017[16], undertaken to identify adult surgical needs, utilised 1487 households, and 2960 individuals were interviewed. Sample size was estimated based on the findings of the pilot study, which had estimated the prevalence of untreated surgical conditions to be at 25%, based on the reports from other African countries that had carried out similar studies[14, 25, 26]. Population and census information was obtained from the Malawi Statistics Office [23, 24]. In the general Malawi population, 51.6% are under the age of 18 years (49% male, 51% females). In our study, the representation for the age group under the age of 18 years was 50% (52% male, 48% female). These very similar findings in our study population were therefore found to be representative for extrapolation of the findings to the national population. However, extrapolations always have a degree of uncertainty and numbers are therefore presented with 95% confidence intervals (Table 1).

A list of enumeration sites was provided based on 2008 Malawi population and census data[23]. We randomly selected 55 settlements (villages with houses for different families) from the 28 administrative districts using computer generated random numbers; 2–4 households were randomly selected from each settlement. Random selection of households was done by spinning a bottle after exiting the initial household, and counting the 3rd, 5th or 7th house in the direction of the bottle top.

Table 1.The age distribution of the Malawi population[26] and the study population by numbers and percent.

Age (years)	Study population (95% CI)			Malawi population (million)[26]		
	M	F	Total n (%)	M	F	Total n (%)
0–5	175	112	287 (11.7)	1.5	1.6	3.1 (18.0)
6–13	329	307	636 (26.0)	2.6	2.5	5.1 (28.3)
14–17	135	167	302 (12.3)	0.7	0.9	1.6 (8.9)
Total <18	639	586	1225 (50.0)	4.8	5.0	9.8 (51.6)
>18	338	879	1217 (49.7)	3. 6	5.1	8.7 (48.3)
Total	977	1465	2442	8.1	9.9	18.5
Missing data for sex			6			
Grand total			2448			

Table 2. Children with a surgical condition by age.

Age	Living children n (%)		Deceased children n (%)		Total n
	Surgical conditions	Non-surgical conditions	Surgical conditions	Non-surgical conditions	
0–4	7 (2.7)	20 (7.8)	22 (8.6)	166 (65.1)	215
5–13	31 (12.2)	90 (35.3)	9 (3.5)	43 (16.9)	173
14–17	29 (11.4)	78 (30.6)	3 (1.2)	12 (4.7)	122
Total	67 (26.3)	188 (73.7)	34 (13.3)	221 (86.7)	510
Grand total	255		255		510

Table 3. Anatomical location for surgical conditions by age (number of children)

Location of surgical condition	Age			Total
	0–4	5–13	14–17	
Living children				
Face, head and neck	2	10	8	20
Torso (chest, back, abdomen, groin and genital)	2	5	8	15
Extremity	3	16	13	32
Total	7	31	29	67
Deceased children				
Face, head and neck	3	1	–	4
Torso (chest, back, abdomen, groin and genital)	19	8	3	30
Extremity	–	–	–	–
Total	22	9	3	34

The number of households depended on village size. Demographic and general family data were collected from the household head. Subsequently another household member was randomly selected for the questionnaire, and included both adults and children. Consent and assent forms were read out to the household members prior to the interview, and those who accepted and gave consent were interviewed. For the youngest age group, below 10 years, the household head present at the moment was responding on their behalf, while the older children responded for themselves.

Data collection was performed by 32 medical students from Malawi College of Medicine who were in their third year of medical training. A pilot study was conducted prior to the main survey at the national level. Data collectors had 5 days' training on usage of the tablet-based data collection tool. All the 28 administrative districts were visited for data collection except for Likoma, which is an island.

Table 4. Surgical diagnosis by age (number of children).

Diagnosis of surgical condition	Age			Total
	0–4	5–13	14–17	
Living children				
Wound from injuries (burn, fracture)	–	13	12	25
Congenital deformity	–	5	6	11
Acquired deformity (non-injury wounds, mass/growth)	5	19	7	31
Total	5	37	25	67
Deceased children				
Wound from injuries (burn, fracture)	2	4	–	6
Congenital deformity	11	3	1	15
Acquired deformity (non-injury wounds, mass/growth)	9	2	2	13
Total	22	9	3	34

Table 5. Cause of injury by age (number of children).

Mechanism of injury	Age			Total
	0–4	5–13	14–17	
Living children				
Traffic accident	–	3	8	11
Other injuries (stab/cut, bite, fall, burn)	1	5	8	14
Total	1	8	16	25
Deceased children				
Traffic accident	–	1	1	2
Other injuries (stab/cut, bite, fall, burn)	1	2	1	4
Total	1	3	2	6

The data collection process lasted for 10 weeks and was undertaken from July to August 2016. Interviews were conducted in the local language.

Survey instrument

Data was collected using a questionnaire. Children between the age of 0 and 18 years were identified as survey respondents. After an initial inquiry of both living and deceased children in the household, a three-component questionnaire was verbally administered by data collectors who input the data on the tablet-based collection tool. The first component of the questionnaire inquired about the general household demographics and household members. It included the number of members, their ages, sex, tribe and occupations. The second and third component focused on the individual information concerning each child. For a living child, the respondent was asked if the child currently had a clinical condition that could be described as a surgical condition. The child or respondent for the child was asked if the child had ever experienced a wound, burn, mass, deformity, problem with eating or drinking, a problem with eyes or ears or an operation. This enquiry was asked for each of the following body regions: head, face and neck, chest/breast, back, abdomen, groin and genitals, and extremities. They were asked if the problem started after an injury or accident, what kind of accident this might have been and when the problem started. They were also asked if they had the problem currently, and if this problem had an impact on the daily life of the child.

The data collectors also enquired whether there had been any death of a person in the household under the age of 18 years within the prior 12 months and the likely cause of death.

The participants were also asked if the child attended a health care facility or not, and the type of care provided including a surgical procedure or operation. The child or respondent for the child was asked about what kind of treatment they had received. The options were: none, major procedure (with general anaesthesia), or minor procedure (wound care, suturing, incision and drainage, wound care and dressing). They were also asked about the main reason for not to going to a health facility to see a doctor, have an operation or receive wound care and dressing. The tool was translated into the main local language, Chichewa before the interview. During interviews in areas where there were difficulties in understanding Chichewa, a translator was used to maintain the uniformity of the collected data. The translation was undertaken by persons identified for that purpose for each specific region.

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Table 6. Access to formal surgical healthcare by age (number of children).

	Age			Total
Reason for not receiving formal health care	0 - 4	5 - 13	14 - 17	
Living children				
No money for Health care	-	-	-	-
No transport money	-	-	-	-
No time to seek health care	-	-	2	2
Fear/lack of trust	-	2	2	4
Unavailable facility/personnel	-	5	1	6
Received formal surgical health care	28	21	6	55
Total	28	28	11	67
Deceased children				
No money for health care	3	-	-	3
No transport money	-	-	-	-
No time to seek health care	4	5	1	10
Fear/lack of trust	3	-	1	4
Unavailable facility/personnel	7	3	1	11
Received formal surgical health care	4	2	-	6
Total	21	10	3	34

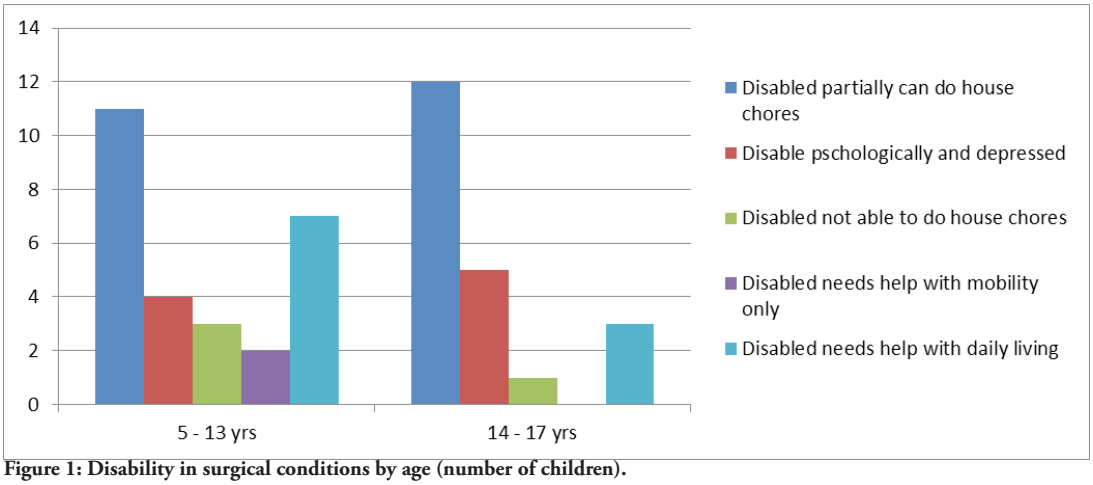

Figure 1: Disability in surgical conditions by age (number of children).

Ethical approval and consent to participate

The research was approved by the College of Medicine Research Ethics Committee (P03/15/1696), and Norwegian Regional Research ethics committee (2016/1392/REK Vest). Consent (for the adults) and assent (for the children) forms were designed and translated into the local languages. These were read out in a local language to the participants to seek informed consent prior to conducting the interviews. The consent and assent forms were approved by the ethics committees as part of the questionnaire for data collection.

Statistical analysis

Data were analysed for two categories of children: living children and the children who had died in the previous 12 months prior to the survey (deceased children). Numbers and percentages were given. Frequencies were reported for age categories.

Pearson chi-square test was used to compare living and deceased children for location of surgical conditions, availability of health facility and health care provider.

Data analysis was done by SPSS version 24 (IBM, New York).

Results

The total number of children analysed was 510. Of these, 255 were alive at the time of the survey and 67 (26.3%) of these children had probable surgical conditions. Sixty of these children were 5 years or older. At the time of the survey, 255 children had died in the prior 12 months, and 34 (13.3%) of these children were identified as having died due to a probable surgical condition. Twenty-two of these children were less than 4 years old when they died (Table 2).

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Of the 67 children living with a suspected surgical condition, the extremities were the most common location, affecting 32 children. Of the 34 children who had died from a suspected surgical condition, the torso (chest, back, abdomen, groin, and genital region was the most common location (Table 3).

Of the living children, acquired deformity and wound from injuries were the most common aetiologies. Seven children had experienced a limb fracture. In the deceased children congenital deformities were the most common, with 15 of 34 children (Table 4).

Injuries contributed to 25 of the 67 children living with surgical conditions. Isolated traffic accidents were the most common mechanism of injury, with almost half (11) of the cases of injured children resulting from road traffic. There rest of the injuries were from different aetiologies, i.e. bite, fall, stab and burn. Six children died from injuries (Table 5).

Of the 67 children living with a surgical condition, 12 did not receive formal health care, due to fear or lack of trust, or no facility available, or having no time to seek health care; for 6 children there were no facility or health care personnel available. Of the 255 deceased children, 28 did not receive health care, and in 11 children there were no available personnel or health facility. A total of 40 (39.6%) of the children with a surgical condition did not receive health care. Of the causes stated by the caregivers of the 34 deceased children, 11 stated they had no access to a health facility and 10 stated to not have the time to seek health care (Table 6).

There were 7 of the 67 children with a surgical condition that had either a major or minor surgical procedure. Four of the deceased children had a major surgical procedure for their condition.

Some type of disability was reported for 48 of the 67 living children above the age of 5 who had a surgical condition. Almost half (23) of these children were able to do normal activities of daily living, such as household chores. A third (16) of the 48 children with a disability were grossly disabled and could not function on their own without assistance with either mobility or their daily living activities and could not do household chores (Figure 1).

Discussion

This study demonstrates a need for better surgical treatment and care among children in Malawi. About one-fourth of the interviewed children or child respondent had health problems due to a probable surgical condition, mostly from the extremities. Almost half of the children lived with problems due to injuries, and traffic accidents were the common cause. Two-thirds of the children with a surgical condition had some kind of disability, and only half of them were able to perform normal household chores; one-third was grossly disabled. Children who had died from a probable surgical condition had different diagnoses than the living children, mainly congenital deformities located in the abdomen/groin/genital region. Some of the children had not received any surgical health care, mainly due to unavailability of care of this type, but also caused by lack of time to seek help for the condition.

According to the population estimates; 26% of living children in our study have a surgically correctable condition. An extrapolation to the whole population of Malawi shows that out of 9.3 million of the total population under 18 years, there could be almost 2.4 million children living with a surgically correctable condition in Malawi, and over a million children might be disabled.

Due to limited surgical care for children in LMICs, many children miss the opportunity for surgical correction of their condition, and may end up with life-long disability, hampering the economic development of their families and the nation as a whole. In our study we demonstrated that 26.3% of the living children in our study group have a condition that could possibly be treated by surgery. These findings coincide with those from a similar study that looked at untreated surgical conditions in Malawi[16]. Untreated surgical conditions account for almost 10% of disabilities among children in Malawi, with 6.7% of all causes of deaths occurring from an untreated surgical condition among these children. With very few surgical care providers for children at a national level, the health and well-being of these children is at stake. Malawi, like many other LMICs, has a ratio of 1–3 paediatric surgeons per 1–2 million children[10,14,27,28].

Other African countries have a low density of surgeons, such as Uganda, 0.73/100,000, and Rwanda, 0.49/100,000[10,14]. This clearly shows the much lower numbers of surgical providers compared with the developed countries, with regional surgeon numbers per 100,000 population of 0.5 in LMICs, compared with 54.7 surgeons per 100,000 population in the USA[10].

Apart from having an insufficient number of surgical providers, facilities available to offer paediatric surgery are also inadequate in these LMICs. In our study, the information gathered on paediatric surgical care is from 2016. The authors consider this is still representative of the current situation, because there has not been significant development in infrastructure and human resource capacity to care for children's surgical conditions in the district hospitals. In Malawi there are a few facilities that offer paediatric surgery and most are located in large urban centres, limiting access to paediatric surgical care for most of the population. Travel to these centres has many challenges, including difficulties of travel and availability of financial support[20]. We have demonstrated that parents for almost 50% of the children will seek some formal health care for their children, but that medical facilities and personnel were not available for 4% of these children. For those that managed to get formal health care, only 10% of the total children were treated by surgery.

Traumatic injuries also contribute to many of the surgical conditions faced by these children. Our study showed that 31% of total surgical conditions in children resulted from injury and 42% of these were due to road traffic accidents. It has previously been shown in Malawi that trauma cases at a referral centre had 36.8% children under the age of 18 years injured over a 7-year period, with 20.1% due to road traffic accidents[30].

Congenital deformities accounted for 24% of all surgical conditions for both the living and deceased children. This was 4.7% of the entire child population in our study, or 340,000 children with congenital anomalies nationwide. Most of these congenital clinical conditions are surgically correctable.

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There are 1125 children born with a club foot in Malawi per year[26]. We noted in our study that the common surgical conditions were mostly in the extremities (32% of surgical conditions, 6.2% of the childhood population). This gives an estimate of 446,400 children with surgical conditions in the limbs. Of these, an estimated 100,000 have these clinical conditions located on the foot, which are most commonly club foot deformities.

Clinical conditions in the groin can be interpreted as mostly inguinal hernias that are surgically correctable, but most individuals do not undergo this surgical repair.

A study on children with disabilities from cerebral malaria in Malawi showed gaps in education, knowledge, rehabilitation infrastructure funding and stigma for caring of the disabled children[30]. We note that surgical conditions also cause much disability to children. In our study 26.5% of the children over the age of 5 years living with a surgical condition needed to be assisted with daily living activities, including feeding, bathing themselves and also mobility. Physical rehabilitation would probably be a good alternative but assistance for most of these children would not be sought from a health care facility for a variety of reasons. In particular, some would not go to a health care facility because of being unable to source funds for transportation and in some cases no such transportation is available[21]. The health care facilities that may be able to offer rehabilitation services may be located far from the rural areas, rendering transportation difficult. The facilities offering surgery and rehabilitation are usually located in the main cities of Malawi. These centres only provide service to cases referred from the secondary level hospitals (district hospitals). Most of these secondary level hospitals lack paediatric surgical providers and sometimes also the basic equipment for physical rehabilitation and surgical procedures.

The Ministry of Health in Malawi takes responsibility to prevent premature deaths and disability in children (Child Protection and Justice Act 2010). The Ministry of Health also promotes health workers to visit disabled children with child protection risks to offer support, which includes identification, advice and recommendation to visit a health facility[31]. There is, however, also a clear need to improve access to health services for children with disabilities and surgical conditions to avoid inequity in access for this vulnerable group of children[32].

Study strength

The size and geographical width of the study had data covering the whole of Malawi. In addition a validated SOSAS tool was used, with trained data collectors who understood the language, culture of the country and the presentations of the children's clinical conditions.

Study limitations

The SOSAS tool was not designed to capture the exact clinical conditions or doctor-confirmed diagnosis. The surgical diagnosis was based on self-reports from the interviewed persons. Obtaining accurate information on the diagnoses would have required a very different study design. Augmenting the interviews with visual aids or pictorial capture of the clinical conditions might have improved the quality of the diagnoses reported, but still, without a specialist opinion, the diagnoses would not have been certain. Another limitation was recall bias, especially related to the deceased children, as the death could have happened months before the interview. Also, the family member interviewed might have been uncomfortable to discuss such events.

Study implication

An extrapolation of the 26% of children who were found to be living with a surgical condition in this study indicates that there could be 2 million children living with a surgical condition in Malawi.

Study recommendation

With this identified surgical need, it is clear that scaling up paediatric surgery services is necessary in Malawi. Promoting paediatric surgery training in the available training institutions and reinforcing infrastructure for paediatric surgery at all levels of health care service is likely to reduce the burden of untreated surgical conditions and related disabilities among children in Malawi, and the region.

Conclusion

This study has uncovered that a large group of children are living with disability from a surgical condition in Malawi. Many children may also die unnecessarily from surgical conditions. The most common cause of death was congenital abnormalities of the abdomen/groin and genitals. Among living children, surgical conditions were most often seen in the extremities, rendering most children disabled. Acquired conditions were mostly associated with trauma. Many of these disorders would have benefited from better surgical care.

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Competing interests

None of the authors have any competing interests to declare.

Authors' contributions

CV: project idea, planning implementation, data collection, first manuscript draft and revisions.

SY: project idea and planning, supervision, data interpretation, manuscript revisions.

NM: supervision, data interpretation, manuscript revisions.

RSG: supervision, data interpretation, manuscript revision.

BN: Manuscript revisions.

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LB: data collection, manuscript revisions.

AV: project idea and planning, supervision, manuscript revisions, assisted with data analysis and interpretation.

BEM: supervision, planning and manuscript revisions.

All the above authors have reviewed and approved the manuscript for submission for publication.

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RESEARCH ARTICLE Open Access

TRANSPORTATION BARRIERS TO ACCESS HEALTH CARE FOR SURGICAL CONDITIONS IN MALAWI a cross sectional nationwide household survey

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Abstract

Background: It is estimated that nearly five billion people worldwide do not have access to safe surgery. This access gap disproportionately affects low-and middle-income countries (LMICs). One of the barriers to healthcare in LMICs is access to transport to a healthcare facility. Both availability and affordability of transport can be issues delaying access to health care. This study aimed to describe the main transportation factors affecting access and delay in reaching a facility for health care in Malawi.

Methods: This was a multi-stage, clustered, probability sampling with systematic sampling of households for transportation access to general health and surgical care. Malawi has an estimated population of nearly 18 million people, with a total of 48,233 registered settlements spread over 28 administrative districts. 55 settlements per district were randomly selected for data collection, and 2–4 households were selected, depending on the size. Two persons per household were interviewed.
The Surgeons Overseas Assessment of Surgical need (SOSAS) tool was used by trained personnel to collect data during the months of July and August 2016.
Analysis of data from 1479 households and 2958 interviewees was by univariate and multivariate methods.

Results: Analysis showed that 90.1% were rural inhabitants, and 40% were farmers. No formal employment was reported for 24.9% persons. Animal drawn carts prevailed as the most common mode of transport from home to the primary health facility - normally a health centre. Travel to secondary and tertiary level health facilities was mostly by public transport, 31.5 and 43.4% respectively. Median travel time from home to a health centre was 1 h, and 2.5 h to a central hospital. Thirty nine percent of male and 59% of female head of households reported lack financial resources to go to a hospital.

Conclusion: In Malawi, lack of suitable transport, finances and prolonged travel time to a health care centre, all pose barriers to timely access of health care. Improving the availability of transport between rural health centres and district hospitals, and between the district and central hospitals, could help overcome the transportation barriers to health care.

Keywords: Transport, Barriers, Health, Access, SOSAS, Survey

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Background

Over the last decade the burden of disease treatable by surgery has been assumed to be arround 11%, based on an expert opinion estimate by Debas et al. in 2006 (Debas H, Gosselin R. et al. 2nd Washington World Bank; 2006 p.1245–1259) Recent estimates indicate that this figure is likely to be much higher. Estimates of the global burden of surgical disease based on a multinational survey from the provider perspective indicate that 32.9% of deaths and 28.1% of disability-adjusted life years (DALYs) could be lost due to surgically treatable conditions (Shrime et al) [1].

In rural sub-Saharan Africa there is limited information available of morbidity and mortality due to surgical diseases. In East African rural communities it has been estimated that mortality from injury related surgical conditions and cancer is 100/100,000 and 60/100,000 population per year respectively [2]. Taira et al. [3] concluded that there is very limited access and availability of surgical care across the developing world. A study in Tanzania showed that more than 90% of the population in the North of the country does not have access to orthopaedic surgical care [4].

The Lancet commission on Global Surgery estimated that 5 billion people do not have access to safe surgery [1], and the access is inequitably distributed. Lin et al. [5] showed that 96% of their study patients experienced a barrier to surgical care. 73% reported that this was due to costs, 8.2% reported that it was due to lack of a provider. They concluded that barriers to surgery were predicted by patients' wealth and home location in The Republic of Congo [5].

Malawi, a sub-Saharan low income country (LIC), is no exception from this situation. Hospitals in rural sub-Saharan Africa, including Malawi, have not met the surgical needs of the population they serve, which has resulted in significant morbidity and mortality [6].

Though it has been shown that the health work force is severely inadequate at different levels of health provision in Malawi [7], there are multiple other barriers faced by rural communities to access health care for different medical and surgical conditions. Some of the many delayed presentations of disease seen in medical practice in low income settings have been shown to be due to the cost of transportation and time taken to reach the health facility [8], but so far there has been no study on factors posing a barrier to surgical care in Malawi.

The Malawi health care system has two main service providers: Non-governmental district facilities under Christian Health Association of Malawi (CHAM) and governmental facilities. CHAM is a network of church-owned health facilities, hospitals and training colleges run by faith based organisations with financial support from Malawi Government. CHAM has 175 health facilities and provides 37% of Malawi's healthcare services. Unlike the free services provided by the government facilities, CHAM offers its services at a cost. The government health structure is designed in a three-tiered network of medical facilities. The primary tier is a network of rural health facilities, referred to as health centres, which are run by medical assistants and nurses, with no doctors. Further, medical supplies are often scarce. The second tier is the district hospital which caters for the critical medical case which cannot be handled in a health centre. These facilities are located centrally in each of Malawi's 28 districts. District hospitals can handle some surgical cases if doctors or clinical officers with some surgical training are available, but they have no specialist surgeons to provide advanced surgical care. The top tier is the tertiary central hospitals which have more advanced equipment, medical supplies and medical personnel including different specialised doctors. The tertiary hospitals are only located in the four main urban areas. While CHAM provides 37% of health care delivery in Malawi, the government health facilities are responsible for 60, and 3% is served by private institutions and organisations [9].

People living in rural Malawi face major challenges due to long distances between the community and the nearest health facility, be it a health centre, district hospital or central hospital. 50% of Malawians live within 5 km from a health facility [9, 10]. Terrain and lack of road infrastructure can be a challenge in itself in some areas. Some areas are accessible by push bicycle, bicycle ambulances, and motor cycles only, others by ox-carts, lorries and motor cars. The transportation means are challenging, and in some areas the most used mode of transport is the bicycle ambulance for transferring especially maternity patients from rural health facility to district hospitals [11]. Occasionally transportation from primary health facility to secondary or tertiary health facility is provided by public hospital ambulances. Most of the roads in rural Malawi are dirt roads and many do not have bridges, making use in the rainy season even more of a challenge.

Even when the roads are passable by different means of transport, the distance from the community to the health facility has in itself been shown to influence health seeking behaviour in Malawi resulting in a gap in the accessibility of the public health service [12].

Transportation cost and cultural factors have also been shown to influence access to health care [11, 13]. Poverty and financial constraints influence decisions on where and when to seek help for health complaints [11]. Financial barriers to surgical care can either be direct or indirect. Direct costs are those directly related to care, such as surgical fees, drugs and other medical supplies, transport to health facility and hospital stay. Indirect

costs are accumulated as a result of the sickness or absence from work, with loss of income and productivity [9], both for the patient, and guardians and family supplying care in the hospital and at home after discharge.

In 2016 a cluster randomised national household survey was carried out using the Surgeons Overseas Assessment of Surgical need tool (SOSAS) to estimate the burden of untreated surgical disease in Malawi [14]. We found that 35% of the population were living with a condition that was in need of a surgical consultation or intervention and that 24% of reported deaths in the preceding 12 months could have been due to a surgical condition [14]. The purpose of this study was therefore to investigate and describe factors affecting access to health facilities for general medical and surgical care in Malawi, with special focus upon transport, finances and travel time.

Methods

Setting

Malawi has an estimated population of 18.4 million, with a GDP per capita of USD 300 (World Bank Group data base 2016). It is estimated that only 9% of health facilities have adequate staff to implement the WHO defined Essential Health Package (EHP) [9]. Malawi has 3 regions; The Northern, Central and Southern Regions. The Central and Southern regions are the most densely populated with 6.4 and 6.8 million respectively [14]. Malawi has 28 districts, of which one, Likoma, is an island in Lake Malawi. The country has a total of 48,233 registered settlements and the vast majority of these are in the rural areas. About 90% of the population live in rural areas and are dependent mostly on subsistence farming and small scale businesses [7].

Study design

This was a multi stage, clustered, probability sampling cross-sectional study, with systematic sampling of participants at the household level. The sample size was estimated at 1487 households based on a pilot study that was carried out in rural areas of the capital city, Lilongwe, in 2016 [14].The sample size for the individuals was estimated at 2994 individuals (95% CI) with a design effect of 1.5 at 25% prevalence of unmet surgical need in reference to the prior LMICs region reports [14–16].

The National Statistics Office provided a list of enumeration areas from the Malawi Census Board for 2008 national census records. There were 48,233 recorded settlements identified as potential enumeration areas. These settlements were randomised through computer generated random numbers, selecting 55 settlements as enumeration areas from each district in Malawi for this survey. Two or four households were systematically selected in each settlement depending on size. Two households were selected in a settlement with less than 10 households, while 4 households were selected in larger settlements. The systematic household selection was based on a floor bottle spin and selecting the third or fifth house in the direction of spin depending on the size of the settlement. Subsequently the bottle spinning was repeated after the household interview to select the next household in the new direction of the spin. The next fifth household was then picked if in a larger settlement or third household if in a smaller settlement, then repeating the process again to select the next household. Two household members were selected and interviewed per household, by first interviewing the head of the household, then selecting another member at random using random numbers based on number of members in the household. If this household member selected was a child (age below six years),mute or for some reason cannot speak, then the guardian was interviewed using the assent form on their behalf with permission granted by them. The total number of included households was 1479, with a total of 2958 people interviewed [14]. The study started out with 1486 households. Two heads of households refused to participate and for 5 households there were no data.

Survey instrument

The Surgeons Overseas Assessment of Surgical need tool (SOSAS) was used to collect data [14–16], and. This is a questionnaire based tool with three components. The first component outlines the general house-hold information i.e. Household size, type, gender and age distribution and demographics i.e. location (urban, rural or slum). The second and third part focused on the different modes of transportation they used in the past 12 months to travel with a sick or injured household member from home to the nearest health facility, to the district hospital and to a tertiary centre, occupation of participants etc. The time taken to reach the health facility was also recorded. Inquiry on the source and availability of money by the household head to reach the health facility in the last visit was done. It also had inquiries on the assumed cost of transport (Local currency) to reach these three levels of health care, and on the different reasons that contributed to the individuals not going to the health facility in time. These were based on household level, as reported by the head of the household.

The questionnaire was installed on 17 tablet computers (iPad 2, Apple Inc.), using File Maker Pro 12.0v3 (File maker inc., USA) software for data collection in English.

Data collection

Data collection was done by medical students trained at the end of their third year of academic training. They all

underwent five days of training on how to use the questionnaire and computer tablet. A pilot study was carried out in Lilongwe prior to roll out of the main study in April 2016, to test the survey tool. Training was done prior to this pilot study and as a refresher after the pilot study in preparation for the national survey [14].

There were 32 trained data collectors, 14 female and 18 male. The period for data collection was from 1st July to 30th August 2016, during the main holiday for the medical students who did the data collection. Data collection was spilt into 2 phases. The first phase involved half of the data collectors covering all identified enumeration sites in the northern part of the Central Region and the whole of Northern Region. The second phase involved coverage of the rest of Central region and the Southern Region. In some of the enumeration areas people belonged to smaller population groups with unique languages or dialects. In these cases local translators were hired to secure good communication between the interviewer and the household member [14].

Each data collector covered approximately 4 households per day, therefore 60–64 households were interviewed every day. Interviews were done in the interviewees private homes. The collected data was merged and exported from the tablets into an Excel (Microsoft 2010) data base at the end of each day. Data was checked and exported directly into the pooled data base on a computer saver at the end of each of day, for data security and to assure the quality of the data collection [14]. Data backup was saved in cloud storage using wireless internet connection.

Statistical analysis

Data analysis was done using SPSS version 24. Univariate and multivariate statistical analysis was done for descriptive, relative frequencies and percentages as presented in the tables.

Pearson chi square test was used to compare the availability of financial resources between males and females for travel to access surgical health care at different levels of health care provision.

Results

Analysis performed on 1479 households revealed that 90.1% of the study population was located in rural areas (Table 1). The most common occupation among the participants was subsistence farming (40%). 24.9% of the population reported not to be formally employed by an organisation i.e. non skilled and not on a payroll by government or non-governmental organisation for monthly salary (Table 1). Home makers i.e. those who are hired on short term contracts or piece works for a few days to weeks for construction of infrastructure represented 8%, while domestic workers i.e. those who are hired to clean homes and take care of young children in the homes represented 1.9% (Table 1).

Table 1 Demographics and household information

	Frequency	(%)
House hold data		
Location		
Rural	1332	90.1
Urban	107	7.2
Slum	13	0.9
Not stated	27	1.8
Median household size (range)	*6 (1-47)*	
Total households	**1479**	
Individual data (Employable age group 15-66 years)	2448	
Sex distribution		
Male	977	39.9
Females	1465	59.8
Not stated	6	0.3
Median age, years (range)	34 (15-66)	
Occupation		
Farmer	979	40.0
Unemployed (non-skilled/no salary)	610	24.9
Own business	437	17.9
Home maker (house Builder)	196	8.0
Non-Government employee	95	3.9
Government employee	67	2.7
Domestic helper (House maid)	47	1.9
Not stated	17	
Total number of people surveyed	2448	0.7

It was reported by the household head that the most commonly reported mode of transport from home to the primary health facility was animal pulled carts (44.8%) while travel to secondary level and tertiary level health facility was by public transport inclusive of public hospital ambulances (31.5 and 43.4% respectively) (Table 2). About a fifth (19.1 and 19.7%) of the respondents would have to travel to their health centre or local hospital by using multiple means of transportation, with only 9.5% of using multiple modes to travel to a central hospital (Table 2). This may, for example, involve walking on foot to a certain place, hiring a push bicycle and possibly end up in a minibus or on the back of a lorry to the health facility.

Regardless of mode of transportation, it took a median of 1 h to travel to the nearest health centre, 1.5 h to travel to district hospital and 2.5 h to travel to the nearest central hospital respectively.

Of the people interviewed, significantly more women than men denied having money for transport to visit health centre, district hospital and central hospital as

Table 2 Transport mode to health facility for 1479 households

Mode of transport	Health centre	District hospital	Central hospital
	N (%)	N (%)	N (%)
Public transport/ambulance	50 (3.4)	466 (31.5)	642 (43.4)
Private hire	17 (1.1)	153 (10.3)	165 (11.2)
Motorcycle	26 (1.8)	34 (2.3)	2 (0.1)
Bicycle	153 (10.3)	125 (8.4)	17 (1.1)
Boat	2 (0.1)	2 (0.1)	–
Animal (Ox) cart	663 (44.8)	216 (14.6)	12 (0.8)
Walking on foot only	26 (1.8)	11 (0.7)	9 (0.6)
Multiple (Combined)	283 (19.1)	292 (19.7)	140 (9.5)
Not stated	285 (19.3)	180 (12.2)	492 (33.3)

n = 1479 Households
* responses from household members in reply to the question: "What is the main way for you or your household members to go to a secondary health facility?"

reported by the household head (Table 3). For the household heads; 54% male and 41.6% female respondents reported to have money available to go to their local health centre, 52.8% males and 43.9% females % to district hospital and 54.5% males and 41.7% females to central hospital respectively (Table 3). At the overall household interview with family heads, less women than men stated that they had financial resources to access healthcare ($p < 0.001$).

Of the interviewed households heads; 56.3 and 27% would have to spend less than 1 US$ to travel to their health centre, and district hospital whereas 9.5% would spend less than 1 US$ to go to their central hospital. (Table 4). Travel to central hospital would cost up to US$ 7 in 20.6% of the respondents and only 1.1% of the same amount to travel to a health centre.

Discussion

This study confirmed the cost of and access to transport as significant barriers to accessing timely health care by rural communities in Malawi. Almost half of the respondents had financial constraints influencing their access to health care for surgical conditions. Inadequate road infrastructure, finances, ambulance services and expensive private transport all play a role as transportation barriers to access a health facility. This is in line with findings from another Malawian study by Abiiro et al. that people from rural areas spend more time travelling than those in urban regions, and that lack of transport, inadequate financial resources and poor road conditions limit the possibilities of people in rural communities to access health facilities [17].

Other reviews on the barriers to surgical health care encountered by patients in rural sub-Saharan Africa have identified cultural, structural, and financial constraints as barriers and concluded that patient and community education and transport needs should be made available [4, 18]. Punchak et al. reported in-adequacy in neurosurgical service in sub-Saharan Africa. The average percentage of the population with access to neuro surgery within 2 h window was shown to be 25.26% in sub-Saharan Africa, while is was 93.3% in Eastern Europe and Central Asia. This was attributed to low numbers of neurosurgery providers, equipment challenges and unreliable access to transportation to neurosurgical centres in Low- and middle income countries, including the sub-Saharan region [19].

In general, district hospitals provide less surgical care than central hospitals. Galukande et al. reported relatively low rates of major surgery at district hospitals in Eastern Africa, ranging from 50 to 450 surgical procedures per 100,000 population [18]. More than 95% of

Table 3 Availability of money for transportation to health care facility for 1479 households

	Local health centre			District hospital			Central hospital		
	Male Head	Female Head	Not stated	Male Head	Female Head	Not stated	Male Head	Female Head	Not stated
Yes (Y)	135(54.0%)	104 (41.6%)	11 (4.4%)	143 (52.8%)	119 (43.9%)	9 (3.3%)	85 (54.5%)	65 (41.7%)	6 (3.8%)
No (N)	185 (36.2%)	296 (57.9%)	30 (5.9%)	277 (38.8%)	394 (55.3%)	42 (5.9%)	214 (37.8%)	315 (55.7%)	37 (6.5%)
Not stated	315 (43.9%)	362 (50.4%)	41 (5.7%)	215 (43.4%)	249 (50.3%)	31 (6.3%)	336 (44.4%)	382 (50.5%)	39 (5.2%)
Chi-sq M/F:	Y/N	$p < 0{,}001$			$p < 0{,}001$			$p < 0{,}001$	

* as judged by the senior household member/household head interviewed in reply to the question: "…Are you always able to provide these means for transport of a sick household member……?"

Table 4 Cost to reach health facility in 1479 households

	Health Centre	District hospital	Central hospital			
	N	%	N	%	N	%
US$ 0.00–0.99	832	56.3	399	27.0	141	9.5
US$ 1.00–1.50	135	9.1	292	19.7	73	4.9
US$ 1.51–3.50	63	4.3	285	19.3	161	10.9
US$ 3.51–7.00	16	1.1	159	10.8	305	20.6
US$ 7.01–13.50	5	0.3	32	2.2	153	10.3
US$ 13.51–25.00			17	1.0	38	2.6
Not stated	428	28.9	295	19.9	608	41.1

US$ 1.00 = Mk 740
Malawi GDP per capita is US$300
* as estimated by the person interviewed in reply to the question: "What does it cost you to provide transportation to a tertiary health facility for a sick household member?……"

the population in South Asia and Central, Eastern and Western sub-Saharan Africa do not have access to surgical care, whereas less than 5% of the population in Australia, high-income America and Western Europe lack access [21]. This demonstrates the unmet surgical need and confirms the barriers to access to essential surgery in rural districts in sub-Saharan Africa [20].

50% of the Malawi population live within five kilometres from their health centre, a walkable distance for a healthy person, though not necessarily for someone seeking health care [9, 10]. Accordingly, it is surprising that only 1.8% of the respondents stated that travel on foot was the main way for their household members to go to a primary health facility, reflecting mostly the use of bicycles and Ox-carts for travelling short distances.Secondary level and tertiary level health facilities, however, are often far from people's homes. District hospitals support health centres with ambulance services to ferry sick people from the health centre to the district hospital, and on to the tertiary central hospitals if needed. This hospital ambulance transport support system usually gives priority to maternity patients, especially urgent obstetric complications. Each district hospital has a minimum of 15 health centres to support within its catchment area, and may have only 2 or 3 ambulances. Unfortunately, these may also be off the road due to lack of fuel or vehicle spare parts, and they often fail to go to health centres to fetch patients.

Eventually, communities have to find alternative transportation from home to the health centre, and also from the health centre to a district hospital. Elderly people may carry children on their back over considerable distances just to seek surgical health care. Sometimes when they get to a health centre, they are informed that the facility does not have resources for surgical treatment e.g. sutures for closing wounds or plaster of Paris (POP) for treating fractures, hence they have to wait for an ambulance coming for obstetric emergency patient to come and collect them together to go to the district hospital. Otherwise they should be prepared to find and pay for alternative means of transportation to travel to the district hospital. This time consuming activity contributes to the delay in presentation to health facility as another barrier.

Central hospitals offer tertiary surgical services for emergency and elective conditions, but are located in the big cities far from most rural areas. These central hospitals serve as both secondary and tertiary level facilities due to inadequate surgical services at the secondary level. Sometimes resources are so limited that health service seekers have to bypass the district hospitals and travel directly to the central hospital in order to be assisted accordingly. When patients get to a district hospital, they get referred to a central hospital, and usually the mode of transport is by public hospital ambulance which sometimes delays time of travel because they have to wait to fill it up with more patients, hence posing as another barrier.

Government public transportation is not available in most rural areas either due to poor road infrastructure or unavailability of public transport supported by government. This has led to private owned sources of transport which are also very costly. This private mode of transportation varies from ox-cart, push bicycle, motorcycles, and motor-tricycles to big lorries, minibuses and buses. Depending on availability of funds, and unpredictability of availability of ambulance services, the only way is to hire an ox-cart, push bicycle or any other mode of transportation to ferry them to hospital. Though it costs less than USD 1 to travel to a health centre, the needed financial resources are often not readily available. About 56% of the population reported to have an equivalent of 1 USD to enable them to travel to a health centre.

White et al. [22] had similar findings of cost of travel to centres that provide surgical care and have recommended that NGOs and other stake holders should be involved in LMICs provision of surgical care by actively engaging in case finding and offer surgical services [22]. This should be done by travelling to the rural location to provide surgical care rather than expecting the patients to travel to access care [23]. This could be achieved by designing surgical camps in the district and upscaling surgical services at district hospital level.

The transport barriers described in this study contribute significantly to inadequate access to general medical and surgical services in Malawi such that the burden of disease is still unacceptalby large, with as many as 35% of the population living with a condition needing a surgical consultation or treatment (Varela et al) [14]. Though human and other resources contribute to this burden, transport availability between health centres and district hospitals and between district hospital and

central hospital also needs to be emphasised in order to improve health for all Malawians, especially surgical health care as a non-communicable disease section of the essential package.

One of the limitations to this study was that the transport limitation was not assessed according to seasonal availability of funds in the communities. In Malawi, during harvest time of farm produce, the availability of money is better than during the field preparation and growing season for example. This study was done during the time farmers were busy preparing their fields for the upcoming growing season. This could be associated with low availability of funds to support transport to hospital because priority is on farm inputs like seed and fertiliser for the farms. Another limitation was that the cost of mode of transport was not estimated in reference to the type of transport used. For example the cost of ox-cart was not easily compared to cost of push bicycle or car because the cost of transportation is based on the distance travelled not the vessel used. Cars and buses are generally more expensive that the other modes of transportation though not readily available. One weakness of using the tool for data collection was that this was based on interviews and hence has a recollection and recall bias may have influenced the results. Also, the information was self-reported and lacked objective measures. Missing information in many reported variables is in general a major concern, although there is no reason to believe that this has introduced a selection bias. The strengths of this study are the size, systematic selection of households and participants, use of a standardized instrument, use of trained personnel and high response rate.

Conclusion

In Malawi, lack of suitable transport, lack of finances and prolonged travel time to tertiary health facilities, all pose barriers to timely access of health care. Improving the availability of free transport for patients between rural health centres and district hospitals, and between the district and central hospitals, could help overcome some of the most pronounced barriers to surgical health care experienced by people in rural Malawi.

Abbreviations

CHAM: Christian Health Association of Malawi; CI: Confidence Interval; DALYs: Disability Adjusted Life years; EPH: Essential health Package; GDP: Gross Domestic Product; LIC: Low Income countries; LMIC: Low and Middle Income countries; NGO: Non-Government Organisations; NORAD: Norwegian Agency for Development; NORHED: Norwegian Programme for Capacity Development in Higher Education and Research for Development; POP: Plaster of Paris; SOSAS: Surgeons Overseas Assessment of Surgical need; SPSS: Statistical Package for Social Scientists; USD: United States Dollar; WHO: World Health Organisation

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Availability of data and materials

The datasets used and analysed during the current study are available from the corresponding authors on reasonable request.

Authors' contributions

CGV: project idea, planning & implementation, data collection, first manuscript draft and revisions.
SV: project idea and planning, supervision, data interpretation, manuscript revisions.
NM: supervising, data interpretation, manuscript revisions.
RG: supervision, data interpretation, manuscript revisions.
LNB: data collection, manuscript revisions.
AV: project idea and planning, supervision, manuscript revisions, assisted with data analysis and interpretation.
All authors approved the manuscript, its results and consented for publication of the article.

Ethics approval and consent to participate

The research was approved by the College of Medicine Research Ethics Committee (P03/15/1696), and Norwegian Regional Research ethics committee (2016/1392/REK Vest). Consent (for the adults) and assent (for the minors and mute persons) forms were designed and translated into the local languages. These were used to seek informed consent prior to conducting the interviews.

Consent for publication

This was not applicable.

Competing interests

There are no competing interests available from all authors.

Publisher's Note

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RESEARCH ARTICLE Open Access

Deaths from surgical conditions in Malawi - a randomised cross-sectional Nationwide household survey

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Abstract

Background: Relatively little is known about deaths from surgical conditions in low- and middle- income African countries. The prevalence of untreated surgical conditions in Malawi has previously been estimated at 35%, with 24% of the total deaths associated with untreated surgical conditions. In this study, we wished to analyse the causes of deaths related to surgical disease in Malawi and where the deaths took place; at or outside a health facility.

Methods: The study is based on data collected in a randomised multi-stage cross-sectional national household survey, which was carried out using the Surgeons Overseas Assessment of Surgical Need (SOSAS) tool. Randomisation was done on 48,233 settlements, using 55 villages from each district as data collection sites. Two to four households were randomly selected from each village. Two members from each household were interviewed. A total of 1479 households (2909 interviewees) across the whole country were visited as part of the survey.

Results: The survey data showed that in 2016, the total number of reported deaths from all causes was 616 in the 1479 households visited. Data related to cause of death were available for 558 persons (52.7% male). Surgical conditions accounted for 26.9% of these deaths. The conditions mostly associated with the 150 surgical deaths were body masses, injuries, and acute abdominal distension (24.3, 21.5 and 18.0% respectively). 12 women died from child delivery complications. Significantly more deaths from surgical conditions or injuries (55.3%) occurred outside a health facility compared to 43.6% of deaths from other medical conditions, ($p = 0.0047$). 82.3% of people that died sought formal health care and 12.9% visited a traditional healer additionally prior to their death. 17.7% received no health care at all. Of 150 deaths from potentially treatable surgical conditions, only 21.3% received surgical care.

Conclusion: In Malawi, a large proportion of deaths from possible surgical conditions occur outside a health facility. Conditions associated with surgical death were body masses, acute abdominal distention and injuries. These findings indicate an urgent need for scale up of surgical services at all health care levels in Malawi.

Keywords: Surgical, Deaths, National survey, SOSAS

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Background

Surgically treatable conditions are a major contributor to the global burden of disease. It is estimated that 11–15% of the global burden of disease, measured as disability-adjusted life years (DALYs), could be treated and corrected surgically [1, 2]. Surgical diseases account for up to 15% of the total DALYs lost globally, or 38 DALYs lost per 1000 people per year [3]. Shrime et al. estimated that of the total deaths globally, 31.3% are related to surgical conditions, and 25.1% of DALYs were lost due to surgical conditions in LMICs [4]. Untreated surgical conditions could contribute to 20% of the deaths affecting young adults in LMICs and to about 10% of all deaths globally [2, 3]. Studies from several sub-Saharan African countries have found a prevalence of 6 to 35% for conditions needing surgical consultation or treatment [5–8].

Surgery has been described as the neglected stepchild of global health. Though there are more studies being done to map the burden of disease, there are few surgical care providers in low- and middle-income countries (LMICs) and low priority is given to surgical conditions by public health care systems [2]. Surgical need assessments in LMIC have shown that injuries, malignancies, congenital anomalies, complications of pregnancy and cataracts are the most predominant conditions requiring surgery [1, 9]. In addition, over 100 million people sustain traumatic injuries globally each year. Of these, more than 5 million people die from their injuries. This is more deaths than from HIV, malaria, and tuberculosis combined. About 90% of these take place in low- and middle-income countries (LMICs) [4]. Deaths and morbidity from surgery-related diseases in LMICs can be reduced by scaling up basic, life-saving surgical care [6, 7].

Malawi is a low income country in south-eastern Africa with limited access to surgical care, especially for the majority rural population [5, 10]. We have previously estimated the proportion of deaths from untreated surgical conditions in Malawi including trauma to be around 24% of all deaths [5]. In this country wide cluster-randomised household survey, more than a third of the population was living with a condition that needed a surgical consultation or treatment. However, little is known about what injuries and surgical conditions result in death in Malawi, and what proportion is likely to be due to lack of access to surgical care.

Reducing deaths from trauma and other surgical conditions, requires knowledge of where the deaths occur, cause of death and what barriers there are to accessing surgical care [11, 12]. The aim of this study, therefore, was to outline the causes and location of deaths from untreated surgical conditions and trauma in Malawi.

Methods

Setting

This study is part of a larger project assessing the unmet surgical needs in Malawi [5, 13]. The research setting has previously been described in detail in the two related previous publications on untreated surgical conditions and transportation barriers in Malawi [5, 13]. The population of Malawi is 18.4 million [10], with a GNI per capita of USD 340 (World Bank Group, 2016) [14]. The country is divided into three geographic regions and 28 administrative districts. There are over 48,000 registered settlements [10], the majority of which are located in the rural areas with poor road infrastructure and limited access to health care [13] .

Survey instrument

Surgeons OverSeas (SOS) have developed the Surgeons OverSeas Assessment of Surgical need (SOSAS) enhanced verbal autopsy tool [6, 8, 15, 16]. SOS granted permission to use and adapt the SOSAS survey tool to suit the Malawi setting. It was translated into the official local language, Chichewa, and was installed on portable electronic tablets that were used by trained data collectors [5, 13].

The SOSAS tool consisted of a questionnaire with three components; one for general household information, and forms for two individual household members who were identified by randomisation of the members of the household. The verbal autopsy included an inquiry on the number of people who died in the household in the 12 months prior to the interview, their gender and age and cause of death. Identification of a household member with the following conditions in the week before they died were considered to be surgical: bleeding or illness during child birth; abdominal distention or pain associated with vomiting and not passing stool; mass, swelling or growth e.g. breast tumours and limb tumours; Injury; acquired deformity; or wound not due to injury, or, in neonates; congenital deformity including conditions of any visible abnormality, feeding problems, problems with urinating or passing stool soon after birth.

Further, data were collected about duration of illness, place of death (home, health facility and elsewhere), and initial care. (SOSAS tool page 5 and 6, *www.surgeonoverseas.org/resources/*,. Causes of death not specified were recorded as other medical conditions.

Pilot study and sample

A pilot study was done in rural areas of the capital city, Lilongwe, in February 2016, to validate the data collection tool in a Malawian set up. Fifteen third year medical students from the University of Malawi, College of Medicine were used as data collectors to interview 100 households, and 200 people in four different settlements within Lilongwe. The pilot study confirmed that the electronic questionnaire functioned well and gave an estimated prevalence of surgical conditions of 25%. This figure was used to estimate sample size for the national survey (5).

The needed study population was estimated to be 1497 households national wide with 2994 (95% CI) interviewees and a design effect of 1.5. The Malawian National Statistics Office provided a list of all enumeration areas from the Malawi Census Board based on the 2008 national census records [10]. From the 28 administrative districts, 55 settlements were randomly selected using computer generated random numbers. From each settlement, 2–4 households were selected randomly depending on the size of the settlement i.e. 2 in smaller settlements and 4 in larger settlements. From each household, the head of the household and another randomly selected person were interviewed.

Data collection

Thirty-two 3rd year medical students received a 10 days training course as data collectors before the pilot study, and a 5 days refresher course was conducted prior to the national survey. It took this team of data collectors (led by authors CV and LB) 10 weeks in July and August 2016 to visit the settlements randomised for inclusion (Fig. 1; *reprinted with permission from Malawi Medical Journal; MMJ 29(3)231–236 Sept 2017*). 27 of 28 districts were visited. It was not possible to reach the remote Likoma Island district in Lake Malawi, due to time and funding constraints.

Due to language barriers in some rural areas with different local languages, some interviews were performed by use of translators. Data was exported directly into an Excel (Microsoft 2010) data-base on a computer at the end of each day for data security and to spot check data quality.

Data analysis

Data analysis was done using SPSS version 24. Pearson's Chi-square test was used to test the difference in rates in two different groups.

Results

A total of 1479 households were included in the study. 1332 (90.1%) of the households were in rural areas. The median household size was 6 persons, and median age was 22 years. The total number of deaths reported due to all causes comprising surgical and medical conditions was 616. 58 entries did not have sufficient data on cause of death. 558 deaths were available for further evaluation. Of these, 150 (26.9%) were assessed as being caused by a surgical condition or injury. 12 deaths (8.3% of surgical deaths) were women in the age group 18–49 who died due to bleeding related to childbirth (Table 2). Children below 18 years represented 45.7% (255 persons) of the recorded deaths and 33.8% were below the age of 5 years (Table 1).

Health care was sought by 459 persons (82.3%) before their death, whereas 99 persons (17.7%) did not contact a health facility for medical care. There was 12.9% that additionally visited a traditional herbalist prior to a health facility. Of the people that died from assumed surgical conditions 32 (21.3%) received surgical care (11.3% major, 10% minor surgical intervention.) Household heads reported that, out of the 459 persons who sought health care, 284 (62.1%) of the total deaths went to a local health facility, while 59 (12.9% of all death) went to a traditional herbal medicine provider additionally for consultation and traditional medicine treatment, and the rest visited other distant health care facilities.

Of the 150 cases defined as related to surgical conditions (24.0% of total deaths), 35 (24.3%) were described as having a swelling or mass, 31 (21.5%) were related to injury and 27 (18.0%) were due to a condition with acute abdominal distension of less than 1 week duration (Table 2). Of the 31 injuries, 16 (51.6%) were related to road traffic accidents. The majority of these deaths (14 persons – 45.2%) occurred in the age group 18–49 (Table 3).

55.3% of probable surgical deaths occurred outside a healthy facility, compared to 43.6% of other deaths ($p = 0.00473$). (Table 4)

Discussion

This study has shown that 55.3% of deaths due to surgical conditions in Malawi occurred outside a health facility. This is higher than for deaths due to other medical conditions. Most of the surgical deaths outside health facilities happened at home. There are few studies on this topic, as most studies of surgical patients are based on hospitalized patients. However, a large study of 80,483 women of reproductive age in Mozambique indicated that 61.1% of deaths of women occurred at a health facility, 27.8% at home and 11.1% occurred somewhere else (for example on way to a health facility). These figures indicate similar problems as seen in the present study [17]. The difference in proportion of deaths happening outside a health facility, between surgical related and non-surgical related deaths can be partially explained by the fact that some road traffic injuries will lead to death at the site of injury. However, this finding still highlights a large lack of capacity for transport and health care in Malawi.

The problem with lack of access to surgery and trauma centres in low income settings has also been described in a study on acute abdominal conditions and other emergency conditions in India and lack of emergency obstetric services in Mozambique [18, 19]. A study done in Zambia demonstrated that only 16.5% of the hospitals met the WHO minimum standards of safe surgical care [20]. There is a similar situation in Malawi with low standards of safe surgery in rural health facilities [21]. In addition, the need of improvement in global surgical

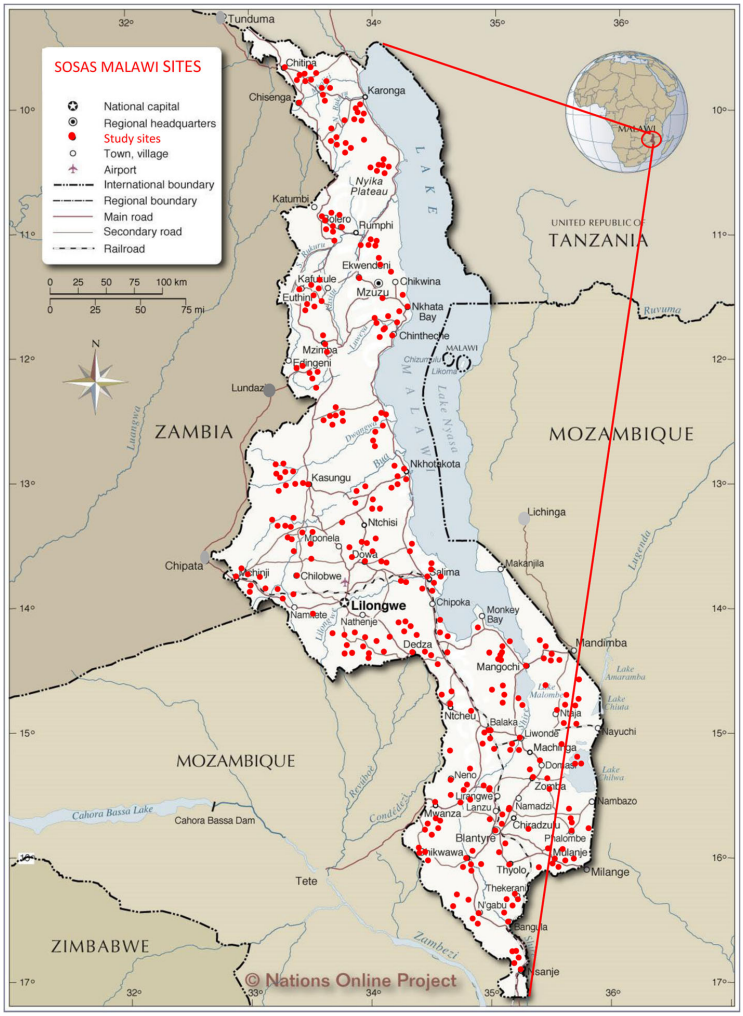

Fig. 1 Map of study sites. Study sites for SOSAS Malawi survey on unmet surgical need. Reprinted with permission from Malawi Medical Journal; MMJ 29(3)231–236 Sept 2017)

care, particularly in low- income and middle- income countries is described in a review from 2019 [21].

Some communities are remote, with large distances to health facilities, and family members may not have enough financial resources to help with transportation to the hospital [13]. This presents a further delay, or barrier, to patients being able to present to the health facility, which in many cases leads to loss of life. People in the rural communities of Malawi often visit a traditional healer before considering visiting a formal health care facility [22]. In our study, 12.9% of patients that died went to a traditional healer prior to visiting a formal health facility, possibly contributing to delayed presentation for surgical health care. Not all surgical conditions need operative interventions, but access to consultation with qualified health personnel can help identify those at risk and the need of surgical intervention or non-operative management.

The present study shows that surgical conditions that significantly affect mortality in Malawi were found to be 26.9% of all deaths. Overall the dominant causes of death were localised body masses, like breast mass,

Table 1 Household deaths in preceding 12 months

	Frequency (n)	(%)
House hold location		
Rural	1332	90.1
Urban	107	7.2
Slum	13	0.9
Not recorded	27	1.8
Total households	**1479**	***100***
Total Reported deaths		
Male	294	52.7
Females	259	46.4
Not recorded	5	0.8
All	558	100
Total Deaths by age group (years)		
0–4	188	33.8
5–17	67	12.1
18–49	172	31.0
Above 50	128	23.1
Missing	3	
Total	558	100

extremity masses and other body torso masses, representing such conditions as tumours, abscesses and hernias. Acute abdominal distension and traumatic conditions were the other dominant causes of untreated surgical condition related deaths. Though abdominal distension can arise from other medical conditions, in this survey death related to abdominal distension was defined by the interviewer as an acute death occurring within 1 week of the abdominal distension. This condition is highly suspicious of a surgical condition e.g. bowel obstruction or bowel perforation with peritonitis. There is little literature on this from Malawi. A previous study at a referral hospital in Lilongwe showed that the common aetiology for peritonitis were appendicitis and intestinal volvulus. It was also found that 11% of acute abdominal presentation with peritonitis was due to perforated peptic ulcer and small intestinal perforation respectively, and mortality from this was 15% [23]. The complications of untreated surgical conditions like bowel perforation, gangrene, dehydration and respiratory compromise can result in high morbidity and mortality rates. A study in East Africa reported morbidity rate of 24% and a mortality rate of 12.9% from abdominal surgical conditions due to bowel obstruction [24].

Children, below the age of 5, represented 18.8% of the surgical deaths with the majority of them dying from congenital disorders (40.7%). A study in a paediatric population in Malawi from 2016, reported a mortality rate of 23.3% in neonates due to different kinds of intestinal obstruction, most of which were congenital [25]. This study also showed that, in children, congenital surgical conditions, such as Hirschsprung's disease and anorectal malformations, accounted for 29 and 18.5% of intestinal obstructions in neonate respectively [25]. This is associated with high mortality if not diagnosed promptly and treated properly in time by surgical intervention. Similarly, a Kenyan study showed that the highest mortality rates among neonates and infants were related to acute abdomen, 7% of congenital deaths [24]. In our study there were 11 neonates that died from congenital surgical conditions after being born alive. This survey did not investigate the burden of still birth, as these are culturally not registered as part of the population in Malawi. Congenital intestinal obstruction in neonates constitutes a major portion of neonatal surgical problems. Similar to our study, the Kenyan study was based on information from households. However, the Kenyan study used other categories for the reasons for death and had a longer observation period [24].

Trauma is another leading cause of death, and in our study it contributed to 21.5% of all surgical deaths, mainly in the age group 18–49. There were 16 persons

Table 2 Causes of death in the past year according to age

	Injury	Infected wound	Bleed from child birth	Regional Body mass	Congenital deformity	Acquired deformity	Acute Abdominal distention	Surgical deaths	Non-surgical/ Medical
0–4 yrs	1	3	0	7	11	0	5	**27**	152
5–17 yrs	3	1	1	4	2	0	7	**18**	49
18–49 yrs	14	8	10	10	0	5	13	**60**	115
Above 50 yrs	13	3	1	14	2	4	2	**39**	88
Unknown age	0	2	0	0	1	3	0	**6**	4
Surgical deaths: n (%)	**31 (21.5%)**	**15 (10.4%)**	**12 (8.3%)**	**35 (24.3%)**	**15 (10.4%)**	**9 (6.3%)**	**27 (18.0%)**	**150 (26.9%)**	**408 (73.1%**

Total deaths 150, 10 missing data for age

Table 3 Deaths due to trauma

	Bite/animal attack	Burn/ explosion	Traffic related injuries	Fall from height	Stab/ slash	Death age group n (%)
0–4 yrs	0	1	0	0	0	**1 (3.2%)**
5–17 yrs	0	1	1	1	1	**4 (12.9%)**
18–49 yrs	1	0	8	1	4	**14 (45.2%)**
Above 50 yrs	1	0	7	2	2	**12 (38.7%)**
Deaths from traumatic cause n (%) (*N*) = 31	2 **(6.5%)**	2 **(6.5%)**	16 **(51.6%)**	4 **(12.9%)**	7 **(22.5%)**	31 **(100%)**

[a]Responses from household members in reply to the question: … ."condolences for your loss … ..which one of the above injuries may have caused the death of your family member?

(51.6% of traumatic deaths) that died from traffic related injuries. This reflects findings from another study in Malawi that showed a rapid rise in road traffic injuries in Malawi from 2009 to 2015 [26].

We registered 12 women who died during pregnancy and childbirth. However, the specific cause of death was in most cases not documented, except that bleeding was reported. Death from child birth complications was due to excessive haemorrhage associated with child delivery, i.e. post-partum haemorrhage. The Maternal Mortality Ratio in Malawi has been estimated at 675 maternal deaths/100000 live births during the period 2004–2010 [20]. It should be noted that this figure is far from Sustainable Development Goal 3.1, where the aim is to reduce maternal mortality to less than 70 per 100,000 live births (www.who.int/sdg/targets/en/).

A study done in Malawi assessing maternal mortality from delays in accessing obstetric medical care showed that the cost of transport and insufficient family finances, poor road conditions or terrain, shortage of health workers and providers, long travel to the nearest health facility and an inadequate referral system contributed significantly to delays in timely obstetric care. In this study 62.2% of maternal deaths occurred at a health facility while 21.2% of the deaths happened at home [27]. Improving health facility systems and implementing models like "saving mothers, giving life" (SMGL) initiatives may help to reduce deaths that happen from acute obstetric complications at rural or primary health care centres [28].

The absence of appropriate surgical care in LMICs results in many unnecessary deaths from curable surgical conditions. This lack of services contributes to significant disability, economic loss and ultimately compromises the quality of life for people living in these regions. Key barriers to accessing surgical services are; cost of transport, distance, poor roads, and lack of suitable transport [13]. Most people present late to health facilities as a result of the different transportation barriers they have faced [13]. Cultural issues like consulting the traditional herbalist for traditional medical intervention might also delay timely surgical intervention.

A limitation of this study was that the information of the causes of death was limited, since in many cases, no clear diagnosis was given. Data relies on the medical understanding of the informant, and this is likely to have weaknesses. However, in a validation study in Nepal, the SOSAS survey was compared with a visual examination and demonstrated high concordance with the self-reports from the participants [29]. Another limitation is that the information might be hampered by recall bias, with the informant thinking back in time over the past year, as well as specific causes of the events surrounding the deaths. However, this study also has many strengths, most obviously its sample size, response rate and covering nearly the whole geographical area of Malawi through randomization of survey sites. The interviewers were skilled and specifically trained for the study, and they used a standardized interview guide developed specifically to assess surgical need. Interviews were chosen because other sources for this information were not available in Malawi. Also, questionnaires were not an option, due to a moderately high illiteracy rate in Malawi [30], and a lack of culture for this type of data gathering.

Table 4 Location of death for persons that died during the last year

	At health Facility	At home	Other location	Unknown location	Total
Deaths related to probable surgical condition	61 (10.9%)	67 (12.0%)	16 (2.9%)	6 (1.1)	150 (26.9%)
Other deaths/medical	227 (40.7%)	164 (29.4%)	14 (2.5%)	4 (0.7)	408 (73.1%)
Total deaths	288 (51.6%)	231 (41.4%)	30 (5.4%)	10 (1.8)	558 (100%)

Total deaths 558, 10 missing data for location

[a]Response of household head" … . Condolences for your loss, where did your family member die from one of the above locations …?"

Conclusion

In Malawi, deaths due to probable surgical causes were characterised by body swellings or tumours, acute abdominal distention and injuries. Over half the deaths from surgical conditions occurred outside a health facility, significantly more than seen for non-surgical conditions. This indicates an urgent need for scale up of surgical services at all health care levels in Malawi.

Abbreviations

CAM: Complementary and Alternative Medicine; CI: Confidence Interval; DALYs: Disability Adjusted Life Years; EHP: Essential Health Package; LIC: Low income countries; LMIC: Low and middle income countries; MMR: Maternal Mortality Ratio; NGO: Non-Government Organisation; NORAD: Norwegian Programme for Capacity Development in Higher Education and Research for Development; SOSAS: Surgeons Overseas Assessment of Surgical need; SPSS: Statistical Package for Social Scientists; SSA: Sub – Saharan Africa; WHO: World Health Organisation

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Authors'contributions

CGV: project idea, planning implementation, data collection, first manuscript draft and revisions. SY: project idea and planning, supervision, data interpretation, manuscript revisions. NM: supervision, data interpretation, manuscript revisions. RG: supervision, data interpretation, manuscript revision. LNB: data collection, manuscript revisions. BEM: supervision, planning and manuscript revisions. AV: project idea and planning, supervision, manuscript revisions, assisted with data analysis and interpretation. Corresponding author. All the above authors have reviewed and approved the manuscript for submission for publication.

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Availability of data and materials

The data sets used and analyses during the study are available from the corresponding author on reasonable request.

Ethics approval and consent to participate

The research was approved by the College of Medicine Research Ethics Committee, a local National Research and Ethics body for all medical research(P03/15/1696), and Norwegian Regional Research ethics committee (2016/1392/REK Vest). Consent (for the adults) and assent (for the minors) forms were designed and translated into the local languages. These were read out in a local language to the participants to seek informed consent prior to conducting the interviews. Verbal consent and assent forms were approved by the ethics committees as part of the questionnaire for data collection.

Consent for publication

This was not applicable.

Competing interests

There are no competing interests available from all authors.

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