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Paediatric Surgery in Uganda –  
burden of disease and barriers to quality of care

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Cover illustration: Happy African children playing in a compound

Paediatric Surgery in Uganda – burden of disease and barriers to quality of care

THESIS FOR DOCTORAL DEGREE (Ph.D.)

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This book is dedicated to my loving parents, Joseph Opio Ebobu and Theresa Akiteng Opio. My late father was one of a few African fathers who valued education of girls, so he educated his daughters contrary to the culture of sending us for marriage. My mum Theresa who dedicated her entire time to taking care of her seven daughters, making sure we ate on time and went to school on time.

To my loving sisters too, Josephine, Agnes, Jane Francis, Ann Grace and Caroline for your untiring care. And to my loving nieces and nephews “Little Angels” Irma, Goretty, Tracy, Bridget, Peter, Raymond, Aaron, Hyginus, Joel, and Walter. Their compliments, smiles and laughter gave me encouragement to continue writing this thesis to the end.

To my dear supervisors for your invaluable time, advice and mentorship – thank you.



## **POPULAR SCIENCE SUMMARY OF THE THESIS**

The four papers included in the present work are linked and give a synopsis of paediatric surgery in Uganda.

If you have not been to Africa, then you must visit Uganda, also known as the Pearl of Africa. Some facts you would want to know about Uganda are that it has a fast-growing population of about 3.3% per year, and a fertility rate of 4.55 births per woman, implying a rapidly growing child population. The paediatric population is currently about 20 million. Like many countries in Africa, Uganda is a low-income country with a budget that cannot adequately support her healthcare system. Several countries in sub-Saharan Africa belong to the group with the highest burden of surgical disease in the world, the estimated prevalence of surgical conditions being greater than 40% of the population.

Globally, surgical conditions account for the loss of 16.9 million lives yearly, which is more than death from tuberculosis, HIV and malaria combined. It is estimated that conditions that are successfully treatable with surgery contribute 28-32% of the world's disease burden. The need for surgical services in LMICs is increasing but development of the delivery of surgical and anaesthesia care is virtually missing from the global health reports. Reduction of death and disability depends on access to surgery and anaesthesia. This should be timely, available and affordable to ensure good outcomes.

Despite the increasing surgical need, there are several challenges to increasing surgical capacity for children in Uganda. These include shortages of workforce across all cadres, dilapidated infrastructure and inadequate equipment and supplies. There are only four paediatric surgeons and three paediatric physician anaesthetists in the country to serve a population that would require about 200 paediatric surgeons. Eighty percent of Uganda's population live in rural settings, but the majority (95%) of her surgeons practice in urban settings, leaving the rural population under-served. Hence a considerable number of children die from preventable surgical conditions. Little has been documented about the economic effects of surgical conditions; for example, managing children with disability is more expensive than the cost of operations to prevent the same disabilities.

Information about the met and unmet need caused by paediatric surgical conditions in Uganda, and about the barriers to life quality, was scarce. Data is vital for planning interventions and improving the health services. The research presented in this thesis sought to address important knowledge gaps within the field of paediatric surgery in Uganda. This included the prevalence of paediatric surgical conditions, the burden of disease, identifying barriers and solutions to surgical care, and assessing the impact of the Covid-19 pandemic on access to surgical care for children.

### **Methods and materials**

The studies used different methods and materials, but all the four papers are related. Study I was carried out in the Iganga-Mayuge Health Demographic Surveillance site (IM-HDSS) in

eastern Uganda. Households from this HDSS were sampled and visited. Interviews and physical examinations were carried out in order to investigate the prevalence of surgical conditions in children.

Study II was a retrospective study in which data was extracted from the operating theatre logbooks of the national referral hospital, all fourteen public regional referral hospitals, and from fourteen general hospitals in Uganda. Volumes, types of procedures and their indications as well as information about who did these surgeries or administered anaesthesia were documented.

In Study III, we explored the barriers to surgical care for children and possible solutions to the obstacles identified. In this qualitative study, data were collected from healthcare workers at Soroti Regional Referral Hospital in eastern Uganda, and from parents of children admitted to that hospital for surgery with a confirmed diagnosis of hernia. Interview guides were used for the data collection.

Study IV was a mixed methods study that combined quantitative data from operating theatre logbooks of all the health facilities performing surgeries in the Teso sub-region in eastern Uganda with qualitative data from interviews with healthcare workers, hospital directors and parents of children who had had surgery.

## **Findings**

The prevalence of paediatric surgical conditions was 16%, the most common being congenital anomalies, infections and trauma. Other conditions included tumours both benign and malignant, while 10.1% of the children had some form of disability verified by physical examination. The unmet need for paediatric surgery was high.

Though operations were being performed in all the four regions of the country (North, East, Central and West), there was great variation in the paediatric surgical procedures performed, with the Northern Region the most under-served. The workforce, too, was unevenly distributed throughout the country: most specialists, including the four paediatric surgeons and three paediatric physician anaesthetists, practised in the central region. Surgery for children was to a large extent performed by non-specialist surgical providers.

Parents and health workers gave their views about the barriers to surgical care but also suggested possible remedies. Delays were summarized according to the three-delay model as follows: 1. delay in seeking care, 2. delay in arriving at the health unit, 3. delay at the point of care.

Religious and traditional beliefs in some communities influenced decisions to seek care. Home remedies were often the first treatment for a sick child, and only when the child did not improve would the family seek medical care. Lack of money to pay for transport and treatment was another hindrance to seeking care. Long distances to hospital were a barrier because transport to hospital was costly. Gender inequality was another factor. Though a



woman was usually the first to identify her child's problem, she could not decide to go to the hospital. She had to ask permission from either her husband or a family elder. Some parents shunned coming to the health facility because they didn't trust the health workers. One parent spoke out, that when his son had a hernia, and the doctors told him surgery was the only cure for this condition, he was given an appointment and was admitted to the ward but was not operated on. The doctors kept re-scheduling that parent's son's appointment for surgery six times, but no surgery was done. The parent's comment was that the doctors needed to be trained again because they didn't know what to do!

The health workers' concern was that the facilities lacked equipment and drugs. When patients came for treatment, their attendants were given a list of items to buy; drugs, sutures and gloves. They had to wait until these items were brought before surgery could take place.

The outbreak of the Covid-19 pandemic caused panic and fear because of the rapid spread of the infection and the associated high mortality rates. Some delays caused by the pandemic were unique. Generally, people feared to go to hospital because Covid-19 cases were admitted there for care. They delayed taking children for surgical care until the condition worsened and they had no choice. Both the parents and health workers believed the number of surgical procedures for children had decreased during the pandemic. On the contrary however, the numbers of procedures increased between 2019 and 2021. The delays in hospital were due to precautions taken to minimize the spread of Covid-19. The screening processes were long and cumbersome: once a patient had a raised temperature, he/she was isolated and samples were taken for screening. Often the samples took 2-3 days before the results were known, causing further delay for surgical care.

Uganda had stringent rules of total lockdown, schools were closed for almost two years. This had profound effects on vulnerable populations such as adolescent girls. There was a general concern by the parents and healthcare providers that teenage pregnancies had increased, leading to an increased number of caesarean deliveries in the hospitals, and school dropout.

## **Conclusion**

There is a high burden of paediatric surgical conditions in Uganda. To meet the children's surgical needs nationwide requires an integrated approach, involving different stakeholders locally and internationally. Funds must be outsourced for training and retention of the workforce involved in paediatric surgery. There are urgent needs to establish an effective referral system from a lower-level facility to a level that can offer definitive management, to equip all facilities nationwide and to ensure a constant supply of materials and medicines. Building infrastructure for managing paediatric surgical conditions, with dedicated operating theatres for children in all the four regions of the country, is a must. Local outbreaks, epidemics and pandemics are expected in the future, and the health care systems must be prepared to limit their impact on routine healthcare and on society at large.



## **ABSTRACT**

### **Background**

In recent years there has been an increased awareness of surgical conditions within global health. A special emphasis is needed for children which constitute a large proportion of the populations in many countries. Many surgical conditions affect children, and an estimated 85% of all children in LMIC aged 15 will require surgery. Also, life-threatening conditions such as incarcerated hernias can be successfully corrected by surgical intervention.

There is compelling evidence that the quality of basic surgical care for children is compromised in hospitals especially in low-resourced countries in Sub-Saharan Africa. This widespread quality gap suggests a potential for improved health systems to cater for children with surgical need at all levels of care. Uganda with a population of 20 million children has enormous unmet need for paediatric surgical care. There are numerous obstacles to increasing children's surgical capacity in Uganda. How far surgical services for children in Uganda are affected has not been investigated.

### **Aim**

The overall aim of the work reported in this thesis was to address knowledge gaps in paediatric surgery in Uganda. This included the prevalence of paediatric surgical conditions, the burden of paediatric surgical disease, identifying barriers and solutions to surgical care, and, finally, assessing the impact of covid-19 on the access to surgical care for children.

### **Methods**

Four studies were undertaken: **Study I** was a cross-sectional, cluster-based study of the prevalence of paediatric surgical conditions in eastern Uganda. It was conducted at a Health Demographic Surveillance Site (HDSS): **Study II** was a nationwide facility-based study with retrospective data collection. It sought to determine the volumes and type of surgical procedures done for children in Uganda. **3. Study III** was a qualitative, interview-based exploration of the barriers and potential solutions for improved surgical care for children with hernia in eastern Uganda. **4. Study IV** was a mixed-method study combining quantitative registry-hospital data and qualitative interview-based data to investigate the impact of Covid-19 on access to paediatric surgery in the Teso sub-region in Eastern Uganda.

### **Results**

**I:** the overall prevalence of paediatric surgical conditions was high at 16%, unmet need was 6.3%, and 10.1% had some degree of disability verified by physical examination. **II:** The average annual rate of 22.0 of major surgical procedures per 100,000 paediatric population in Uganda was assessed in 2013-2014. The rate varied between the four regions from 12 per 100 000 children in Northern Uganda to 27.7 per 100 000 children in Central Uganda. The most common conditions were congenital (n=3111, 39%), infections (n=2264, 28.7%) and trauma (n =1210,15.3%). Specialist surgeons performed 60% (n=4758) of the procedures,

and anaesthesia was administered by specialist physician anaesthetists in 11.6%, n =917. **III:** Traditional beliefs and gender inequalities were considered major issues; others included lack of funds, transport, long distance and mistrust in the health system care. Possible solutions included partnering with the local community leaders to increase knowledge and acceptability in the community in general and by the parents. Another solution was capacity building for the health workers. **IV:** Total procedures for children increased by 24% between 2019 (n= 1407) and 2021 (n=1751). Procedures performed for pregnancy-related conditions increased most (58.3%). Some 12 parents and 25 health workers participated in the interviews. Using reflexive thematic analysis, two themes emerged, i) conflicts between reality and perception of the situation during the pandemic, and ii) lessons learned and a way forward.

## **Conclusion**

The prevalence of paediatric surgical conditions in Uganda is high with a huge unmet need for paediatric surgery. Procedures are performed in the country in a fairly decentralized manner, but with variation in the four regions, especially the northern region being under-served. Health-policy makers should promote programmes that are geared to the training and retention of a surgical workforce evenly distributed throughout the country. It is key to improve infrastructure and ensure regular supply of equipment and medicines. In partnership with non-governmental organizations the Government need to introduce programmes geared to empowering the country's youth with skills for survival.

## **Keywords**

Global surgery, paediatric surgery, paediatric surgical procedures, healthcare providers, barriers to access to care, impact of Covid-19.

## LIST OF SCIENTIFIC PAPERS

I. Mary Margaret Ajiko, Viking Weidman, Pär Nordin, Andreas Wladis, Jenny Löfgren (January 1, 2022)  
*Prevalence of Paediatric Surgical Conditions in Eastern Uganda: A Cross-Sectional Study*  
*World J Surg*  
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II. Mary Margaret Ajiko, Julia Kressner, Alphonsus Matovu, P Nordin, Andreas Wladis, Jenny Lofgren (2021)  
*Surgical procedures for children in the public healthcare sector: a nationwide, facility-based study in Uganda*  
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[doi:10.1136/bmjopen-2020-048540](https://doi.org/10.1136/bmjopen-2020-048540)

III. Mary Margaret Ajiko, Jenny Löfgren, Solvig Ekblad (2021)  
*Barriers and potential solutions for improved surgical care for children with hernia in Eastern Uganda. Scientific Reports* (2021) 11:11344 |  
<https://doi.org/10.1038/s41598-021-90717-2>

IV. Mary Margaret Ajiko, Solvig Ekblad, Aaron Edward Wange, Ocen Innocent, Pär Nordin, Andreas Wladis, Jenny Löfgren  
*Impact of Covid-19 on access to surgery for children in Teso sub-region in Eastern Uganda*  
*Manuscript- under review*



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## PROLOGUE

Following my graduation from Makerere University with Master of Medicine in Surgery (General Surgeon) in 2006, I was posted to Kitovu Hospital in Masaka, a privately run district missionary hospital in Uganda. I was actively involved in performing surgeries and teaching junior doctors. Under the guidance of a senior consultant surgeon, I perfected my surgical skills, and got involved in the activities of the Association of Surgeons of Uganda (ASOU). I became an executive member and served as assistant editor in 2009.

In a developing country like Uganda, a general surgeon in a rural setting often does all surgeries including fixing broken bones, trepanation to evacuate subdural/ extradural hematomas, releasing burn contractures, operating both on children and adults, urology procedures, removing foreign bodies in airways, and sometimes doing dental procedures. With limited medical or lab equipment available to assist with diagnosis, my clinical assessment skills grew. With extreme poverty and cultural superstitions, many postpone seeing a doctor until their case is severe!

In 2011, I was transferred to Soroti Regional Referral Hospital (SRRH), a government health facility, where I now work as consultant surgeon. SRRH, located 356 kms from Kampala in the north-east of Uganda, provides specialized and general health care, training, research and support supervision to other health facilities in a region of more than two million people.

I became interested in treating children when I was transferred to SRRH, after I observed the enormous disease burden and the challenge faced in the delivery of surgery, especially to the children. On the wards, mothers were on the floor with their children. They often waited for over a week for an operation. Sometimes they had to re-schedule appointments. Paediatric surgical conditions such as hernia, appendicitis, burns, gastroschisis require timely surgery, and if not properly managed lead to complications. In others, delay of surgery lead to death.

In my quest for a solution to the heavy burden of paediatric surgical conditions in my community, I resorted to conduction paediatric surgical camps in which a big number of children were operated. I shared my experience with colleagues at a conference in Vancouver and there was a dramatic response: we conducted surgical camps yearly at my hospital for six years. We received support from hospital managers, teams from University of British Columbia, Yale, Einstein, and Mulago University teaching hospitals. Specialist and their trainees, (paediatric surgery, general surgery, anaesthesia, urology) and nurses (ICU, perioperative care) participated in the surgeries and perioperative care.

The effects of the surgical camps were tremendous. For the children and families, having this type of specialized surgery, mostly in a hospital near to their homes, meant a lot. Vulnerable children born with abnormalities were given the opportunity of a better life. Conditions such as Hirschsprung's disease, imperforate anus and hypospadias require staged operations. Without proper surgery and care these children drop out of school. A colostomy but no colostomy bags is bad news! Marriages break up as men often blame women for giving birth to an abnormal child.

Usually after running these camps, parents continue bringing children in big numbers for surgery, now that they are aware that such conditions can be treated successfully. The experience and patient loads are overwhelming! However, I've realized that surgical camps are not the remedy to this problem. To make an impact and a real difference, I needed to carry out research. Scientific evidence was needed for me and my colleagues to explain the gravity of this problem to our policy-makers and political leaders. This is the reason why I enrolled to do a PhD course in paediatric surgery at Karolinska Institutet in Stockholm, Sweden.

For me as a PhD student, it was a period of intense mental nourishment, full of evidence-based learning. Step-by-step I learnt to be patient, persistent, and work hard to achieve my goal. I've interacted with people with different expertise and learnt skills in different disciplines. This has been a great learning experience, the opportunity to work with different groups. To participate in education of both Ugandan and international trainees was fun and professionally fulfilling and rewarding personally. I had outstanding supervisors and a mentor who guided me to do good research in paediatric surgery.

So far, we have done a nationwide and regional study. We had planned to look at the outcomes of paediatric surgery, and how to improve them, but the outbreak of the Covid-19 pandemic brought all the planned activities to a standstill. Should I choose to continue conducting further researches with facilities, outcomes of surgery on children is the way to go!

The future of any species lies in its offspring, and to ensure the continuity of any species, the older members protect and nurture their young. Woman has gone a step further and wishes the future generation to live better and healthier lives than she did.

It is my passion and aspiration that paediatric surgery be made by the policy makers a component of primary child health care.

## **ABBREVIATIONS**

Covid-19	Coronavirus disease, started 2019
DALY	Disability Adjusted Life Years
ENT	Ear Nose & Throat
GICS	Global Initiatives for Children's Surgery
GIPS	Global Initiative for Paediatric Surgery
GH	General Hospital
GPAS	Global Partners of Anaesthesia and Surgery
HC	Health Centre
HIC	High-Income Country
HIV	Human Immunodeficiency Virus
HDREC	Research Ethics Committee
IBM SPSS	IBM's Statistical Package for Social Science
ICU	Intensive Care Unit
I/M HDSS	Iganga-Mayuge Health Demographic Surveillance Site
IRB	Institutional Review Board
LMIC	Low- and Middle-Income Countries
MDGS	United Nations Millennium Development Goals
NGO	Non-Governmental Organization
NRH	National Referral Hospital
PI	Principal Investigator
PNFP	Private Not For Profit hospital
RRH	Regional Referral Hospital
RA	Research Assistant
SAVE	SAVE the Children International Organization
SOPS	Standard Operating Procedures
UG-REC	Uganda Research Ethics Committee
UN	United Nations
UNCST	Uganda National Council for Science and Technology
UNEPI	Uganda National Expanded Programme on Immunization
UNICEF	United Nations Children's Fund

USD	United States Dollar
VHT	Village Health Team
WFSA	World Federation of Societies of Anaesthesiologists
WHO	World Health Organization

## **Glossary and Definitions of terms as used in this work**

Anaesthesia	Insensitivity to pain, induced by administration of medicines or gases for purposes of carrying out surgical procedures
Anaesthetic assistant/officer	Health care worker with 2-3 years' training in anaesthesia at a reputable institution and certified by the Allied Health Professionals Council of Uganda (1).
Burden of disease	An aggregate measure of disease with respect to disabilities in a community.
Child	According to the Ugandan constitution and the UN Convention on the Rights of the Child, a child is defined as any person below the age of 18 years of age
Covid-19 pandemic	On March 11, 2020, the WHO classified Covid-19 as a pandemic caused by the coronavirus SARS-CoV-2. The first case in Uganda was diagnosed in March 2020 at Entebbe airport, in a passenger returning from Dubai (UAE)
DALY	The sum of potential life lost due to premature mortality and the years of productivity life lost due to disability
Disability	Any restriction or lack (resulting from an impairment) of ability to perform an activity in a manner or within the range considered normal for human being (2) (3)
Global health	An area of study, research, practice that places a priority on improving and achieving equity in health globally

Global surgery	The area of study, research, practice and advocacy that seeks to improve health outcomes and achieve health equity for all who need surgical and anaesthesia care (4)
HDSS	A research site with a known population, where population census is routinely done twice a year, and demographics of all births, deaths, and migrations are documented: the population is monitored regularly (5).
Hernia	Protrusion of a viscus or part of it through a defect or weakness in the abdominal cavity in which it is normally situated (6)
Health-seeking behaviour	Any action or inaction undertaken by individuals who feel they have a health problem or ill, for the purpose of finding an appropriate remedy (7)
Intern	Medical doctor who holds a degree in MBchB and is under placement in an accredited hospital
Major Surgery	Any procedure done in an operating theatre which requires incision, excision of tissues, when a patient is under general or local anaesthetic so as to control pain. (8)
Medical Officer	Medical doctor with five-year training in medical school and one year internship
Met need	Met need are children who have received the surgical care 07/02/2023 11:24:00
Minor surgery	Surgeries performed on superficial without general anaesthesia or respiratory assistance (10)
Paediatric surgery	A subspeciality of general surgery: “the diagnosis, operative, post-operative surgical care for children with congenital, and acquired anomalies and diseases, be they developmental, inflammatory, neoplastic or traumatic.” Notably, paediatric surgery is an operation done by a paediatric surgeon, the subspeciality with the same training (11)
Prevalence	The number of individuals in a defined population who have a particular disease condition or characteristics

Qualified Specialist	A doctor who has completed advanced education and training in a specific field of medicine
Residents	Medical officer doing a master's course in either surgery or anaesthesia
Snowball sampling	A technique in which one subject selects another. The process is repeated so that the group continues expanding like a rolling snowball (12)
Surgical disease	Any condition that requires incision, or excision and suturing or manipulation of tissues, and sedation under local, regional or general anaesthesia for intervention (13)
Timely access to surgery	Timely access to essential surgery is when a good percentage of a population can access surgery within two hours in a health facility that can perform emergency caesarean sections, laparotomies, fixing fractures, and hernias (14)
Unmet need	When a patient has a condition that requires surgical intervention but has not received the surgical care needed (15)(16)
Three-Delay Model	A three-delay-model framework provided a useful tool to examine factors influencing the timeliness of care (17)
VHT	The village health teams are non-statutory community(village) structures selected by the people themselves to manage all matters related to health. VHTs functions is to bridge the health service delivery between the community and the health facilities (18)
HC II &III	can diagnose and treat simple cases and refer others to HC IV
GH & HC IV	offer basic preventive, curative, and rehabilitation in their immediate catchment area. They provide second-level referral services including life-saving medical, surgical, and obstetrical emergency care as blood transfusion services are available (19)
RRH	Regional Referral hospitals offer specialised services such as psychiatry, ear, nose and throat, radiology, ophthalmology, higher-level surgical, obstetric and medical services. RRHs also teach and do research as well as the services offered in the general hospitals (19)
NRH	The National Referral Hospitals offer specialised, and super-specialised services such cardiothoracic, neurology, urology, and nephrology, in addition to the services offered at the regional referral hospitals (19)

## **1 INTRODUCTION**

### **1.1 UGANDA**

#### **1.1.1 Country profile**

Uganda, the Pearl of Africa, is a land-locked country, bordering Sudan to the North, the Democratic Republic of Congo to the West, Kenya to the East, and Tanzania and Rwanda to the South. It has a fast population growth of 3.3% per year, and a fertility rate of 4.55 births per woman (20, 21). As a result, the population increased from 23.6 million in 2010 to 45.7 million in 2020 (22). Over half the population (51.6%) is below 18 years of age (23). Uganda is a low-income country with more than 20% of her population living below the poverty line. In 2021 the GDP corresponded to USD 40.4 billion, and GDP per capita to USD 858.1 (24).

#### **1.1.2 Structure of the Health System**

The health care system of Uganda has been decentralized and the health services are delivered through tiered hierarchical levels of care with increasing scope and complexity from the Village Health Teams (VHTs) at community level to the national referral hospitals. In between these levels are Regional Referral Hospitals (RRHs), general hospitals and Health Centres (HC) IV, III, and II within seven tiers (Fig 1) (25).

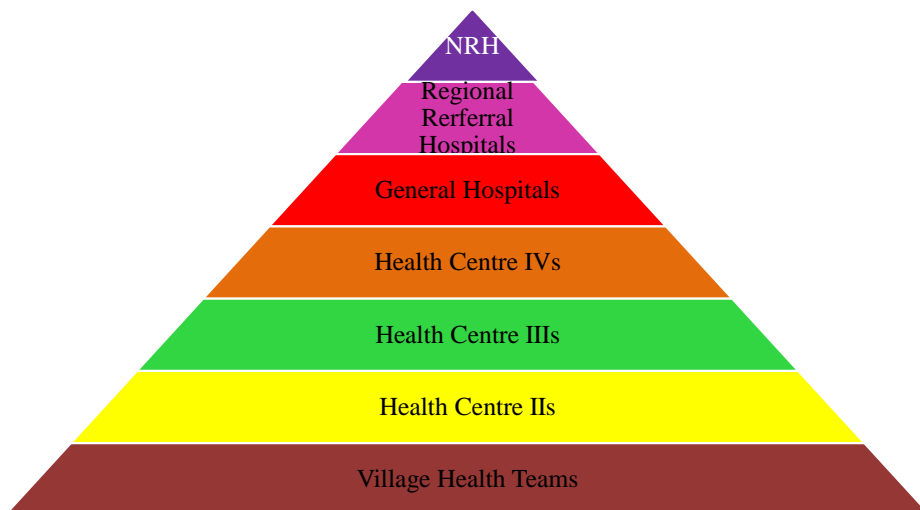
The village health teams are non-statutory community (village) structures selected by the people themselves to manage all matters related to health. Their function is to bridge health service delivery between the community and the health facilities (18). Therefore, the starting point of contact in the health system is through the VHT, which then refers the patient to health centre II. Patients are also free to go to hospital at any level if they wish, depending on the urgency and type of medical service required. HCs II and III have the capacity to diagnose and treat simple cases and refer others to HC IV or higher.

HC IV and General Hospitals (GHs, level V) are mostly intended for a catchment population of about 500,000. They offer basic preventive, curative, and rehabilitation services in their immediate catchment area. They provide second-level referral services including life-saving medical, surgical, and obstetric emergency care with blood transfusion services available (19).

The Regional Referral Hospitals with a catchment population of about 2 million offer specialised services such as psychiatry, ear, nose and throat (ENT), radiology, ophthalmology and higher-level surgical, obstetric and medical services. RRHs also teach and do research in addition to the services offered in the general hospitals (19).

The National Referral Hospitals were designed to provide the entire population with specialized and super-specialised services such cardiothoracic, neurological, urological, nephrological and paediatric surgery, in addition to the services offered at the regional

referral hospitals (19). Since these facilities were constructed and equipped the population has greatly increased.



**Figure. 1** Structure of the health care system in Uganda  
NRH – National Referral Hospital

At present (2023) there are 6,937 health facilities in Uganda. These include public/government-owned 45%, Private Not For Profit (PNFP) 40.29%, Private 14.44% and community-owned facilities (0.10%) (26). Both the public and private sectors play an important role in supporting communities to improve their health.

### 1.1.3 Surgical human workforce

A well-performing health workforce is crucial for timely delivery of surgical services. This is possible if there are adequate numbers for all cadres required to deliver this service. Health staff of different disciplines include general surgeons, medical doctors, those trained in anaesthesia, nurses, as well as support staff. Despite a numerical improvement from 45,000 in 2008 to about 118,236 in 2020, Uganda's health workforce remains insufficient to achieve universal health coverage. This has led to inadequate distribution with low staffing in rural areas as compared to urban areas.

According to the human resource audit of 2020, the overall national staffing level is 74% of the approved public sector positions (27). A study done in Uganda to assess surgical capacity and anaesthesia found a rate of 0.3 non-physician anaesthesia providers per 100,000 people and concluded that the surgical capacity of Uganda's public hospitals falls below international standards: evidencing a lack of an adequate, vital workforce to provide safe surgery in the country (28).



A comprehensive analysis of the surgical workforce in Uganda identified challenges to workforce development, representative of other low-income countries (29). For the individual patient, the surgical workforce includes those with skills to identify and prepare patients for surgical procedures, to perform safe operations with appropriate anaesthesia, and to care for these patients after surgery.



## **2 LITERATURE REVIEW**

### **2.1 GLOBAL SURGERY**

During the past few years, surgery has been put on the global health agenda. Global surgery is defined as: “An area for study, research, and advocacy that places priority on improving health outcomes and achieving health equity for all people worldwide who are affected by surgical conditions or have a need for surgical care” (30).

Surgical conditions account for the loss of 16.9 million lives yearly worldwide, which is more than deaths from tuberculosis, HIV and malaria combined. It is estimated that conditions that could be treated successfully with surgery contribute with 28-32% of the world’s disease burden expressed in DALYs (31). Many countries in sub-Saharan Africa belong to the group with the world’s highest burden of surgical disease, where it has been estimated that the prevalence of surgical conditions may exceed 40%. (32).

Surgery has previously been regarded as too costly to serve as an important part of global health initiatives (33). This misconception is part of the reason why the burden of surgical disease has not been matched with adequate resource allocation for the treatment of these conditions. This has resulted in a large unmet surgical need in the world (34). Contrary to this belief, surgical interventions such as inguinal hernia repair, hydrocephalus, and cataract repair, have cost-effectiveness ratios per DALY that match that of undisputed health interventions such as immunization programmes and bed nets to prevent malaria (35).

A key message in the 2015 Lancet Commission on Global Surgery report was that “5 billion people do not have access to safe, affordable surgical and anaesthesia care whenever it is needed”. Most of these five billion people live in low- and middle-income countries (LMICs) where nine out of ten people lack access to surgery (31). The people living in the poorest third of the world only receive 6.3% of the surgical procedures carried out globally (36). Of the 48 countries in sub-Saharan Africa, 37 have a per capita health care expenditure below 100 USD per year (37).

Also, in 2015, the sixty-eighth World Health Assembly noted that surgically treatable conditions are among the 15 leading diseases causing disability in the world and that the burden of disease due to these conditions will increase in coming years. Emergency and essential surgical care must therefore be strengthened as a component of universal health coverage (38, 39).

In LMICs, essential surgical procedures have the potential to avert about 1.5 million deaths per year, or 6-7% of the global burden of disease (40). If access to surgery does not improve between 2015 and 2030, there will be loss of income to LMICs, of about 12.3 trillion USD (31).

LMICs have young populations, and therefore, a large proportion of people without access to timely and affordable surgical services are children. Their access to surgical care is even more constrained than adults' (32, 41). Among other institutions, the WHO Global Initiative of Emergency and Essential Surgical Care has pointed out that paediatric surgery should be a priority within the global surgery movement (14).

## 2.2 PAEDIATRIC SURGERY OR SURGERY FOR CHILDREN

Paediatric surgery is a subspeciality of general surgery and is defined as “the diagnostic, operative, post-operative surgical care for children with congenital, and acquired anomalies and diseases, be they developmental, inflammatory, neoplastic or traumatic. It is broad and includes surgical problems *in utero*, in infancy, childhood and young adulthood” (11). Notably, paediatric surgery means operations performed by paediatric surgeons, the subspeciality with the appropriate training. Paediatric surgery is mostly considered to be a speciality that provides advanced surgical care for children. Examples of conditions treated are diaphragmatic defects, Hirschsprung's disease, gastroschisis, oesophageal atresia, and vascular malformations. Other procedures such as groin hernia repair and appendicectomy may not require paediatric surgical specialists and often general surgeons perform these procedures. This however varies much between countries and even hospitals. To a certain extent, paediatric surgery is used interchangeably with surgery for children

**Surgery for children** is any operation/surgery that is done on children (42). Several surgical specialities are involved in the delivery of surgical care for children. These include neurosurgery, orthopaedics, plastic surgery, urology, and ENT and, depending on the setting, they may be further subspecialised to perform surgery on children. Therefore, a tonsillectomy done in a child is called ENT surgery and not paediatric surgery. There is extensive overlap between specialities, in particular general surgery and paediatric surgery.

The Global Initiative for Children's Surgery (GICS) was founded in 2016 to identify solutions to children's problems in surgery, utilising the expertise of practitioners from around the world. This initiative encompasses all surgery for children. The GICS has promoted the development of partnerships within LMICs and between HICs and LMICs (43). Worldwide collaboration with leadership providers from LMICs will lead to the improvement of timely and affordable surgical care for all children.

The GICS vision is that every child in the world with a surgical need should have access to resources that would enhance his or her surgical care (44). GICS members named four pillars for priority improvement for children's surgical care: service delivery, training, research, and infrastructure. They also developed guidelines for delivery of care at every healthcare level (43). The guidelines were ranked according to the subspeciality and level of healthcare as: first, second, and third hospitals and the national children's hospital (45). GICS document also specified the personnel, equipment, paediatric surgical procedures, training, research, and quality improvement at all levels of care (43).

### **2.2.1 Surgery for children in sub-Saharan Africa**

Children are vulnerable and dependent on their parents or caretakers for care. The Ugandan constitution and the UN Convention on the Rights of the Child define a child as any person below the age of 18 (46, 47).

Despite the increased awareness of surgical conditions in global health, little has been done in the field of paediatric surgery. However, there are numerous reasons why paediatric surgery should receive more attention. A considerable proportion of all surgical conditions affect children (48), and it has been estimated that 85% of all children in LMICs will require surgery before their 15<sup>th</sup> birthday. Also, life-threatening conditions such as incarcerated hernias can be successfully corrected by surgical intervention (49).

There is compelling evidence that the quality of the basic surgical care for children is compromised in hospitals especially in low-resourced countries in Sub Saharan Africa. This widespread quality gap suggests a potential for improved health systems at all levels to cater for children with surgical need (50).

Advocacy for child health, including surgical care, requires a multidisciplinary approach, (i.e., paediatric surgery, general surgery, anaesthesia, nursing) to create awareness of surgical conditions in children. This starts with the individual child and their family and extends to local, regional and national levels. It is also very important to design programmes that include patient follow-up, and that parents are supported and educated on how to identify post-operative complications and to report to responsible health providers.

### **2.2.2 Surgery for children in Uganda**

Uganda with a population of 20 million children has an enormous unmet need for paediatric surgical care (16). There are numerous obstacles to increasing surgical capacity for children, especially in rural regions. These include shortages of workforce, poor infrastructure and equipment, late presentation due to the poor referral system, and long distance to the nearest health facility (51). The World Health Organization recommends that surgical care should be available within a radius of about 50 kms (52).

As mentioned above, there are at present only four paediatric surgeons in the country to serve a population that would require about 200 (53). All four are based in urban settings (54). Although 80% of the population live in rural areas, 95% of surgeons practice in the cities (55). Surgery for children is therefore delivered by general surgeons and this ensures some access to paediatric operations for those living in rural regions (56).

Anaesthesiologists are essential providers of surgical services. The training of paediatric anaesthesiologists and subspecialists is still very low (57). A study in 64 Ugandan public hospitals found only 5% of the hospitals met the requirements of the World Federation of Societies of Anaesthesiologists (WFSA): 84% had no trained physician anaesthetist, and 8% had no trained anaesthetist at all (58). Some hospitals lacked equipment for safe delivery of anaesthesia, and there were frequent stockouts of essential anaesthetic drugs (58).

To increase access to surgical care for children, Uganda introduced surgical camps to deal with volumes of patients needing surgery (59). However, these were not a sustainable solution for these procedures which are needed continuously. A policy change is required that prioritises a sustainable improvement of surgical care for children.

### **2.2.3 Burden of disease due to surgical conditions in children**

By defining the need, the United Nations Millennium Development Goals (MDGs) through the ongoing work on Sustainable Development Goals (SDGs) has made progress towards reducing childhood mortality (60). Despite this, children with surgical diseases remain under-prioritised, and under-represented in health care provision (61). Congenital abnormalities make up 9% of the surgical burden of disease worldwide, of which two-thirds can be avoided with surgical interventions (62). Tumours, abdominal emergencies and trauma contribute to the burden of disease at all ages (63). It is estimated that one-third of all childhood deaths worldwide are due to a surgical condition (64).

Population-based research into paediatric surgical conditions has been carried out in Uganda, Sierra Leone, Rwanda and Nepal. It was found that 19% of the children had a surgical condition and a majority of these had at least one unmet need (65). In Uganda, the prevalence of untreated surgical conditions was 7.4% (66). These studies however used questionnaire-based interviews and the results were not confirmed by physical examination of the children, which is essential for accurate estimation (67). Therefore, research employing physical examination to confirm the diagnoses is called for.

Surgical conditions can be grouped in several ways. Important groups for children are congenital anomalies, injuries/trauma, infections and cancer.

### **2.2.4 Congenital anomalies**

Congenital anomalies constitute a wide group of conditions. Each year, approximately 240,000 children worldwide die due to congenital anomalies within four weeks of birth (68). Studies in developing countries show that the incidence of congenital anomalies is as high as 84.85 per 1000 children (69). A study done in Uganda demonstrated that anomalies that are not immediately lethal contribute to long-term disability with subsequent effects on the individual, family and economy (70).

Many congenital anomalies are amenable by surgery which can save lives and reduce morbidity with good cost-effectiveness (71). Examples of congenital anomalies that require surgical care in Africa include inguinal hernias, malformations in the genitourinary and anorectal tracts, cleft lip and palate, and meningocele (49).

### **2.2.5 Traumatic Conditions**

Injury and violence kill 900 000 children annually and cause lifelong disabilities for millions of children (72). Disability has been defined as any restriction (resulting from an impairment) of ability to perform an activity in a manner or within the range considered normal for

humans (2, 3). Children in low-resource countries are at increased risk of unintentional injuries compared to children in rich countries (72, 73). In a previous publication from Uganda, Butler et al showed that injury-related conditions accounted for nearly 50% of the surgical need in children (74).

A large proportion of the deaths and disability due to injury and violence could be prevented and mitigated by surgical interventions. The quality, availability and access to medical care are important for surviving an injury. Few LMICs have information systems for injuries and long-term consequences thereof (72). Therefore, the actual extent of paediatric trauma is not known (75). Developing intervention strategies to address the burden of trauma is limited due to the absence of primary data. (76).

Burns in children are reportedly amongst the most prevalent traumatic injuries in the world (77). Burns can be devastating injuries for children; the immediate effect is pain often requiring serial dressings and sometimes surgery. If not adequately managed these injuries can lead to complications such as contractures that require plastic surgery (78). Considerable progress has been made in middle- and high-income countries in lowering the rates of injury and death due to burns for children. However, most of these advances have been applied but minimally in low-income countries, where most deaths due to burns occur (79).

Despite the heavy toll of injury in LMICs, there is great limitation to accessing surgical care because of the major deficiencies in the health system (80). In 2017, Uganda was ranked number 4 of 15 Sub-Saharan countries with disability-adjusted life years (DALY) due to road traffic collisions (81). Most injured patients involved in road traffic accidents were either passengers or drivers. Almost 62.7% of the road traffic collisions involved a motorcycle (76). Motorcycles are a common mode of transport in Uganda and most riders do not use helmets. They often carry more than one passenger against the traffic rules, endangering lives.



**Figures 2, 3, 4** Unsafe motorcycle riding

### **2.2.6 Malignant conditions**

Over 400,000 children and adolescents worldwide each year develop cancer (82). Most common cancers are solid tumours such as neuroblastomas, Wilms' tumour, Hodgkin's lymphoma and non-Hodgkin's lymphoma such as Burkitt's lymphoma; and brain cancers (83). Survival of cancer patients depends on early and accurate diagnosis. In the study by



Butler et al, tumours contributed 23.8% of the conditions detected, and children with abdominal conditions requiring surgical intervention accounted for 4.7% (84).

In high-income countries (HICs), more than 80% of children with cancer are cured as compared to less than 30% in LMICs (85). Most childhood cancers can be cured by generic medicines, surgery and radiotherapy (83). The low cure rate in LMICs is due to delay in diagnosis, inability to obtain an accurate diagnosis, inaccessible therapy, abandonment of treatment, death from toxicity, and relapse (86).

Only 29% of low-income countries report that cancer medicines are generally available to their population as compared to 96% of high-income countries (86). Survival of children with cancer depends on improving access to care, essential drugs and technology that is highly cost-effective and feasible for all (86). Palliative care relieves cancer symptoms and improves the quality of life of patients and their families. Current studies show that about 10% of all children with cancer have a genetic predisposition, but further research is needed to identify the factors affecting cancer development in children (87)

### **2.2.7 Factors affecting access to paediatric surgery**

Many factors contribute to the lack of access to paediatric surgery. These can be classified in the three-delays model, which characterises the delay between onset of symptoms and an appropriate health care intervention (88) as follows.

*The first delay in seeking surgical care* includes issues relating to health-seeking behaviour of a family that makes decisions when a child is sick. An elder in the family plays a role in giving permission to go for health care. Women's status in that community is another barrier (89). However, women with education act swiftly whenever their children need medical care (90). Lack of finances is a big hindrance too, delaying treatment until funds are available (91). Sometimes the caretakers did not seek surgical care because the health facilities are very far away. Quality of care in the health facility is also an important consideration in a decision to seek care. A study done in Uganda confirmed that home-based care remains the first line of treatment. Only when a child fails to improve will he or she be brought to hospital (92). Parents sometimes resort to other remedies such as those offered by traditional healers, often with poor outcome, as shown in the photo below, Figure 5.



**Figure 5.** Late presentation of fracture of radius and ulna, after home treatment by a bone setter, a traditional healer

*Second delay, transport to the health facility.* This depends on availability of transport to health facilities including financial resources to pay for them. Sometimes travel time to a hospital for definitive treatment can be several days, causing delay. Bad roads, especially during the rainy season; floods destroy bridges, preventing caretakers from reaching the facility (93).

*Third delay, provision of adequate care.* Delays in delivering care at the health facility depend on several issues including human resources. There is a major shortage of paediatric surgeons in Africa, where there are often fewer than one paediatric surgeon per million children (89). The situation is worsened by the lack of trained paediatric anaesthesiologists (94). Other factors include lack of specialized paediatric nurses, essential equipment and supplies, drugs, blood, and infrastructure to perform operations. Limitations to the structural level of the healthcare system also exist (95). Some health workers have a bad attitude towards their patients; others are not competent to perform the required surgical care. These factors contribute to delays in timely provision of needed care (93).

Barriers to surgery for children in Uganda are reportedly not well understood and further research is warranted.

The limited access to and utilisation of surgical services for children result in late presentation with advanced disease that is challenging to manage, as illustrated in Figure 6.



**Figure 6.** Late presentation of: 1. Hirschsprung's disease, 2. imperforate anus, 3 obstructed gangrenous right inguinoscrotal hernia.

### 2.2.8 Local outbreaks, epidemics and pandemics

Local outbreaks such as the recent Ebola outbreak in Uganda, and epidemics and pandemics such as the COVID-19 pandemic are expected to occur in the future. Healthcare systems must be prepared to limit the impact on routine healthcare and on society at large. Therefore, each outbreak or epidemic is a source for new knowledge that can be used to improve preparedness for the future.

The COVID-19 pandemic has had an enormous impact on healthcare delivery worldwide (96). People lived in fear of contracting the deadly virus. Globally, as of 14th November 2022, the cumulative number of deaths was 6,588,850 people (97), and in Uganda it was 3,630 (98). In 2020 UNICEF and Save the Children projected that one-hundred-and-fifty million additional children in the world would be living in poverty, without access to education, health care, housing, nutrition, water or sanitation due to the impact of Covid-19 pandemic (99).

To minimize the spread of Covid-19, Uganda introduced a total, phased lockdown. From March to June 2020 the lockdown included a ban on social gatherings, motorcycle taxis and busses, and only cargo transport and essential emergency services were allowed. Only essential workers were allowed to travel and in hospitals elective surgical procedures were suspended (100). A second total lockdown was declared on June 7, 2021. Schools for children aged 5-17 were closed from March 2020 to January 2022 when most restrictions were revoked (100). This resulted in a high rate of school dropout and teenage pregnancies.

“Schools at least provide girls some degree of protection from domestic abuse; when the schools closed down, they had nowhere to go” (101)

The extent to which surgical services for children and access to these in Uganda were affected had not been investigated.

### **3 RESEARCH AIMS**

The overall aim of the work reported in this thesis was to address the knowledge of paediatric surgery in Uganda. This included the burden of disease and the met and unmet needs for surgery for children, identifying barriers and solutions to quality surgical care and, finally, assessing the impact of covid-19 on access to surgical care for children.

Specific aims were to:

- investigate the prevalence of paediatric surgical conditions in Eastern Uganda. (Study I),
- determine the volume and type of surgical procedure for children in the public healthcare sector in Uganda. (Study II),
- explore the barriers to, the factors promoting and the quality of, hernia surgery for children in eastern Uganda. (Study III),
- investigate the impact of Covid-19 on access to paediatric surgery in eastern Uganda. (Study IV).



## 4 MATERIALS AND METHODS

The methods and material used for conducting the studies are shown in Table 1.

Table 1. Methods used in the four studies

Study	Methodology	Inclusion criteria	Outcome measure
I. Prevalence of Paediatric Surgical Conditions in Eastern Uganda: A Cross-Sectional Study	Cross-sectional, cluster-based study	Children below 18 years of age at the Iganga-Mayuge Health Demographic Surveillance site at time of study	Prevalence of paediatric surgical conditions in children
II. Surgical procedures for children in public healthcare sector: nationwide, facility-based study in Uganda	Retrospective facility-based records review	Data included for all major surgical procedures for children below 18 years in the study hospitals	Number of procedures performed, indications and types of procedures performed, level of training of surgeons and anaesthetists providing surgical services for children
III. Barriers to and potential solutions for improved surgical care for children with hernia in Eastern Uganda	Qualitative, interview-based study	Parents with children below 18 presenting to SRRH with confirmed diagnosis of hernia during study period	Barriers to surgical services and potential solutions to overcome these barriers
IV. Impact of Covid-19 on access to surgery for children in Teso sub-Region in eastern Uganda	Mixed method study combining quantitative registry-based hospital data and qualitative interview-based data	Ability to give written or thumb-printed informed consent, and willingness to take part in study	Volumes of surgery for children performed before and during the Covid-19 pandemic, barriers to surgical care for children and potential solutions to overcome these barriers

### 4.1 STUDY I. PREVALENCE OF PAEDIATRIC SURGICAL CONDITIONS IN EASTERN UGANDA: A CROSS-SECTIONAL STUDY

#### *Study setting*

This cross-sectional cluster-based study was conducted at the Iganga-Mayuge Health Demographic Surveillance Site (I/M HDSS) in Eastern Uganda. The I/M HDSS is a defined geographical area with, normally, a routine biennial population census. All births, deaths, and migrations are documented (5). The Site has 65 villages and all the house structures in them have an identification number (5). Using the HDSS for epidemiological research is useful as it provides a denominator to calculate incidence and prevalence of conditions by

age. It was started by Makerere University in partnership with Karolinska Institutet to serve as a platform for training and research (5).

#### *Study sample*

A sample size of 490 households was calculated according to the B.S. Wood et al. formula shown below (102):

$$C = \frac{p(1-p)D}{s^2b} \quad \text{Where } s = \frac{\text{CI-width}}{C\text{-alpha}}$$

C= Number of villages; P=0.54; D= design effect =1.5; s=standard error; CI-width=0.054; C-alpha=1.96; b= number of households per village=10.

A statistician at the I/M HDSS sampled villages and households from the database through a two-cluster stage process. First, 49 of the 65 villages were randomly sampled. Thereafter, 10 households based on their identification number in each village were randomly selected, making a total of 490 households.

#### *Recruitment of study participants*

All children below 18 years, and resident at the I/M HDSS were eligible for the study. A resident was defined as a person who had lived in that area for at least four months. New-borns under the age of 4 months residing in an H/M HDSS household were also considered residents.

#### *Data collection*

Before data collection commenced, all the leaders of the 49 villages were invited for a meeting at which they were informed about the visit of the research team to their villages and the purpose of the visit. They were tasked to create awareness in all their people.

A team of two doctors, one of them a consultant surgeon (the primary investigator, PI) and two research assistants (RAs) set off to collect data from the community. In pairs they visited the households and conducted a questionnaire-based interview with the parents/guardians of children below 18 years after the former had signed informed consent forms. Children above 8 years also signed the informed Assent forms. The data included demographic information, type of delivery, place for delivery, and who conducted the delivery.

Any disease or abnormality or previous injury stated by the study participants was noted.





**Figures 7 and 8.** Village leaders attending the meeting

Included in the questionnaire was the number of children the family had, any death registered and cause of death. Weight, height, arm circumference and head circumference were measured. Prior to data collection, the PI and a team from the I/M HDSS trained the research assistants on how to administer the questionnaire tool to ensure accuracy of the results.

Thereafter, the doctors did a physical examination from head to toe, noting the presence of any surgical conditions and signs of previous surgery (scars). The findings were noted in the data collection tool. Below are illustrated some of the activities.



**Figure 9.** A PI and research team at the I/M HDSS



**Figure 10.** The research team sets out from the I/M HDSS



**Figure 11.** Group 1,  
(PI & Research Assistant)



**Figure 12.** Group 2  
(Medical Officer & Research Assistant)



**Figure 13.** Children aged 8 years and above  
signing the Assent form



**Figure 14.** Weighing...



**Figure 15.** Measuring head circumference    **Figure 16.** Child had surgery once at three weeks

#### *Ethical considerations*

All photos were taken following informed written permission from the participants.

Young children were examined in the presence of their parents, while for privacy reasons adolescents were examined alone. Individual solutions were found for the children who were found to have a surgical condition. The PI organized a surgical camp where conditions such as hernia, cryptorchidism, simple masses, hydroceles, polydactyly were operated on. More complex cases were referred after personal communication with the surgeon at the receiving institution.

## **4.2 STUDY II. SURGICAL PROCEDURES FOR CHILDREN IN THE PUBLIC HEALTHCARE SECTOR: A NATIONWIDE, FACILITY-BASED STUDY IN UGANDA**

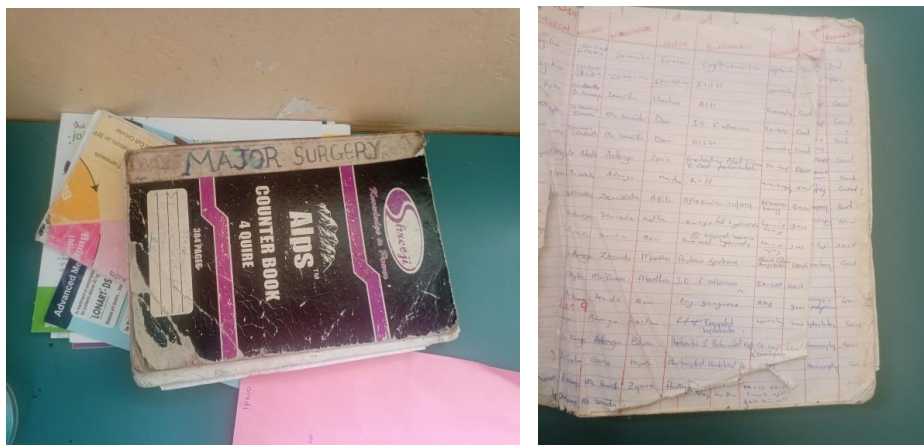
### *Study setting*

This retrospective study reviewed operating theatre logbooks in 29 hospitals throughout Uganda. Among these were the National Referral Hospital (Mulago), all Regional Referral Hospitals at the time (n=14), and one district-level hospital located in the catchment area of each Regional Referral Hospital (n=14). The study period was 2013-2014.



### *Data collection*

The data were collected in 2015 and 2017. All 29 hospitals were visited, and the logbooks were photographed after covering the names of the patients. The hospital directors of each hospital approved the data collection in their respective hospital.



**Figure 17.** Operating theatre logbooks

Thereafter, data on major surgical procedures performed on children below 18 years were entered into Excel spreadsheets. “A major surgical procedure” was defined as any procedure conducted in an operating theatre and involving incision, excision, manipulation or suturing of tissue, which usually requires regional or general anaesthesia, or profound sedation to control pain” (8). The data included age and sex of the patients, month, year, diagnosis, type of surgery performed, surgeon, anaesthetists and type of anaesthesia used.

### *Data analysis*

Only complete data was used for identification of common conditions and procedures. Two hospitals with incomplete data were subsequently excluded from the analysis. One lacked data for the complete study period and the other omitted patients’ ages, making it difficult to extract paediatric data.

Pearson’s *t* test was used for group comparison, while for the identification between indications for surgery and patients’ characteristics we used a chi-squared test. Missing data on the number of procedures performed were handled by multiple imputation. The 2014 national census for Uganda was used for calculating the rate of surgical procedures for children per 100,000 child population (age group 0-17) in 2014 (103). Calculation of the Ugandan paediatric population for the years 2013 and 2014 was based on the 2014 population census.

#### **4.3 STUDY III. BARRIERS AND POTENTIAL SOLUTIONS FOR IMPROVED SURGICAL CARE FOR CHILDREN WITH HERNIA IN EASTERN UGANDA**

##### *Study setting*

This qualitative study was carried out at Soroti Regional Referral Hospital in Eastern Uganda where the population predominantly live in rural locations. The primary investigator carried out the interviews using two interview guides consisting of a set number of open-ended questions (appendices 1 & 5).

##### *Study participants*

The study participants were parents of children below 18 years who had been admitted to hospital for hernia surgery, and health workers at the hospital. A snowball sampling technique was used for recruiting health workers to participate. “Snowball sampling is a nonprobability sampling technique, where existing study subjects recruit further subjects from among their acquaintances. Thus, the sample group is said to grow like a rolling snowball” (12).

##### *Data collection*

The parents were interviewed in the local language, Ateso or English depending on their preference. All health care workers were interviewed in English. The questions explored barriers to and promoting factors for surgical care for children, Appendix 1.

All the interviews were voice-recorded so that no information was lost. Interviews were transcribed verbatim by the PI. The analysis was done with qualitative thematic content analysis as described by Burnard et al. This process starts from the transcribed text and step-by-step leads towards a higher level of condensation and abstraction (104). The analysis was carried out by the first author and third author. The latter had access to the transcribed material and contributed to the precision of the content analysis by independently double-coding as well in discussions throughout the process. The first and second authors then open-coded independently, noting words and short phrases that summed up what was being said in the interviews. The second step was to match subcategories and group them into new categories. Meaningful units were identified consisting of paragraphs and phrases constituting a special meaning. Finally, the subcategories and categories were summarized into two main themes.

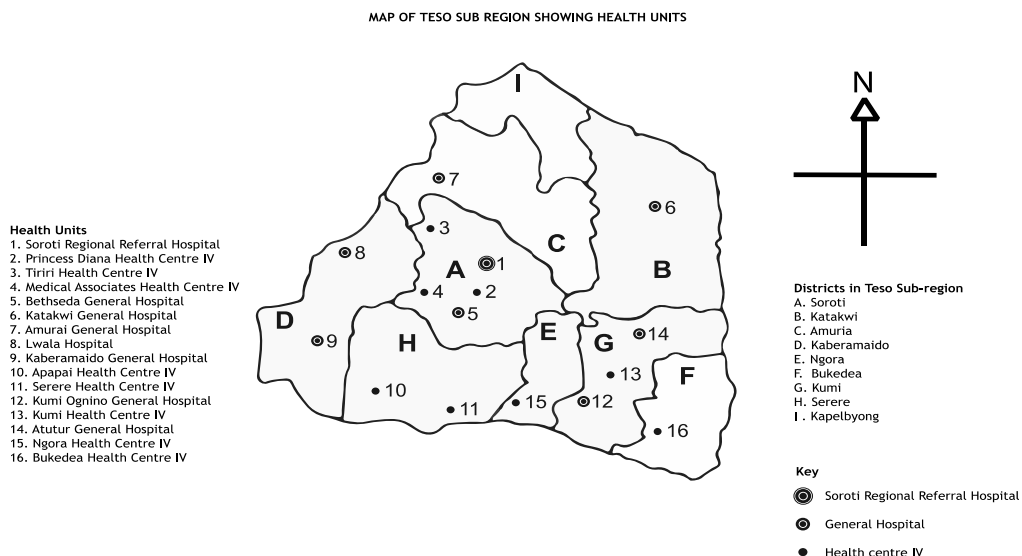


**Figure 18.** Soroti Regional Referral Hospital where the interviews were conducted

#### **4.4 STUDY IV. IMPACT OF COVID-19 ON ACCESS TO SURGERY FOR CHILDREN IN TESO SUB-REGION IN EASTERN UGANDA**

##### *Study setting*

Study IV, a mixed-methods study, combined hospital data from operating theatre records with qualitative data obtained by interviewing selected health facilities and communities within the Teso sub-region in Eastern Uganda, Fig 19.



**Fig 19.** Map of Teso sub-region showing the districts and health facilities

### *Data collection*

This study was carried out during the Covid-19 pandemic, and standard operating procedures (SOPs) had to be strictly adhered to. A team of three led by the primary investigator visited all 19 health facilities that perform surgery in the Teso sub-region. However, three health facilities were excluded because by the time of the study no surgery was being undertaken. Digital cameras were used for capturing data from the operating theatre logbooks. Data of patients below 18 years at the time of their operation were entered into Excel spreadsheets. All types of surgical procedures were included, regardless of surgical specialty and both major and minor procedures were considered. Patient's age, sex, diagnosis and type of procedure were captured.

For the second part of the study, seven healthcare facilities were randomly selected from the 16 health units performing surgery in the Teso sub-region, and the health workers were interviewed by the primary investigator. Informants included doctors, theatre and ward nurses, and non-physician anaesthetists. For the interviews with community members, one urban and one rural community were selected. Their community leaders were asked to identify a family where a child had recently been operated on. Snowball sampling was used for subsequent households.

Interviews were conducted after written informed consent from the informants and the staff-in-charge of all the health units. All photos were taken with the participants' permission.



**Figure 20.** The PI having an interview with a doctor



**Figure 21.** The PI having a discussion with a nurse





**Figure 22.** The PI with a parent of a child with a hernia

### *Quantitative data analysis*

Data on all surgical procedures, both minor and major, carried out on patients below 18 years were captured by the first author. Date, age, sex, indication for surgery and surgical procedure done were extracted and entered in Excel spreadsheets. The data were analysed using the IBM Statistical Package for the Social Sciences (SSPS).

### *Qualitative data analysis*

The first author, who was also the PI, conducted all the interviews. The interviews were recorded using an Olympus digital voice recorder and thereafter transcribed verbatim by the primary investigator. This resulted in close familiarity with the material, which is desirable in reflexive thematic analysis. The analysis procedure was carried out according to the six-phase model described by Braun & Clarke (105).

#### **Phase I.** Familiarization with the data

The first phase was an active reading of the transcribed text while writing down ideas and thoughts.

#### **Phase II.** Generating initial codes

In the second stage, the transcripts were read again with the aim of creating initial “codes”. A code corresponds to the content of the material that answers the research question and is created by reformulating the content of the text that is interesting for the question, the “data

extract”. The same data extract often receives several different codes at this stage. See example of the data extracts below.

**Table 2.** Example of data extract and code according to the analysis procedure. Data extract consists of verbatim quotes from the informant. Codes representing how the quote is interesting for the questions (Braun and Clarke,2006) were compiled and sent to the other authors for joint review and checking for agreement.

Data extract	Code
Some parents feared to bring children for surgical care, because they heard covid-19 patients were in hospital, so they feared to bring children for surgical interventions, resulting in some arriving in bad conditions and prognosis was bad.	<ol style="list-style-type: none"> <li>1. People were fearing to go to hospital</li> <li>2. Children were brought in bad condition, with poor prognosis</li> </ol>

### **Phase III.** Searching for themes

Data extracts and initial codes. This phase involves sorting the different codes into potential themes, collating all the relevant coded data extracts within the identified themes. The codes were then collected by the first author based on relevance to initial themes and sub-themes that emerged during the previous phase of analysis. At this point there comes a sense of significance of each individual theme.

### **Phase IV.** Reviewing themes

Phase IV involved a joint review of the initial themes, first in relation to the data extracts behind the codes and then in relation to the material. This step is crucial to ensure that the initial themes are consistent with the material.

### **Phase V.** Defining and naming themes

In the fifth phase, two themes; (a) conflict between reality and perception of the situation during the pandemic and (b) lessons learnt/ way forward. Four subtypes identified were first delay, second delay, third delay, also known as organizational regulations, and economic constraints. The authors then created a thematic map of the analysis, and the entire material was read through once more to identify additional data extracts that could fit under the respective themes and subthemes.

## **Phase VI. Producing the report**

The first author then wrote an account of each theme and respective subthemes based on its content in a report that was sent to the other authors for joint review and discussion. This was the final step in the analysis process. The sub-themes and the main text were later slightly revised, and the essence of the themes was further defined and named. The results are presented under the heading Themes in Results, below. De-identified quotes approved by the informants exemplify the themes and sub-themes.

## **Ethical Considerations**

Studies were all done following ethical approval from a recognized institutional review board, and written permission from those in charge of health units when applicable.

### **4.5 ETHICAL APPROVAL**

#### **4.5.1 Studies I and III**

Studies I and III were carried out after ethical approval from Makerere University School of Public Health (protocol identification number 542) approved on April 22, 2019). Approval from the National Council was also obtained (identity number SS 4608).

Interviews with the respondents in Study I were undertaken after written or thumb-printed informed consent. Children over 8 years gave written or thumb-printed informed assent prior to carrying out physical examination.

For Study III, the Hospital Director of SRRH gave written permission to conduct the study in the hospital.

#### **4.5.2 Study II**

Ethical approval was granted by the Makerere University School of Public Health (HDREC 076) and the Uganda National Council of Science and Technology (HS1892). The Medical Superintendent of each hospital approved collection of data from the theatre log books. The retrospective nature of the study meant that the treatment delivered to the patients was not affected. To protect their integrity, patients' names were not included.

#### **4.5.3 Study IV**

The study was conducted following ethical approval from the Research Ethics Committee (REC) Mbale, ref number UG-REC-011. The Uganda National Council of Science and Technology (UNCST) ref HS2205ES approved the study on April 04, 2022.

Permission was also granted by the Hospital Director/ Medical superintendents of all the health facilities visited. Interviews with the respondents were undertaken following their written or thumb-printed informed consent.

The retrospective nature of the quantitative data collection meant that there were no potential risks to the patients. Also, the qualitative aspect of the study did not directly involve patients, so no risk was caused.

#### **4.5.4 Dealing with sensitive personal data**

We ensured that only the researchers had access to the data, which were secured under lock and key within the research institutions. They are presented anonymously and only at group level.

#### **4.5.5 Research on patients unable to provide consent**

Our study participants were children unable to sign informed consent forms. Their autonomy was also compromised in other regards. Their parents/guardians signed the informed consent forms on their behalf. However, children eight years and above were given to sign informed assent form before physical examination. Since all the studies (I, II, III, and IV) were non-invasive, there were no risks of physical harm to the study subjects. The informed consent also had a provision for parents to withdraw from the study with no consequences, with the aim of maximizing personal benefit and minimizing personal burdens: nonmaleficence within a legitimate social structure of justice.

#### **4.5.6 International collaboration and data transfer**

Research data are an asset that is valuable for the patients and the setting studied. To reduce the risk of what has recently been described as global health colonialism, all the studies were designed in collaboration with local researchers to be locally relevant, and all sought to build the capacities of local researchers, clinicians and systems while doing research. All the research was carried out in Uganda.

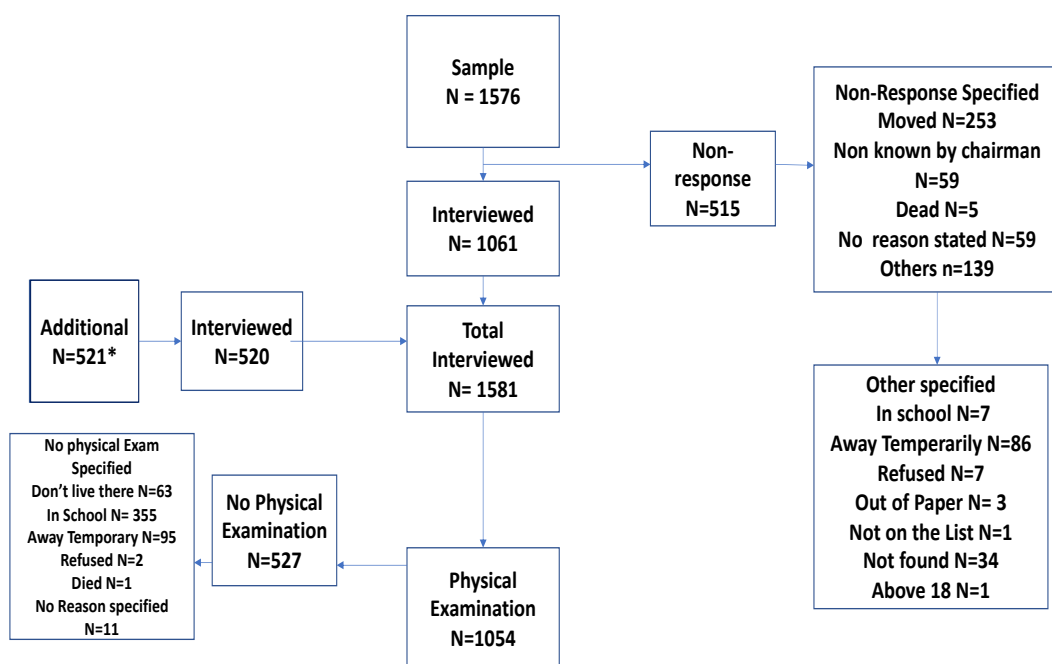
#### **4.5.7 Study II, Prevalence study**

All the children found to have surgical conditions during the physical examinations were offered free surgery (hernia, masses, cryptorchidism). Children with complex conditions requiring specialized surgery were referred to the respective disciplines for e.g. cardiothoracic, neurosurgical or orthopaedic surgery.

## 5 RESULTS

### 5.1 STUDY I. PREVALENCE OF PAEDIATRIC SURGICAL CONDITIONS IN EASTERN UGANDA: A CROSS-SECTIONAL STUDY

A total of 1576 children resided in the 490 sampled households according to the I/M HDSS register. We were able to find only 357 of these since some had been destroyed. Of the 1576 children, 1061 took part in the study. In the households were an additional 520, unregistered (in the I/M HDSS data base) children and these were also included, resulting in a total of 1,581 children in the study. Of them, 1054 were present in the household at the time of the study, and these were physically examined by the two doctors. The remaining children were not available as some had gone to boarding school and others had gone visiting relatives and friends (Figure 23).



\* **Additional study participants:** children that had lived in the households for more than four months but who were not registered by the I/M HDSS and therefore not part of the random sample.

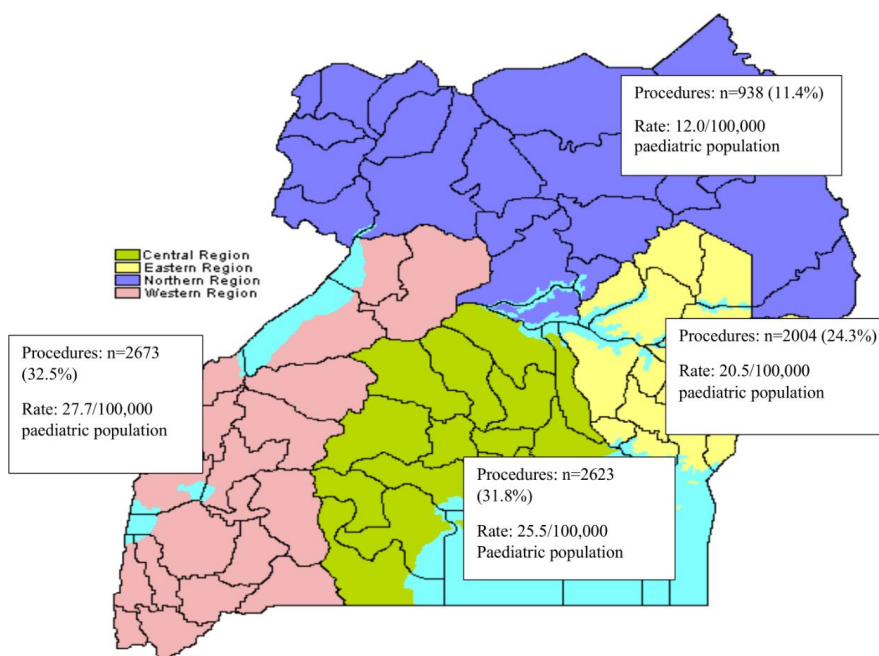
**Figure 23.** Summary of study findings

Six children had died in the households within the previous 12 months. All were girls and all had fever prior to their death. Of the 1054 children physically examined, 169 (16.0%) had a surgical problem. The prevalence of any surgical condition revealed by physical examination was 16%. The prevalence of self-reported surgical conditions was only 5.4%.

The most common group of conditions detected was congenital anomalies (n=134, 12.7%), and trauma-related conditions (n=42, 4%).

## 5.2 STUDY II. SURGICAL PROCEDURES FOR CHILDREN IN THE PUBLIC HEALTHCARE SECTOR: A NATIONWIDE, FACILITY-BASED STUDY IN UGANDA

In this study, 7886 children who had undergone major surgery in the 27 hospitals were recorded. After imputation, the grand total of surgical procedures was 8238. Of these, 4680 were operated on in 2013 and 3558 in 2014. This was a representation of an annual rate of 22 major surgical procedures per 100,000 paediatric population. However, this rate varied in the four regions of the country, with the largest number in the western region (27.7/100,000 population) fig. 24



**Figure 24.** Volumes and rates of paediatric surgery per region in Uganda. **Northern region:** 7 188 139 inhabitants (Apac General Hospital (GH), Nebbi GH, Kitgum GH, Matany GH, Lira RRH, Gulu Regional Referral Hospital (RRH) and Moroto RRH). **Eastern region:** 9 042 422 inhabitants (Lwala GH, Tororo GH, Iganga GH, Soroti RRH, Mbale RRH and Jinja RRH). **Western region:** 8 874 862 inhabitants (Kilembe GH, Kisoro GH, Masindi GH, Itojo GH, Hoima RRH, Fort Portal RRH and Mbarara RRH/University Teaching Hospital). **Central region:** 9 529 227 inhabitants (Entebbe GH, Kalizizo GH, Mityana GH, Masaka RRH, Naguru RRH, Mubende RRH and Mulago NRH/Makerere University Teaching Hospital). Uganda Bureau of Statistics, National Population and Housing Census 2014, [https://www.ubos.org/wpcontent/uploads/publications/03\\_20182014\\_National\\_Census\\_Main\\_Report.pdf](https://www.ubos.org/wpcontent/uploads/publications/03_20182014_National_Census_Main_Report.pdf). Total population: 34.6 million with ages 0–17 years old=55.1%.

Specialist surgeons performed 60.3% (n=4758) of the procedures, and anaesthesia was administered by physician anaesthetists in 11.6% (n= 917) of the cases Table 3.

Table 3 Basic characteristics of patients and human resources performing surgery for children, per hospital type					
	General hospital (GH), n=1276	Regional referral hospital (RRH), n=4475	National Referral Hospital (NRH), n=2135	Total n=7886	P value
Sex, n (%)					
Boy	945 (74.1)	2516 (56.2)	1336 (62.6)	4797 (60.8)	<0.001*
Girl	324 (25.4)	1620 (36.2)	756 (35.4)	2700 (34.2)	
Not indicated	7 (0.5)	339 (7.6)	43 (2)	389 (5.0)	
Age distribution (years)					
Mean (SD)	7.4 (5.5)	7.1 (5.5)	5.8 (5.7)	5.3 (4.7)	<0.001*
<5	488 (38.2)	1790 (40.0)	1144 (53.6)	3422 (43.4)	
>5	777 (60.9)	2677 (59.8)	980 (45.9)	4434 (56.6)	
Not indicated	11 (0.9)	8 (0.2)	11 (0.5)	30 (0.4)	
Level of training of surgical provider					
Specialist surgeon (including three paediatric surgeons)	324 (25.4)	3063 (68.4)	1371 (64.2)	4758 (60.3)	<0.001*
Resident	0	437 (9.8)	708 (33.2)	1145 (14.5)	
Medical officer	904 (70.8)	700 (15.6)	12 (0.6)	1616 (20.5)	
Intern	0	232 (5.2)	5 (0.2)	237 (3.0)	
Not indicated	48 (3.8)	43 (1.0)	39 (1.8)	130 (1.6)	
Level of training of anaesthesia provider					
Physician anaesthetists (one paediatric anaesthesiologist)	0	807 (18.0)	110 (12.0)	917 (11.6)	<0.001*
Residents in anaesthesia	0	163 (3.6)	655 (30.7)	818 (10.4)	
Self/by surgeon local anaesthesia	47 (3.7)	162 (3.6)	10 (0.5)	219 (2.8)	
Anaesthetic assistant or officer	1190 (93.3)	3132 (70)	1147 (53.7)	5469 (69.4)	
Not indicated	39 (3.1)	211 (4.7)	213 (10)	463 (5.9)	
Type of anaesthesia					
General anaesthesia	1097 (86.0)	3811 (85.2)	1913 (89.6)	6821 (86.5)	<0.001*
Spinal anaesthesia	66 (5.2)	186 (4.2)	82 (3.8)	334 (4.2)	
Local anaesthesia±sedation	106 (8.3)	161 (3.6)	64 (3.0)	331 (4.2)	
Not indicated	7 (0.5)	317 (7.1)	76 (3.6)	400 (5.1)	

\* Represents p values of comparison of gender, age, level of training of surgical and anaesthesia provider and type of anaesthesia between GH, RRH and the NRH, respectively.

The most common indications for surgery were congenital conditions (n=3111, 39%) followed by infectious and inflammatory conditions (n=2264, 28%), and thirdly injuries (n=1210, 15.3%) as shown in Table 4. below.

<b>Table 4.</b> Indications for surgical procedures for children in the public healthcare sector in Uganda (2013–2014)				
	<b>General hospital 1276 patients, n (%)</b>	<b>Regional referral hospital 4475 patients, n (%)</b>	<b>National Referral Hospital 2135 patients, n (%)</b>	<b>Total 7886 patients, n (%)</b>
<b>Abdominal and colorectal symptoms and conditions (n=3774)</b>				
Groin hernia and hydrocoele	499 (39.1)	650 (14.5)	120 (5.6)	1269 (16.1)
Peritonitis	49 (3.8)	318 (7.1)	106 (5.0)	473 (6.0)
Umbilical hernia	113 (8.9)	185 (4.1)	72 (3.4)	370 (4.7)
Gut perforation	31 (2.4)	240 (5.4)	61 (2.9)	332 (4.2)
Imperforate anus	13 (1.0)	109 (2.4)	163 (7.6)	285 (3.6)
Intussusception	18 (1.4)	130 (2.9)	126 (5.9)	274 (3.5)
Intestinal obstruction	47 (3.7)	124 (2.8)	89 (4.2)	260 (3.2)
Appendicitis	24 (1.9)	60 (1.3)	42 (2.0)	126 (1.6)
<b>Abdominal injuries (blunt and penetrating)</b>				
Ruptured spleen	12 (0.9)	60 (1.3)	18 (0.8)	90 (1.1)
Colostomy/closure of colostomy	10 (0.8)	44 (1.0)	20 (0.9)	74 (1.0)
Others	19 (1.5)	74 (1.7)	19 (0.9)	112 (1.4)
<b>Orthopaedic conditions (n=1264)</b>				
Orthopaedic trauma	62 (4.9)	366 (8.2)	224 (10.5)	652 (8.2)
Chronic osteomyelitis and septic arthritis	137 (10.7)	254 (5.7)	82 (3.8)	473 (6.0)
Clubfoot	61 (4.8)	53 (1.2)	25 (1.2)	139 (1.8)
Total	260 (20.4)	673 (15.0)	331 (15.5)	1264 (16.0)
<b>Ear, nose and throat conditions (n=721)</b>				
Tonsillitis/enlarged adenoids/foreign body, goitre	1 (0)	548 (12.2)	172 (8.0)	721 (9.1)
<b>Urology (n=444)</b>				
Cryptorchidism	30 (2.4)	63 (1.4)	12 (0.6)	105 (1.3)
Testicular torsion	8 (0.6)	41 (0.9)	36 (1.7)	85 (1.1)
Others	7 (0.5)	138 (3.1)	107 (5.0)	251 (3.2)
<b>Neurosurgical conditions (n=316)</b>				
Spina bifida, hydrocephalus, meningocele, subdural haemorrhage, trauma	0 (0.0)	135 (3.0)	181 (8.5)	316 (4.0)
Congenital heart disease (n=122)	0 (0.0)	0 (0.0)	122 (5.7)	122 (1.5)
<b>Plastic surgical conditions (n=503)</b>				
Cleft lip and palate	27 (2.1)	107 (2.4)	10 (0.5)	144 (1.8)
Burns (acute and secondary surgery)	50 (3.9)	243 (5.4)	66 (3.1)	359 (4.6)
Malignancies (n=92)	1 (0.1)	68 (1.5)	24 (1.1)	92 (1.1)
Others*, (n=896)	67 (5.3)	630 (14.1)	212 (9.9)	896 (11.4)
Not indicated (n=51)	7 (0.5)	36 (0.8)	8 (0.4)	51 (0.6)
* Indications with ≤1% grouped together under 'others'. Some patients had more than one indication for surgery; hence, total number of conditions and symptoms exceeds number of patients.				



5.3 STUDY III. BARRIERS AND POTENTIAL SOLUTIONS FOR IMPROVED SURGICAL CARE FOR CHILDREN WITH HERNIA IN EASTERN UGANDA

The main finding in Study III was that traditional beliefs and gender inequality were considered a major issue. Possible solutions included partnering with the local community in efforts to increase knowledge and acceptability in the community in general and by parents. A formation of a surgical team dedicated to management of children with surgical conditions was suggested to improve quality and increase volumes of surgery for children. Fig 25

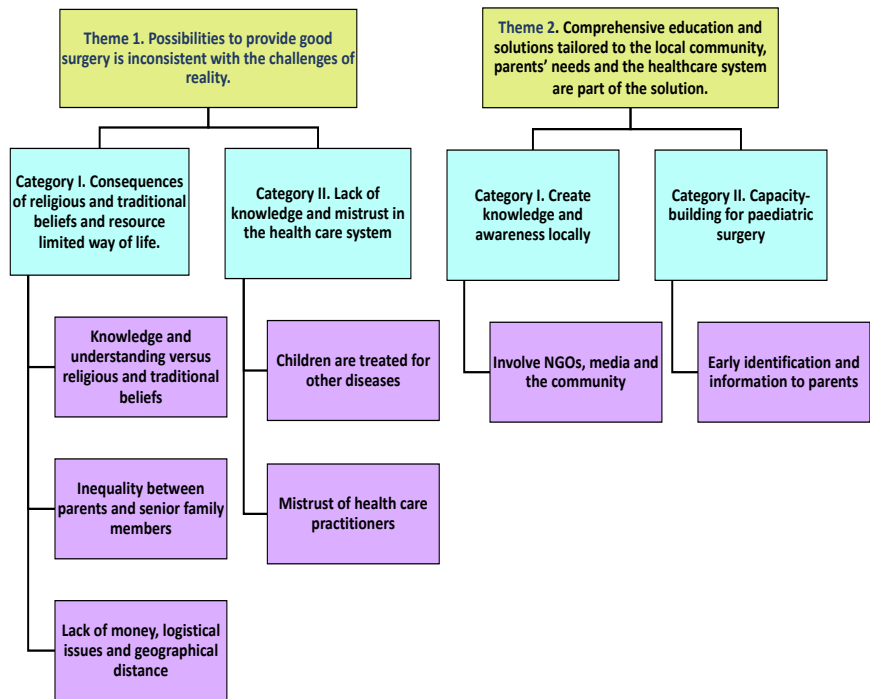


Figure. 25. Themes, categories and sub-categories

*Barriers to surgical care*

The parents and health workers interviewed gave their views about the barriers to surgical care and solutions to the problems as included below.

Religious and traditional beliefs in some communities influenced parents' decisions to seek care. The community believed the disease was a 'witchcraft' that needed traditional treatment, and women were blamed for the misfortune. Home remedies were often the first treatment given to a sick child. Only when the child did not improve would they seek medical care. Lack of money to pay for transport and treatment was another hindrance to seeking care. Long distance to hospital was a barrier because transport was costly. Gender inequality was

another factor. Though a mother is always the first to identify the problem in her child, she often cannot herself make the decision to go to hospital. She may have to get permission to take the child for medical care from either her husband or a family elder.

Some health care providers observed that, in the lower-level health units or private clinics, children presenting with vomiting were first treated for malaria before the correct diagnosis of a surgical problem was made. By the time a child reached hospital, he/she would be weak. Some parents mistrust health workers because when they come to a healthcare facility and a correct diagnosis is made, surgery might still not be carried out. Instead, the doctors kept re-scheduling the date for surgery. Some parents, too, had expected their children to be treated for free at the government health facility, but the health workers charged them, or asked them to buy drugs.

#### *5.3.1 Potential solutions to improvement of access to surgical care*

The health workers suggested that the community be mobilized to create awareness of surgical conditions in children. Health workers also recognized the help that non-government organizations (NGOs) have contributed to the care of children with surgical problems. Since these organizations were operating in the community, the health workers wanted to collaborate with the NGOs to increase access to surgical care. Parents too, wanted doctors to give talks to the community about hernia, since it was a common and often mismanaged problem. All parents should know that the only treatment for groin hernia is surgery.

#### *5.3.2 Increasing capacity-building for paediatric surgery*

The health workers requested the formation of a paediatric surgical team (paediatric surgeons, physician anaesthetists, and paediatric nurses) to adequately manage children in the hospital. They also wanted infrastructure built specifically for management of children with surgical conditions (operating theatre, wards, and intensive care unit (ICU) for very sick children). Lastly, health workers wanted the government to supply equipment, and drugs regularly for managing children with surgical needs.

### **5.4 STUDY IV. IMPACT OF COVID-19 ON ACCESS TO SURGERY FOR CHILDREN IN TESO SUB-REGION IN EASTERN UGANDA**

#### *Quantitative results*

All the surgical procedures done on children and adolescents below the age of 18 years were included if carried out in the operating theatres of the study hospitals. This meant that minor procedures such as circumcision, and procedures done for gynaecological and obstetrical indications, were included in the present study. Surgical procedures totalling 4535 were done for children and adolescents during the study period in the 16 hospitals visited. There was an increase of 24.4% of surgeries done between 2019 (n=1407) and 2021 (n=1751). The increase cuts across all health facilities, with the most prominent increase between 2019 and

2021 (58.3%) was for pregnancy-related conditions. Also, the number of procedures for congenital anomalies (32.5%) and trauma (54.9%) increased considerably, see Table 5.

**Table 5. Surgical procedures per year (2019 to 2021)**

<b>Type of procedure</b>	<b>2019, n (%)</b>	<b>2020, n (%)</b>	<b>2021, n (%)</b>	<b>Total (%)</b>
Abdominal and colorectal	92 (6.5)	119 (8.7)	149 (8.5)	360 (7.9)
Hernia and hydrocele surgery	235 (16.7)	237 (17.3)	327 (18.7)	799 (17.6)
Orthopaedic procedures	44 (3.1)	31 (2.3)	106 (6.1)	181 (4.0)
ENT procedures	59 (4.2)	61 (4.4)	63 (3.6)	183 (4.0)
Urological procedures	85 (6.0)	72 (5.2)	79 (4.5)	236 (5.2)
Plastic surgical procedures	105 (7.5)	7 (0.5)	6 (0.3)	118 (2.6)
Surgery for infections	197 (14.0)	157 (11.4)	164 (9.4)	518 (11.4)
Surgical management of cuts and wounds	143 (10)	160 (11.7)	160 (9.1)	463(10.2)
Excision (including biopsy)	47 (3.3)	43 (3.1)	63 (3.6)	153(3.4)
Procedures for pregnancy-related conditions	391 (27.8)	472 (34.4)	619 (35.4)	1482(32.7)
Gynaecological procedures	8 (0.6)	11 (0.8)	13 (0.7)	32 (0.7)
Others	1 (0.1)	2 (0.1)	2 (0.2)	5 (0.1)
<b>Total</b>	<b>1407(31.1)</b>	<b>1372 (30.3)</b>	<b>1751 (38.6)</b>	<b>4530 (100)</b>

### *Qualitative results*

For the qualitative aspect of the study, 37 informants were interviewed (25 health workers and 12 parents) during March to June 2022.

The general perception of the parents and health workers was that the surgeries for children and adolescents decreased during the Covid-19 pandemic. Eminently, the challenges the parents had in accessing care were unique to the Covid-19 pandemic and can be divided into the three-delay-model as follows.

#### *First delay in seeking care*

When the people learned about Covid-19 in the mass media, everyone was in shock and feared to contract the deadly virus. Parents resorted to self-medication, buying drugs from nearby kiosks within the community and would only risk going to the health facility when the child was very sick. Others did not want to go to hospital because they heard that cases of Covid-19 were being admitted, and they only sought care when they had exhausted all other options including traditional medicine. Some health workers noted that parents delayed bringing their children to hospital early because they didn't know they had surgical conditions requiring surgical expertise and potentially intervention.

#### *Second delay*

Uganda had very stringent rules during lockdown. People were not allowed to move from one district to another. Though patients were allowed to travel to hospital, they had to get written permission from the political leader in the area first. Securing these letters in one day was not possible, causing further delay for parents to take their children for treatment. There was a ban on public transport except essential vehicles such as ambulances, Police patrol cars, and garbage collectors. Unavailability of transport was a big challenge, which meant that parents had to hire a motorcycle or car to transport a sick child to hospital themselves. Transport costs were high, and many had even less money than usual, causing further delay in accessing surgical care.

#### *Third delay at the point of care*

The health workers, too, feared to contract the deadly Covid-19 virus, and strictly adhered to the standard operating procedures (SOPS) and regulations. So, if a patient was brought with fever, he/she was isolated, and samples taken for screening. Sometimes patients had to wait for 2-3 days before the results came back, making it difficult to achieve timely treatment.

Almost all the health units in this study had only one operating theatre. If a confirmed Covid-19 patient was operated on, the theatre had to be fumigated and closed. Once that happened, other patients had to wait for 24 hours before the theatre could be used again. All these many precautions to prevent the spread of Covid-19 brought more delays to accessing surgical care. Shortages of gloves and drugs were common due to the high demand by the emergency teams. This caused delays for children to access surgery. Parents too, complained that surgery had become expensive because they had to buy most of the items required.

### *Economic Constraint*

The restrictions imposed by the government of Uganda to minimize the spread of Covid-19 paralyzed most money generating activities that people used to do. People became poor, they did not have money to pay for transport, or to buy drugs, or to pay for investigations and surgery. Some children who needed surgical care died, because their parents were not able to bring them to hospital for care. There was a general inflation of prices in the market, and the respondents wanted the government to give an explanation why this was happening.

#### **5.4.1 Positive changes resulting from the Covid-19 pandemic**

Some positive Covid-related changes were observed by the study participants. People in the communities strictly adhered to standard operating procedures (SOPs) guidelines including improved hand hygiene and no unnecessary movement. These measures limited the spread of Covid-19 infections, and no cases were reported in most rural communities. Health workers and parents alike acknowledged that other infections, too, had reduced through following improved hand hygiene practices.

Emergency teams were formed countrywide, and each region received ambulances to facilitate the evacuation of Covid-19 cases. Other patients also benefited from these services. Whenever there was an emergency, the ambulance team was informed, and the patients were taken for medical or surgical care. The health workers noted that the health system had been strengthened, too, as more staff were deployed, and emergency drugs were delivered in a timelier fashion than before. There were strict regulations for daily data collection for Covid-19 cases, including deaths. These improved documentation of data for the covid-19 pandemic was a good practice. The health workers wanted this strict documentation to be maintained in routine clinical practice even after the pandemic.

As a way forward, health workers wanted surgical services for children to be improved. They also wanted the government to build hospitals dedicated to children's surgical care and to train a specialized workforce for their management.



## **6. DISCUSSION**

### **6.1 MAIN FINDINGS**

The main findings of these studies are that children in Uganda with surgical conditions are common. Surgical procedures are performed in a decentralized system by medical doctors with different levels of training, while anaesthesia is predominantly administered by associate clinicians. Volumes of surgery vary between the four regions, the northern region having the lowest number of operations performed per population. The workforce is a critical driver of surgical volumes in the public health sector in Uganda, more paediatric surgeries were done in the central region where surgeons were concentrated.

Several barriers to surgery for children exist and some were unique to the COVID-19 pandemic. Limiting factors to access to surgical care for the children included gender inequality, traditional beliefs, lack of transport, financial constraints, and long distances to hospital. In addition, the present studies have found that patients sometimes must seek health care several times before the correct diagnosis is made. Challenges at the point of care included infrastructure and unavailability of drugs and supplies. Collateral damage caused by the COVID-19 restrictions was extensive.

### **6.2 EPIDEMIOLOGY OF PAEDIATRIC SURGICAL CONDITIONS**

The burden of paediatric surgical conditions in Uganda is high, hospital productivity is inadequate, and several barriers exist from community level to hospital level. This signifies that many children need surgery; others with morbidities are suffering. Uganda has a fast-growing population (106), where over 56% are under the age of 18 years (107). It is imperative that the capacity to manage children with surgical conditions must increase. The qualitative aspect of studies III and IV explains barriers to accessing surgical care and calls for intervention at every level so that more children with surgical conditions may get care.

In Study I, the common paediatric conditions were congenital, and included trauma similar to the findings of a study that featured paediatric surgical conditions as part of global public health (48). Congenital conditions are the fifth leading cause of death under five years, and if not fatal can lead to long-term disability, with subsequent effects on family and economy (70). Neonatal survival with surgical conditions in high-income countries is between 80-90%, while on the contrary in low income countries it is minimal (108). Mortality can therefore be prevented by timely surgical intervention.

A population-based study of the burden of paediatric disease in Kenya found an overall prevalence of congenital abnormalities of 6.3 per 1000 live births, amounting to 1000 DALYs per 1000 children (48). An epidemiological study conducted in four LMIC countries reported that at least 18.5% of the children had a surgical need, and 62.5% of these children had at least one unmet need, representing an unmet need of 11.5% in the study population (74). In our study at Iganga- Mayuge HDSS the unmet surgical need was 6.3%, defined as any conditions that have not received adequate necessary surgical treatment (15).

Identification of the paediatric surgical need is essential for crucial planning of intervention by our policy makers. This calls for accurate data quantifying the paediatric surgical burden (109).

The health goal (Goal 3) of the 2030 Agenda for Sustainable Development promote well-being for all ages. The Agenda's target 3.2 categorically relates to child health and focuses on ending preventable death of new-borns and children under five years of age (110). To achieve these ambitious health goals in Uganda, children's access to surgical services of high quality must be ensured at all levels.

## **6.3 HEALTH SYSTEMS AND PAEDIATRIC SURGERY**

### **6.3.1 Surgical capacity**

Surgical conditions are common in children, and the unmet need is high, but the paediatric workforce in Uganda is still very small. Findings in study II revealed an average annual surgical rate of 22 major surgical procedures per 100,000 paediatric population. There was outstanding variation in the number carried out within the country. This correlates to the availability of the surgical workforce and the distance to the appropriate health facility. The northern region had the lowest rates of major paediatric surgical procedures: it is also the furthest from Kampala, the capital, where surgeons are concentrated. Previous research in Uganda found a similar correlation between distance to a healthcare unit and burden of surgical disease (70).

Approximately 234.2 million major surgical procedures are done per year worldwide (111). However, the rate per population varies from one country to another. Countries spending US\$100 or less per head on health care had a mean rate of 295 major procedures per 100,000 population per year, while those spending more than US\$1000 had a mean rate of 11,110 major surgeries per 100,000 population per year. Middle- expenditure countries were spending between US\$401 and US\$1000 (111).

Ethiopia for example reported a major surgical rate of 148 per 100,000 population, while Hungary reported 23,369 per 100,000 population (111). This shows unacceptable discrepancies between LMICs and HICs in the numbers of major surgical procedures done. It is evident that budget restrictions limit the capacity of the low-income countries to meet the surgical needs of their population.

Another study done in Uganda specifically for children found a rate of 172 per 100,000 population of children needing surgical intervention, but because the funding was meant for cleft palate surgery many of these were children with a cleft palate (112). Using a model of cumulative incidence, a study done in Gambia found that about 85% of children will require surgery by the age of 18. (113).

Other factors, too, influenced the volume of paediatric surgery performed by the health units in each period. For example, in studies III and IV parents' or elders' health-seeking behaviour



determined when families sought healthcare for their children. Utilization of surgical services in a health unit by the community depended on availability of staff, equipment and drugs. Lack of confidence in the health facility was a unique finding, in which parents shunned coming for surgical care because the doctors commonly kept on re-scheduling surgery for their children or making wrong diagnoses. To the parents, this was a confirmation that the doctors lacked surgical skills.

This calls for an integrated approach to ameliorate these barriers to surgery for children needing it. Community involvement is a key to improving access to surgical care. In their submission the health workers in Study II promised to collaborate with NGOs such as World Vision working in the local communities to educate the people about surgical conditions in children. Community leaders, known as village health team leaders in Uganda, play a big role in these activities. Engaging the community in improving access to surgical care has been a popular approach used by LMICs with great success (114). The qualitative aspect of studies III and IV explored possible solutions to these barriers by interacting with the parents of children with surgical problems, as well as with health workers. Data were generated that can be useful for policy makers.

Health systems make key decisions about resource allocation for hospitals, infrastructure, staff levels and priority among routines. Such decisions should be guided by available data and their significance in defining the burden of paediatric surgical care; and the challenges faced when accessing this care.

### **6.3.2 Human Resources**

Uganda with a fast growing and predominantly young population has only four certified paediatric surgeons and three paediatric anaesthesiologists. They serve a population of about 20 million children (51). Findings in Study II indicated that surgery is done in a decentralized fashion and task sharing is also practised for children, especially in anaesthesia. Non-physician anaesthetists administered the anaesthesia in the majority of the cases. Perhaps increasing the workforce will require the government to employ more surgeons and medical officers and deploy them to hospitals performing surgery to strengthen the existing facilities – or build new hospitals for children.

A proficient workforce for paediatric surgery is vital to serve Africa's young population of whom 85% of paediatric patients reportedly have a surgical condition by the age of fifteen (49). Studies have emphasized specialist shortages, with tens of millions of children served by at most one paediatric surgeon (115). Perhaps the greatest barrier to surgery is the unavailability of paediatric anaesthesiologists (116). Therefore, the problem for Africa's surgical workforce cuts across all specialities such as anaesthesia, surgery and nursing.

A mixed-methods study examining surgical and anaesthesia workforce services in sixteen rural hospitals reported that 55.1% of rural communities lacked surgeons, 81.2% had no anaesthesiologists and 58.1% had no registered nurse anaesthetist (117). This represented a big challenge in providing surgical care to children.

Previous studies found that Malawi had one paediatric surgeon for 13 million people and Egypt had 120 for 80 million people (118). These findings were far below the recommendations of the American Paediatric Surgical Association, i.e. one paediatric surgeon for 100,000 children (119).

A study conducted in Sierra Leone reported that ten surgeons working in public hospitals served a population of 5.3 million people (120). Another study indicated that 90 % of paediatric surgeons work in tertiary centres based in major cities (115). This resembles the situation in Uganda where paediatric surgeons and paediatric anaesthesiologist are urban based. Children in rural areas must travel long distances to access specialised surgical care. This causes delays often with poor prognosis. In Study II most paediatric surgery was provided by specialists in general surgery and other disciplines. An assessment of the current status and future needs of paediatric surgical capacity in Africa, too, reported that general surgeons were core providers of paediatric surgery (121).

In addition to the inadequate paediatric workforce, delivery of paediatric surgery in Uganda faces several challenges including a high paediatric workload with poor infrastructure and equipment. In Study III, health care workers suggested there was a need for paediatric surgical capacity-building to improve access to surgery. The teams should include paediatric surgeons, paediatric anaesthesiologists, paediatric general and ICU nurses to manage children with surgical conditions. Unfortunately, most of the trained health workers leave for greener pastures because of poor remuneration and working conditions. This issue needs to be addressed by relevant authorities to improve employment conditions and retention of the health workforce.

By increasing the surgical workforce, that is surgeons, anaesthesiologists and obstetricians, the lives of many children would be saved (51). Increasing the paediatric surgical workforce density has potential to reduce the burden of surgical conditions in children.

### **6.3.3 Surgical timing – elective versus emergency surgery**

The optimal timing for surgery is crucial for good outcomes and better prognosis. It also prevents disability, morbidity and mortality. Several studies indicate that early compared to delayed operation is associated with a better prognosis and improved quality of life (122). Timely access to essential surgery is when a good percentage of a population can access surgery within two hours in a health facility that can perform emergency caesarean sections, laparotomies, fixing fractures, and hernias (14).

For an intervention to be done, early diagnosis is crucial to allow timely planning for the type of surgery required. In Study II, congenital anomalies were the most common paediatric surgical conditions. Several other studies, too, have reported congenital anomalies as the commonest (51). The major cause of neonatal mortality worldwide is neonatal anomalies, many of which are curable with timely surgery (122). With an unmet need for surgery at 6.3% detected in study I, it is apparent that many children miss the opportunity of early detection of congenital anomalies at birth. Of the children, 82% had been delivered by a nurse

or midwife, and 13.7% of the children were delivered at home, 8.1% of the cases were assisted by a traditional birth attendant. In order to detect abnormalities at birth, nurses must have adequate knowledge and skills to assess the newborns. Possibly the village health teams could have a role to play for babies delivered at home or by traditional birth attendants. Improved community awareness of surgical conditions in children could be another strategy to reduce delays to adequate care. This was also suggested by the study participants in study III.

Uganda has made progress in child survival over the past few years and measures are in place to ensure the child survives to adulthood, with nutrition and immunization among the vital priorities (123). Uganda's National Expanded Programme on Immunization (UNEPI) acts within Uganda's minimal health care package and directly contributes to the Ministry of Health vision and goal (123). The MOH vision is to ensure that the Ugandan population is free of vaccine-preventable disease and thus reducing morbidity, mortality and disability due to vaccine preventable diseases (123).

Perhaps the introduction of a point for physical examination of all children undergoing immunization will diagnose some surgical conditions in children early, and a policy to fix treatable surgical conditions before the first birthday could be recommended. Among these congenital conditions groin hernia was the commonest found in the present study II, and yet this condition continues to be unnoticed until a child presents with a complication of hernia such as obstruction or, even worse, gangrene with poor prognosis. Other people present in adult life with chronic morbidities due to a neglected groin hernia (124) and yet had this condition been managed countrywide early in life, we would have a healthier, more productive nation. Other life-threatening congenital conditions which are expensive but require urgent management are cardiac and colorectal anomalies. The majority of parents cannot afford the costs for investigation and surgery. Like cases identified in study I, parents whose children had congenital heart conditions were stranded at home because they could not afford the treatment. These problems should be addressed by health policy makers in collaboration with international bodies such as the World Health Organization, because the funds required for their management are large.

Emergency operations carry a higher rate of complications, morbidity and mortality than elective surgery (125). Trauma, burns and infections impose a big toll on children in the form of morbidity and mortality. In Study II, among the common conditions were infections 28.7% and trauma 15.0%. A multi-centre study in Zambia reported injuries as the leading cause of death (126). Saving lives following trauma and in surgical emergencies requires timely arrival to the appropriate facility for definitive care. For this goal to be achieved, accident and emergency units should be set up, with an improved ambulance system. These have potential to contribute to better outcomes and prevent disability, also for non-surgical conditions. At policy-maker level, a logical next step would be to integrate paediatric surgical care into the existing child health programmes in Uganda and other LMICs.

Another challenging condition is childhood tumours, which can sometimes present as emergencies. The challenges in LMICs have been late presentation, late accurate diagnosis, limited investigation services and limited supply of drugs (86), often resulting in high mortality rates. In high-income countries the reverse is true: cure rates are high because of early presentation, accurate diagnosis and timely treatment (86).

#### **6.3.3.1 Reducing delays to surgical care**

The ability to receive surgical care when needed depends on the accessibility of the surgical health facility, availability of workforce of all cadres, good infrastructure, equipment, drugs and blood (127). Study IV summarized the delays to accessing timely surgical care by using the three-delays framework developed by Thaddeus and Maine (128): 1) delayed decision to seek care; (2) delayed arrival at a health facility; and (3) delayed provision of adequate care.

Children are vulnerable; dependent on decisions made by their parents to access surgical care. Awareness campaigns targeting the community was desired by the study participants in study III in order to improve chances for children to be brought in time to a facility where surgical services are available. The blaming of women for their children's illnesses combined with the inability of many women to make decisions regarding the health of their children represents a vicious circle that must be broken. As decision making is often related to money, providing free health services for children in reality as well as on paper can be expected to reduce the first delay.

The second delay could be reduced, at least for emergency situations, with a reinforced ambulance system where patients and their families do not have to cover the cost of fuel. An important aspect to reduce second delays are also to provide services whenever possible in a decentralised fashion. It is important that surgical services for common conditions in children can be delivered in all Regional Referral Hospitals, at least. No family should have to travel far to have a hernia repaired.

To reduce the delays within the referral system and at individual facilities, it is paramount that all healthcare workers have adequate knowledge so that correct diagnosis can be made. In study III, it was evident that late presentation was also caused by misdiagnosis and resulting mismanagement. It appears that in order to reduce the third delay, all levels of the healthcare system would benefit from the presence of more skilled staff. Professional development activities for all levels of healthcare providers is important. Infrastructure improvements including the continuous availability of equipment, materials and medicines is necessary.

Unusual causes of delay are bound to happen when there are local epidemics and pandemics such as Ebola and Covid-19. The Covid pandemic had devastating effects on health-system delivery worldwide (129), and the high mortality rates caused panic and fear. Countries imposed strategies for infection control consisting of bans on gatherings, home isolation. All non-essential social services, including non-urgent healthcare, were halted. The Study IV

participants, both in the community and in healthcare, expressed concerns that the measures instituted to control the spread of Covid-19 further caused delays in accessing surgical care. Uganda had stringent rules on total lockdown, and schools were closed for two years. This had profound effects on vulnerable populations such as girl children. There was general concern among parents and healthcare providers that teenage pregnancies had increased, leading to a high rate of school dropout. The collateral damage and the long-term effects on the Ugandan people and economy is an important aspect for future research.



## **7. CONCLUSIONS**

Surgical conditions in children are common and the unmet need for surgical procedures is immense. With the fast-growing population, Uganda's needs for paediatric surgical capacity will further increase. The procedures are performed in a decentralized system and task sharing and task shifting in surgery and anaesthesia for children is widely practiced in Uganda.

There is great variation in volumes of surgery performed in individual hospitals as well as the four regions of the country. This variation can in part be explained by a shortage of specialized surgical workforces to detect and manage surgical conditions in children. Health policymakers should promote programmes geared to training and retention of a surgical workforce evenly distributed throughout the country.

Barriers to accessing surgical care were explained using a three-delay model. In order to improve access to and quality of surgical services, interventions at community level as well as in the healthcare system are needed. There is also a need for the government to create a conducive environment for service delivery with skilled human resource, good infrastructure, equipment, drugs, laboratory and X-ray services available at all times.

Local outbreaks, epidemics and pandemics are to be expected in the future. The Covid-19 pandemic affected health systems worldwide, with the health services in the LMIC affected most. Limits on surgical procedures were expected to worsen during the pandemic but on the contrary, more surgical procedures for children were done. Some positive effects resulted from the interventions in the healthcare system and the restrictions during the pandemic but for children, the majority of the effects were negative. The long-term effects are yet to be seen. The lessons learned from the Covid pandemic afford important momentum for constructing a resilient healthcare system for future challenges.





## 8. PERSPECTIVES

The findings presented in this thesis, filling a knowledge gap about surgical conditions in Uganda, can be used for improvement of surgical care for children. The findings are vital and can also be used by policy makers.

Most studies on the prevalence of paediatric surgical conditions have relied on reported information by study participants who can sometimes be biased. In our research, physical examinations of the children were done to verify any surgical conditions. Surely the surgical needs of these children were distinct! For example, you should see a hydrocephalic child who has had no stenting at all: she or he has an enormous head. Children with cardiac anomalies need surgery but parents are unable to pay for investigations and surgery despite obvious difficulty in breathing with central cyanosis.

We recorded the names of the surgeons and anaesthesia providers in the data collection for study II. This enabled us to know how task sharing for paediatric patients undergoing surgery is widely practised in Uganda. Children have a unique physiology and anatomy – especially of the airway – and this can be a big challenge for those administering anaesthesia. Task sharing and task shifting in surgery for children is a fact and is bound to continue for many years. The safety and quality of these services could be addressed by training a workforce including all cadres involved in the diagnosis and management of surgical conditions for children.

Paediatric surgical conditions, particularly congenital, are common, and most can be managed surgically. The barriers to surgical care are many. The solution calls for a health policy to plan for intervention at every stage of the three-delay model, to improve access to surgical care for the children in all regions of Uganda. Emphasis has been on communicable diseases such as malaria, HIV, tuberculosis and immunizable diseases in children. Now it is time for a surgical package for children to be included in child health programmes.

Data is very important for planning and intervening in many health problems. Record management in high-income countries is very organized because all the systems are computerized. The reverse is true for low-income countries that are still using paper for documenting patients' information. The challenge we observed in some health facilities that patients' information was incomplete; in two hospitals completely missing. This was one of the limitations of the retrospective facility-based study.

Proper documentation and storage of data is important; creating a registry is 'the way to go'. During the Covid-19 pandemic, a national policy was to document all cases including the dead. All health facilities nationwide kept these records: it remains do-able, so this approach is maintained so that all statistics of every condition are known. Having a database makes it easy to detect epidemics early.

## **8.1 THE WAY FORWARD**

Our study focused on volumes of paediatric surgical conditions, as well as on the barriers to access to surgical care, but not on outcomes. Follow-up studies on outcomes after surgery in children are very much needed. In particular, research on the safety and effectiveness of surgical services delivered through task sharing in the decentralised Ugandan system would be of interest for future capacity building and reinforcement of the already existing system.

To meet the surgical needs of Ugandan children, requires an integrated approach, involving different stakeholders locally and internationally. Funds must be mobilized for training and retaining the surgery workforce. We need to establish an effective referral system from a lower-level facility to a level that can offer definitive management for children. We must equip all facilities nationwide and ensure a constant supply of drugs. Dedicated teams and operating theatres for children in all the four regions of the country are needed.

Strict rules that were imposed to minimize the spread of Covid-19 infection have, however, generated more problems. Yes, Covid-19 infection was a matter of life and death, but now we must deal with the consequences, especially those created by school closure. Some children dropped out of school and need to be helped. Girls got pregnant and now we have young mothers who need financial help. Other students too, failed to return to school because their parents lacked funds to pay their fees. All money-generating activities were closed during the lockdown, so there is no money for buying food, or paying treatment or paying tuition. Government in partnership with non-governmental organizations need to introduce programmes geared at empowering our youth with skills for survival.

### **8.1.1 Information dissemination**

The purpose of medical research is to fill knowledge gaps and to generate information for use by health professionals and policy makers. One of the researcher's responsibilities is to disseminate information. The findings of the research have been published and results have been presented at scientific conferences, workshops, and to students of global surgery. This work will continue with the aim of improving access to paediatric surgery.

Policy makers are important recipients of the research findings. The findings of this research can provide exactly the information required for intervention to increase access to surgical services for our children. I have already presented some of the results at the Uganda Ministry of Health and I intend to continue to directly communicate research findings to them.

Further health-policy decisions are beyond the researcher and involve an integrated approach by different ministries in government and international bodies.

### **8.1.2 Partnership and collaboration**

Conducting this study was made possible through collaboration between Uganda and Sweden. All the four studies were conducted under the guidance of proficient supervisors from Sweden. In addition, we have been involved in teaching students of global surgery from different universities locally and internationally. I intend to write another paper on qualitative study under the guidance of my supervisors from Sweden. After completion of my PhD programme, I will continue with the partnership, and plan to do follow-up research indicated under 8.1 The way forward.



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## 11. APPENDICES

Study I

Study II

Study III

Study IV