

Mixed-Method Analysis of Barriers to Surgical Care in Uganda

by

Joseph James Incorvia

Duke Global Health Institute  
Duke University

Date: \_\_\_\_\_

Approved:

\_\_\_\_\_  
Michael M. Haglund, Supervisor

\_\_\_\_\_  
Joao R. Vissoci

\_\_\_\_\_  
Henry E. Rice

Thesis submitted in partial fulfillment of  
the requirements for the degree of  
Master of Science in the Duke Global Health Institute  
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ABSTRACT

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## **Abstract**

Background: Barriers to surgical care in low- and middle-income countries have basis in theoretical frameworks, but are often left undefined and understudied. Based on the Access Evaluation Framework and Healthcare Barrier Model, this study implemented two consumer decision tools and a qualitative interview to elucidate significant barriers to seeking surgical care in Uganda.

Methods: Participants were recruited from a convenience sample within the surgical wards of one national referral hospital and one regional referral hospital in Uganda. Individuals selected for the study answered a brief questionnaire and a ranking and rating exercise followed by an in-depth semi-structured interview. The questionnaire evaluated demographic, economic, transportation, and care-seeking characteristics, while the ranking and rating exercises assessed potential barriers to surgical care. Descriptive statistics were used to assess characteristics of the sample. Ranking and rating medians were compared between the two exercises for each barrier.

Results: Among the 214 participants, cost of surgery, distance to hospital, and transportation to hospital were identified as the most significant barriers to care. Language barrier, no control over decision making, and no caretaker available at the hospital were identified as the least significant barriers to care. Mulago National Referral Hospital had significantly greater costs and transportation times indicating larger scale

barriers to care than Jinja Regional Referral Hospital even though top barriers were similar.

Conclusions: Both the ranking and rating exercises and interviews indicated that cost was the most significant barrier to surgical care among care-seekers in Uganda. Transportation to the hospital and distance from the hospital remain large barriers that need to be considered as well. These complementary analysis tools provide evidence that future policies and research need to consider mitigating cost, distance, and transportation issues for patients that need a surgical intervention. Next steps in determining more granular level differences between barriers will help understand how best to address these issues.

## **Dedication**

This work is dedicated to all those who pushed me to be the individual I am today, throughout my time as a student and as I look towards my career. To my parents, who have sacrificed much to afford me the opportunities I have had thus far in life. To Jeff and Eric for unconditional support, encouragement, and humor. And to Amy for constantly being a reminder of why I am pursuing my dreams.

I further dedicate this thesis to all those fighting for their lives within the hospitals of Uganda, those without the ability to receive the care they need, and the selfless healthcare workers who work day in and day out to provide services to many, often at their own expense. This work is for a better future for you all.

# Contents

Abstract.....	iv
List of Tables.....	x
List of Figures.....	xi
Acknowledgements.....	xii
1. Introduction.....	1
1.1 Non-communicable Diseases and Need for Surgical Intervention.....	1
1.2 Global Estimates of Surgery Burden.....	2
1.3 Lancet Commission on Global Surgery Identification of Surgical Barriers.....	3
1.4 Surgeon Overseas Assessment of Surgical Need.....	4
1.5 Healthcare Access and Barrier Frameworks.....	6
1.6 Recognition of Surgical Barriers for Seeking and Reaching Care.....	18
1.7 Business Analytics and Behavioral Economics.....	21
1.8 Rationale and Study Aims.....	23
2. Methods.....	26
2.1 Setting.....	26
2.2 Mixed-Method Design.....	28
2.3 Quantitative Methods.....	28
2.3.1 Participants.....	28
2.3.2 Procedures.....	29
2.3.3 Measures.....	31

2.3.3.1 Surgeon Overseas Assessment of Surgical Need .....	34
2.3.3.2 Ranking and Rating Exercise .....	34
2.3.4 Analysis .....	35
2.4 Qualitative Methods .....	36
2.4.1 Participants.....	36
2.4.2 Procedures.....	36
2.4.3 Analysis .....	37
3. Results.....	38
3.1 Description of the Sample .....	38
3.2 Economic Demographics.....	40
3.3 Care-Seeking Description of the Population .....	42
3.4 Transportation Description of the Populations.....	45
3.5 Overall Barrier Trends .....	48
3.6 Qualitative Interviews: Respondent’s Accounts of Barriers .....	52
3.6.1 Availability .....	54
3.6.2 Affordability.....	55
3.6.3 Acceptability .....	57
4. Discussion .....	59
4.1 Sample Characteristics and Hospital Comparison.....	60
4.2 Ranking and Rating Analysis .....	62
4.3 Implications for policy and practice .....	63
4.4 Implications for further research.....	65



4.5 Study strengths and limitations .....	66
5. Conclusion .....	68
Appendix A: Quantitative Survey .....	70
Appendix B: Semi-Structured Interview Guide .....	76
References .....	80

## List of Tables

Table 1: Access to surgical care barrier origin and model association.....	33
Table 2: Sample demographic characteristics.....	39
Table 3: Population economic characteristics.....	41
Table 4: Sample care-seeking characteristics.....	44
Table 5: Sample transportation characteristics.....	47
Table 6: Categories and themes of qualitative data.....	53

## List of Figures

Figure 1: McIntyre’s Access Evaluation Framework [28] .....	14
Figure 2: Healthcare Barrier Model [30] .....	17
Figure 3: Median rating for each barrier to surgical care along with interquartile range for all participants. Variables are ordered from highest median ranking (5) to lowest(1). .....	49
Figure 4: Median ranking for each barrier to surgical care along with interquartile range for all participants. Variables are ordered from most significant median ranking (1) to least (10).....	50
Figure 5: Comparison of ranking and rating analysis of barriers to surgical care listed in order from most significant to least significant by median and interquartile range. Arrows represent the differences between the findings of the two types of analysis. ....	51

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# 1. Introduction

## ***1.1 Non-communicable Diseases and Need for Surgical Intervention***

Over the last 20 years, there has been a global epidemiologic shift from infectious disease to non-communicable diseases (NCDs) that has been enhanced by both longer life expectancies and effective prevention and treatment for infectious diseases [1]. Many NCDs may potentially require surgical care. Among these include several of the top 10 global causes of mortality as of 2017 such as ischemic heart disease (1), stroke (2), COPD (4), lung cancer (5), diabetes (6), and road injury (10) [2]. While a necessity for many years, surgical care typically has been an unrecognized component of global health policy frameworks until recently with the Lancet Commission on Global Surgery.

However, surgery is critical to improve maternal and child health and to prevent HIV/AIDS, which encompass three major Millennium Development Goals (MDG 4, 5, 6) and more recently play a large role in Sustainable Development Goal 3: Ensure healthy lives and promote well-being for all ages [3]. Surgery is critical to the success of these goals, yet the capability of low- and middle-income countries (LMICs) to adequately perform operations that can aid this issue - such as Cesarean sections, corrections of congenital malformations, or male circumcisions - is low [4]. In 2008, Paul Farmer and Jim Kim referred to surgical care as the “neglected stepchild of global health” among funding agencies across the globe and within localities [5]. Since then, much has improved as global surgery has become a larger priority for economies and

organizations around the world with more literature being published and research being done on the disparities in surgical care.

## ***1.2 Global Estimates of Surgery Burden***

The estimation of the burden of surgical disease is the first step in strengthening systems of surgical care in resource limited settings [6,7]. The Disease Control Priorities Project first published a global estimate of surgical burden of diseases in 2006; this study found that an estimated 11% of all global disability-adjusted life years (DALYs) can be attributed to surgically-treatable conditions [8]. While this was stated to be a crude estimate by the authors, depending highly on international expert opinion and healthcare provider surveys, it was a critical first step in assessing the surgical burden. It estimated that ninety percent of mortality from NCDs occurred in LMICs, with Africa having almost twice as many surgical DALYs lost compared to Europe (38 and 21 per 1000 population, respectively) [9]. Further, the poorest 2.2 billion people lack adequate access to safe surgery and the poorest one-third of the world's population receive only 3.5% of operations [10, 11]. These numbers were reevaluated in a comprehensive response to a call for better metrics assessing the global surgical burden, which culminated in the Lancet Commission on Global Surgery and their reported findings in 2015.

### **1.3 Lancet Commission on Global Surgery Identification of Surgical Barriers**

Launched in 2014, the Lancet Commission on Global Surgery, led by Dr. John Meara of Harvard Medical School and Boston Children's Hospital, brought together a multidisciplinary team of 25 commissioners supported by advisors and collaborators in 110 different countries [12]. Key takeaways established that the human and economic consequences of unmet surgical needs in LMICs have largely been unrecognized and the scaling up of surgical care in LMICs would provide substantial health and economic benefits [12].

Their data supports higher estimates than in the initial 2006 burden of disease study. For example, an estimated 5 billion people do not have access to safe, affordable surgical and anesthesia care, which is worse in LMICs where ninety percent of people cannot access basic surgical care, compared to the 2.2 billion in 2006 [12]. Further, 313 million surgical procedures occur worldwide, with only 6% of those occurring in LMICs, nearly doubling the estimate from 2006 [12]. Over 143 million additional surgical procedures are required in LMICs each year to save lives and prevent disability [12]. Economically, over 33 million people face catastrophic health expenditure while attempting to pay for the surgical and anesthesia care they need each year, without considering all other costs incurred in the process, which results in another 48 million facing catastrophic expenditure [12]. These statistics show the dearth of surgical care

that LMICs face and emphasize the need for further studies elucidating ways to solve these problems.

Yet, provision of surgical care is possible and affordable for governments to implement. A major issue has been the barriers preventing patients from accessing the care that they need. Meara and colleagues utilized the Three Delays framework, which was born out of the delays mothers faced when seeking proper care, to assess the different delays faced by patients [13]. The First Delay is the delay in seeking care when individuals have difficulties seeking care for a variety of factors ranging from financial means to geographical barriers to lack of education [13, 14]. The Second Delay is the delay in reaching care, manifested in not having hospitals with the capacity for surgical care in proximity to the patient and having lack of access to transportation [15]. The Third Delay is the delay in receiving care, which is limited by lack of infrastructure, technology, fully functioning operating theatres, and essential medications [4, 16, 17, 18, 19]. Research on global surgery has been critical to assessing what further barriers beyond cost are preventing people from getting access to the surgical care that they need.

#### ***1.4 Surgeon Overseas Assessment of Surgical Need***

Surgical burden assessments were necessary to help inform the main obstacles that create the unmet need issues we face across the world. The Surgeon Overseas Assessment of Surgical Need (SOSAS) has been verified as a household survey tool to be



used in a cross-sectional, cluster sampling design in LMICs to elucidate the surgical burden [20]. Prior to being implemented by Fuller and colleagues, SOSAS was used in Rwanda and Sierra Leone [21, 22, 23]. Since then it has been piloted in Nigeria, completed in Nepal, and plans are to implement the survey in Malawi in the future [24, 25].

The determination of surgical need within the Ugandan population yielded about 10.6% unmet need for surgical procedures [26]. The most frequent barrier to surgical care was the lack of financial resources for the direct cost of care. Of 153 household deaths recalled, 53 (34.2%) were associated with surgically treatable symptoms and thus could have been potentially averted by surgical intervention (95% CI, 22.1% to 46.3%) [26]. Shortage of time was the most frequently cited reason for the deceased not receiving surgical care. Subsequently, it was identified from this data set that between adjacent districts of Uganda there are disparities in the abilities of these districts to meet their respective prevalence of surgical need [27]. Utilizing geospatial analysis, it was shown that unmet surgical need was significantly associated with distance to nearest surgical center, geographic catchment area of the surgical center, and respondent-reported travel time [27]. This data informs current understandings of barriers to surgical care as well as emphasizes the findings of the initial Uganda study. The current study, utilized this data through the lens of existing frameworks defining healthcare access and barriers to seeking care.

## **1.5 Healthcare Access and Barrier Frameworks**

The literature provides many pre-existing frameworks and models through which access to healthcare is viewed from. Ultimately, the concept of 'access to healthcare' has yielded no consensus or commonly accepted framework [28, 29]. Multiple dimensions of access to healthcare are provided in the literature. The theoretical framework through which I decided to view my study is McIntyre's Access Evaluation Framework and Irfan's Healthcare Barrier Model [28, 30]. In tandem, these frameworks conceptually describe an individual's interaction with a healthcare system and the potential barriers they may face. The development of these frameworks come from differing approaches and decades of literature on the topic.

The development begins in the 1950s with the Health Belief Model (HBM), a psychological model that attempts to explain and predict health behaviors [31]. Originally designed in response to the failure of a free tuberculosis screening program, this concept has been adapted for many long- and short-term health behaviors [31]. The core assumption behind the theory is that an individual will make a health-related action if the individual:

1. feels that a negative health condition can be avoided,
2. has a positive expectation that taking a recommended action can make them avoid a negative health condition, and
3. believes that they can successfully take that recommended action.

Different modifying factors, from demographic variables to internal cues to act in one's own benefit, affect an individual's ability to assess the perceived threat of their disease or condition, net benefits of acting (seeking care), and ultimately changing their behavior from not-seeking to seeking care [31]. However, the shortfall of this theoretical model is that it does not fully investigate how external factors such as those at the community, health system, or government levels impact health beliefs and behaviors, focusing internally on the individual. The complexities of care-seeking behavior expand past the individual and more expansion was necessary to understand why one chooses to act for their own health benefit over taking no action.

Thirty years later, Ajzen and Fishbein developed the Theory of Reasoned Action (TRA) and Theory of Planned Behavior (TPB) as an existing framework for health seeking behavior. This theory focuses on the theoretical construct that individual motivational factors determine the likelihood of performing specific behaviors [32]. The underlying premise of the TRA is that behavioral intention is the most important determinant of behavior [32]. An individual's attitudes towards performing the behavior and subjective norms associated with the behavior are direct determinants of the person's behavioral intentions [32]. Attitudes are determined by behavioral beliefs about outcomes from performing behaviors, while subjective norms are determined by normative beliefs coming from environmental interactions with referent individuals that

may approve or disapprove of performing those behaviors [32]. The TPB adds perceived control to the TRA, which considers that individuals may not have complete volitional control over their behaviors [32]. This is influenced by control beliefs that represent the presence or absence of facilitators and barriers to behavioral performance, weighted by the impact of each factor to facilitate or inhibit the behavior, known as the perceived power [32].

In relation to healthcare, this means that individuals will most likely prescribe to positive health-seeking behavior if positive attitudes, neutral subjective norms, and facilitative perceived control align. While still being used today as the modern theoretical model for healthcare seeking behavior, the TPB/TRA fails to address external barriers and factors that prevent health seeking behavior and relating those factors back to individual access to healthcare. We may be able to determine how an individual influences their own decision to seek care on an intrinsic level, but falter in determining what outside of their control alters their decision making to hinder their ability to access the care they need. This elucidates the need for relevant access and barrier to care models which in the past ten years have become more developed and studied.

The concept of access to healthcare has been previously defined by Obrist and colleagues in terms of five dimensions (availability, accessibility, affordability, adequacy, and acceptability) [29]. This definition is crafted within Obrist's Health Access

Livelihood Framework, which combines health service and health-seeking approaches, placing access to healthcare within the broader context of livelihood insecurity [29].

Obrist argues that once an individual recognizes the need for treatment, access then becomes a critical issue [29]. However, even when these dimensions are well known, they are not considered until an individual recognizes they need care. This depends largely on their access to livelihood assets which consist of human capital (local knowledge, education, skills), social capital (social networks, affiliations), natural capital (land, water, livestock), physical capital (infrastructure, equipment, means of transport), and financial capital (cash/credit) [33]. These assets are not universally available, and Obrist suggests that the availability of these assets depend on a vulnerability context, which is defined as the aspects of life that individuals typically are unable to control, such as economy, politics, technology, climate, environmental disasters, armed conflicts, and epidemics [29]. By this framework, improved access to care can only be achieved when combined with a high quality of care for those most in need [29]. The key outcome of the framework to be measured would be the health status of the individuals seeking care, which would increase if all aspects of the framework were met.

Additionally, Peters and colleagues utilized four dimensions (geographic accessibility, availability, financial accessibility, acceptability) to define access to healthcare [34]. This framework focuses on those that are living in poverty, particularly those in LMICs. The poor in LMICs typically suffer from a disproportionate burden of

disease, but usually have less access to health care [35, 36]. Peters builds on previous definitions of access to healthcare to create their conceptual framework, which largely includes dimensions that have a supply and demand element [34, 37, 38]. The center of Peters' conceptual framework is quality of care; this is because ultimately the technical ability for health systems to affect the people's health is the key indicator to determine to what degree the system meets each of four dimensions. Other inputs to the framework include factors that impact the provision health services at policy, macro-environmental, household, and individual levels [34].

Despite their use in the literature and relevance to the topic, the approaches that Obrist and Peters use are similar and therefore have similar flaws in relation to this study topic. Regarding our primary focus, of individuals interacting with the healthcare system, we preferred McIntyre's approach in combination with Irfan's Healthcare Barrier Model to explore how individuals' circumstances affect their ability to interact with their healthcare system and how specific barriers and multiple levels of society can impede care-seeking behavior. Obrist or Peters alone would not be sufficient to understand this sought connection between behavior, access, and barriers. Alternatively, as will now be shown, the use of Irfan's model in tandem with Obrist or Peters would be devoid of the interaction piece that is the main strength of McIntyre's approach.

McIntyre uses three dimensions (availability, affordability, acceptability) to define the concept of access to healthcare [28]. This framework builds upon the previous

ones by looking at the interactions between the health care system and the individual. McIntyre acknowledges that regardless of setting, the economic problems of resource management, provision, and scarcity yields no healthcare system being able to provide sufficient services for all those that require them [28]. They argue that access to care represents empowerment of an individual to use the care that is provided and reflects the individual's capacity to benefit from the services given their circumstances and experiences in relation to the healthcare system [28]. This approach puts more of a focus on the individual and responding to individual needs and the context of the social constructs and environments in which the individual comes from. In this sense differences in access, and therefore empowerment, between individuals create differences in the use of healthcare services, yet differences in use also may occur in environments with equal access [28]. Attitudes, beliefs, and cultural norms all effect an individual's interaction with healthcare systems. This thinking of interaction presented by McIntyre, and similarly described by Grimes, differs from the frameworks and other concepts of access to healthcare in literature [14, 28].

For example, some researchers view access simply as a supply-concept relating to the spatial availability of services via proximal locations and provider-population ratios or hospital catchment areas [38, 40, 41]. Conversely, access can be seen solely as a demand-concept relating to the affordability of or ability to pay for services [42, 43].

Third, service use can be seen in absolute terms, indicated by who is using the service, or

relative terms, indicated by use differing between groups with different needs and needs differing between groups with similar use [44, 45]. Lastly, there have been approaches to understand access and service use by determining the full cost, including direct costs of services and indirect costs of transportation and using care. [46, 47, 48, 49, 50]. These on their own provide distinct views of what access to healthcare services encompasses and are utilized in the frameworks presented by both Obrist and Peters.

McIntyre's framework focuses on their definition of access as empowerment and incorporates the interaction of availability, affordability, and acceptability, each providing a specific role in the interaction between an individual and the healthcare system (Fig 1). The definitions used by McIntyre reflect those previously mentioned in this paper. Availability represents whether the providers and services are supplied at the right place and time to meet the needs of the individuals [28]. Affordability is concerned with the fit between the full cost incumbent upon the individual and the individual's ability to pay for the services within the context of their household budget and other demands on that budget [28]. Acceptability is related to the compatibility between the viewpoints and understanding of the provider and patient [28]. Interactions between these dimensions are the focal point of their framework. For example, availability of only male health care providers for the provision of women's healthcare may create acceptability problems for the women whom the services are intended [28]. Availability of drugs between private and public pharmacies may significantly affect the



affordability of the medications [28]. Point of service fees create tension between affordability and acceptability if individuals believe that providers are primarily concerned with making money, rather than treating patients [28].

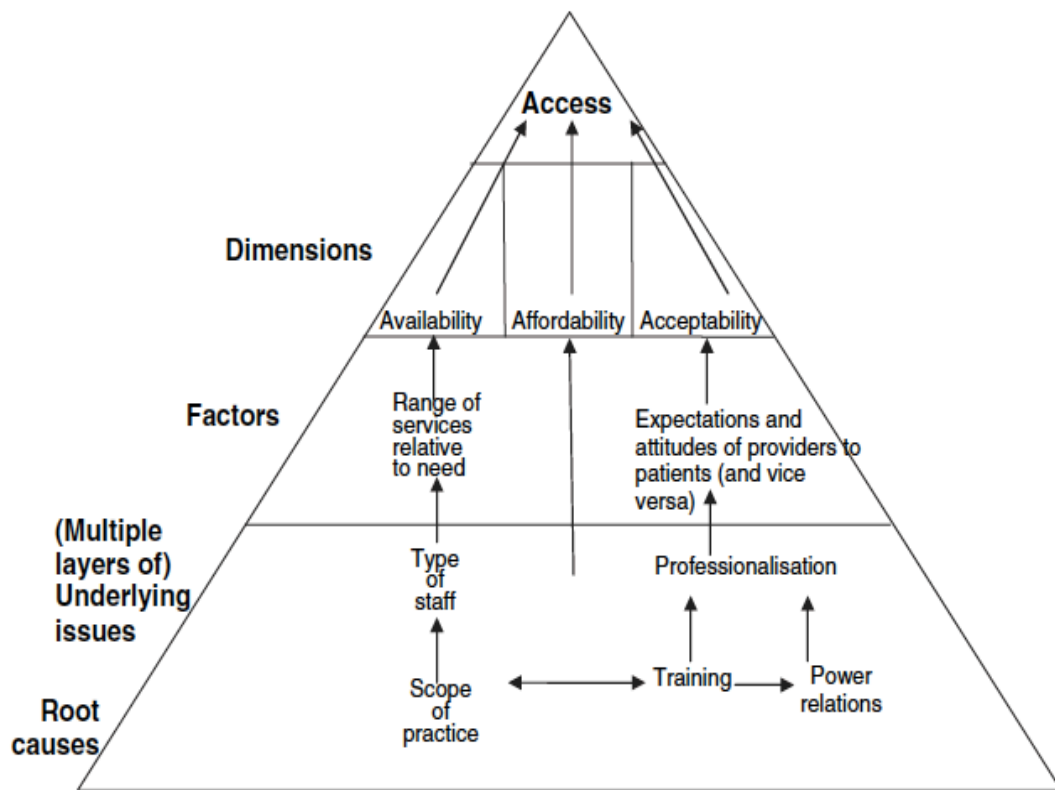


Figure 1: McIntyre's Access Evaluation Framework [28]

The discussion of interaction between patients and the healthcare system as explained by McIntyre is implemented within Irfan's framework. Irfan's Healthcare Barrier Model articulates identifying barriers within accessing healthcare. This model integrates specific parts of Phillip's modification of Andersen's behavioral model of Health Services Utilization [51, 52] with the World Health Reports health system building blocks [53, 54]. Andersen's model states that a population's health services use is determined by predisposing, enabling, and need based factors [45, 51, 55]. Predisposing factors describe a patient's tendency to use healthcare services, including their demographics, attitudes, and beliefs about healthcare systems [55]. Enabling factors are the individual and community resources for access to healthcare and the ability to mobilize those resources [45]. Need factors are related to patient symptoms, clinical and self-perceived disease status, and overall health state [45].

This framework assesses barriers at four distinct levels. The level of the patient, the environment, the health system, and the provider (Fig 2) [30]. The different factors in each stage of the model were developed from Phillip's modification of Andersen's model, the World Health Report, and a thorough literature review outlined in Irfan [30]. Being interconnected, any change in any level variable will impact the barriers at other levels. This model was first utilized in Pakistan to assess barriers to care.

These models in tandem, therefore, can look at multiple barriers to healthcare, ranging from the individual to the governmental level, and can be used to interpret their

interaction through the three dimensions of access of availability, affordability, and acceptability. Used as a frame of reference to influence the questionnaire and interviews, the Access Evaluation Framework and Healthcare Barrier Model provided insight and the correct lens through which to develop this current study and will also drive future research that comes from this study.

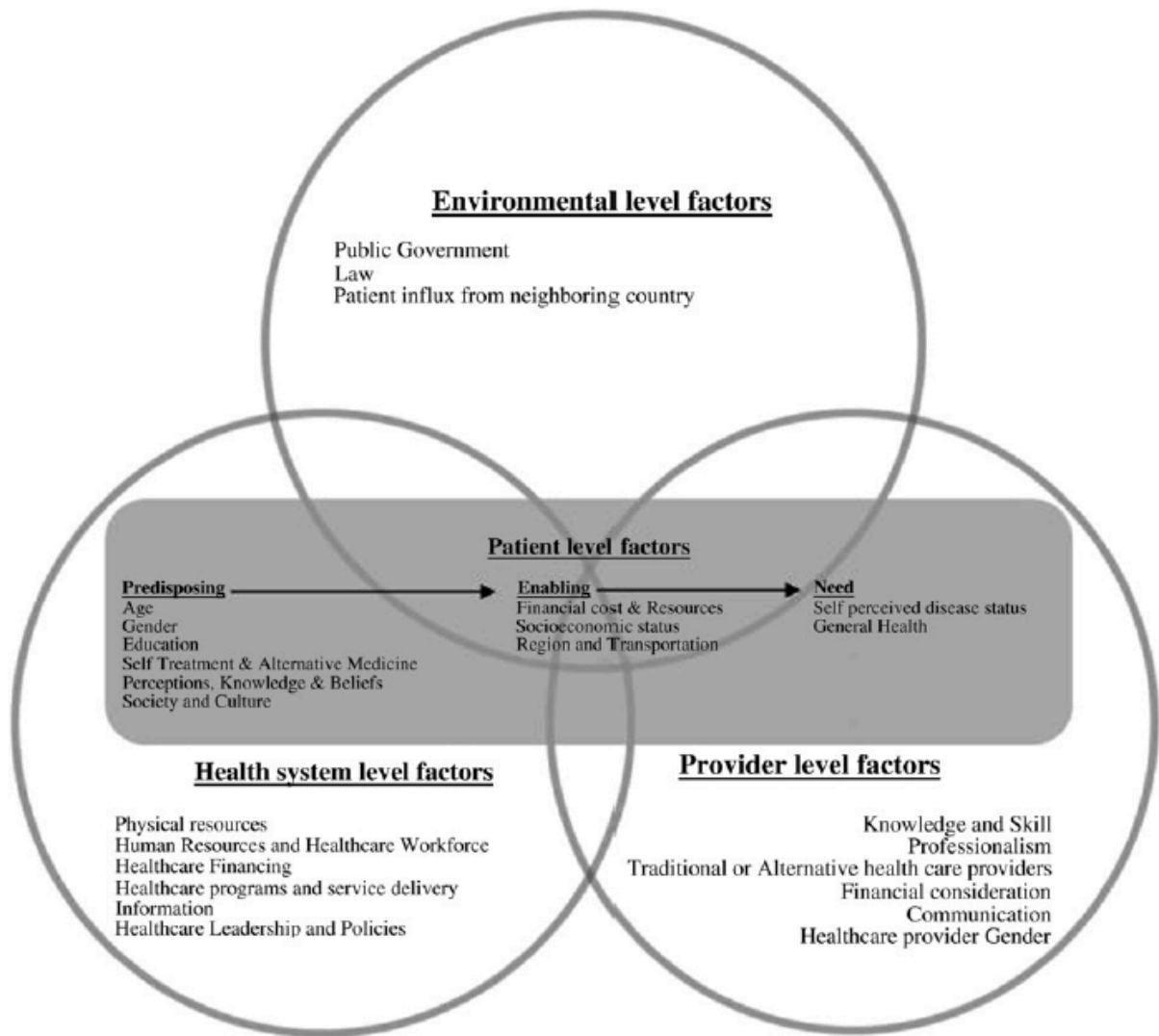


Figure 2: Healthcare Barrier Model [30]

## **1.6 Recognition of Surgical Barriers for Seeking and Reaching Care**

For the purposes of this study, we focused on the First and Second Delays highlighted by the Lancet Commission on Global Surgery: Delay in Seeking Care and Delay in Reaching Care [12]. This was deliberate to better understand what obstacles patients face as they travel to surgical facilities. The literature supports many different barriers to seeking and reaching surgical care, the primary focus of this study. We utilized the following dimensions of care through which to assess healthcare access: accessibility, affordability, and acceptability [12, 56, 57]. Further, categories of barriers from the Healthcare Barrier Model were used to develop the specific barriers included in the study. These categories, cited by McIntyre and summarized by Grimes, were chosen for the basis of which further barriers were elucidated and selected, as well as the theory for which the qualitative aspect of this study was developed [14, 28].

Cost, as previously stated, is one of the largest barriers to care seen across the globe. Both indirect and direct costs of surgical care are responsible for individuals being unable to seek and reach the care that they need [58, 59, 60, 61, 62]. Confirmed in the SOSAS data to be an obstacle for patients in Uganda, this barrier is also among the most highly cited barriers to surgical care [26].

Geographical access to surgical centers is a critical component of a care-seeker's ability to access the care that they need. Therefore, the farther distance one is away from a surgical center, the less likely they will be able to access the care at that facility [34, 63].

Closely associated with distance and a priority for data collection of SOSAS studies is the barrier that transportation to the hospital can be. Not being able to provide transportation or having transportation obstructed by poor road infrastructure is a critical obstacle to care [64, 65, 66]. Particularly in LMICs, transportation barriers can mean the difference between life and death, yet still are numerous as not many countries have standardized emergency transportation services [24, 67].

Transportation and distance often come about from not having access to close surgical facilities, and lacking available hospitals and surgical facilities provide a large barrier of their own. With surgical centers sparsely located in some LMICs, the location of these centers is important to providing access, as their catchment areas may dictate how easily patients will be able to get surgery [27, 64, 68, 69, 70]. However, even when there are hospitals available, the quality of care varies largely due to varying levels of resources and funding allocated to the surgical centers and hospitals that must counter the burden of surgically treatable diseases and conditions [71, 72, 73, 74, 75]. Further delays in care result from having to wait for extended periods of times throughout the care-seeking process. This ranges from waiting for transportation to waiting for financial support to waiting to be admitted to the hospital [73, 74, 76].

Finally, regarding the patients' care-seeking behavior, many factors contribute to the obstacles individuals face when interacting with the healthcare system and being able to make the decision to go get care in the first place. Language barriers often exist in

the healthcare system, as patients, particularly from rural areas, have difficulty sharing a common language with their healthcare providers [69]. Past interacting, just deciding to go to the hospital can be a difficult decision. Not being able to take time off to travel in fear of losing out of financial security because of loss of production or being unable to sacrifice time away from schooling is a large barrier [60, 77]. Assessed for the context of Uganda, and supported in the literature, the final chosen barriers for this study were not having a caretaker present to be at the hospital with you and having no control in the decision-making process. In many healthcare systems, having a caretaker or attendant with you is imperative to making sure that daily patient needs are attended to, as nursing staffs are often overburdened [59, 78]. Finally, not having control over the decision leaves patients unable to get care when they feel they should and relies on multiple factors involving the community, families, and healthcare workers associated with the patient [79, 80, 81].

In review, upon searching the literature for main barriers to surgical care, the above rationale was reached, in congruence with well-known frameworks for both access and barriers to healthcare, to come up with the ten barriers that patients were questioned about: Cost of Surgery, Distance to the Hospital, Waiting Time, Language Barrier, Transportation to the Hospital, Ability to Take Time Off of Work to Travel, Quality of Care, Lack of Available Hospital, No Caretaker Available at Hospital, and No Control of Decision Making.



## **1.7 Business Analytics and Behavioral Economics**

The current frameworks through which access and barriers to care are assessed have some severe limitations. First, many frameworks do not address the individual basis of decision and how that relates to overall concepts of access and barriers. For example, frameworks used by Irfan, McIntyre, Peters, and Obrist all can elucidate the key factors in having access to or barriers from care [28, 29, 30, 34]. However, none specifically address the specific barriers and how individuals make decisions about those barriers. Irfan recognized this, acknowledging that further research is needed to be done to assess barriers down to local level, which will be important to confirm the theoretical models of access and barriers in the literature.

Patients negotiating barriers to care is essential to understanding the barriers' impact on access to healthcare and how individuals make decisions based on what barriers they are confronted with. Elucidating the trade-offs individuals are willing to make when faced with multiple barriers supports what current frameworks try to model. This is particularly important when discussing cultural relevance, as large theoretical models need to be simplified and applied locally to fully have relevance in any cultural context [30].

To remedy these limitations, business analytical methodologies can be used. The use of business analytics is common approach to help determine how people view different variables when making complex decisions and allow researchers to assess

trade-offs between different levels of a variable. Methodologies in this area typically refer to elicited preference or stated preference procedures [82]. These are broken up into three different categories: ranking, rating, and choice techniques [82]. The most common type of ranking exercise is a simple ranking exercise, which allow respondents to give ordinal ranks to a set of variables, indicating highest significance with the highest ranking [82]. Rating exercises involve presenting individuals with scenarios or statements and asking them to respond on either a numerical or semantic scale [82, 83]. Likert scales are typically used as respondents rank variables, statements, or scenarios to indicate their opinion [82]. Choice-based techniques force individuals to choose between alternatives presented to them [82, 83]. Simple choice exercises provide scenarios that vary in respect to one characteristic, and the respondent chooses which they prefer [82].

Overall, these types of analytics usually lead to the use of a conjoint analysis (CA). CA is rooted in Lancaster's theory of value [84]. This theory assumes that goods can be described by their characteristics, and that these goods create benefit for the individual, known as utility, as a combination of variables, where the total utility gained from consuming a good is a function of the individual utilities from the characteristics of that good [84]. This method has five distinct stages:

1. Identification of attributes, characteristics, or criteria important to the overall objective of the study.
2. Assigning levels to those criteria.

3. Using experimental designs to create manageable amounts of scenarios for participants.
4. Eliciting preferences using ranking, rating, and/or choice exercises.
5. Analyzing the data using statistical regressions.

For CA to be utilized, previous elucidation of preferences is needed to inform attributes and levels to be used. Therefore, this study focused primarily on ranking and rating exercises to determine the complex decision respondents were faced with. That complex decision was deciding to seek surgical care when faced with different factors that affect one's access to said care. The utilization of these tools in tandem offers us the ability to understand how the different variables impact the decision to seek care.

### ***1.8 Rationale and Study Aims***

Given the large burden of unmet surgical need in Uganda, estimated at 10.6%, it is valuable to understand what the barriers are to people seeking and reaching a surgical facility within Uganda [26]. Data elucidating patient preferences when seeking surgical care is limited. In LMICs there is limited use of patient preference elucidation in general. Most studies that use elicit preference methodologies refer to health systems, providers, or specific services. In the United Kingdom, Gerard utilized a discrete choice experiment to determine patient preferences for emergency services [85]. Preferences for services and quality of hospital was elucidated in South Africa and Zambia, respectively [86, 87]. A study also looked preferences for job attributes in Ethiopia among healthcare workers

[88]. Stated preference methodologies have further been used to identify preferences for patient specific interventions, treatments, and procedures ranging from wheelchair choice to HIV antiviral therapy to cancer screenings [89, 90, 91]. The literature remains scarce in both HICs and LMICs, none of which specifically addresses how patients make decisions for surgery. However, the literature does give models for how these studies are feasible in low-income settings [92].

Therefore, research considering perceptions on barriers will provide foundational research to the development of a tool to evaluate these preferences. Since the barriers to surgical care in low-income countries are many, assessment of patients experiences with these barriers can provide valuable information to benefit the development of the healthcare system. The objective of this study was to determine which obstacles and barriers to surgical care are perceived to be the most significant to individuals seeking care and making those care-seeking decisions.

To address this goal, we developed several specific aims. First, we wished to understand the differences in care-seeking behavior and demographics between Mulago National Referral Hospital and Jinja Regional Referral Hospital. Second, using quantitative ranking and rating exercises, we wanted to assess how individuals perceive the different barriers to care. This aimed to determine which barriers to surgical care are the most significant, further showing which parts of the care-seeking process could use the most improvement. Third, we wanted to qualitatively investigate patients' opinions

and perceptions on barriers to surgical care, relating their experiences to quantitative responses on barriers to surgical care. Findings from the study have the potential to inform further quantitative analysis of decision making, the development of tools to assess surgical care-seeking behavior, and elucidate areas in which governments can enhance services for the people who need surgical care the most.

## **2. Methods**

Our study evaluated and identified perceived barriers to seeking surgical care for surgical patients in Uganda. A mixed-method approach was utilized, incorporating a cross-sectional quantitative survey of 214 individuals as well as qualitative interviews with thirteen caretakers of surgical patients. The ethical review boards of Duke University, Makerere University of Health Sciences, and Mulago Hospital approved all study procedures.

### **2.1 Setting**

The study was conducted over a six-week period between June and July 2016 in two hospitals in Uganda. The two study settings were New Mulago National Referral Hospital (MNRH) in Kampala and the Jinja Regional Referral Hospital (JRRH) in Jinja. MNRH has a bed capacity of 1565 and JRRH has a bed capacity of 600 [93]. Mulago conducted 13,397 major surgical procedures in the 2014-2015 fiscal year, while Jinja conducted approximately 2,000 based on estimates from SustainUganda [94, 95].

The two hospitals were chosen to develop a comparative sample, as each individual site have different catchment areas that allow them to provide services for different people throughout the country. Currently under renovation, MNRH has many infrastructural and logistical issues that compound the problems that already exist due to overcrowding and reduced resources. JRRH, being a smaller, regional hospital,

services less patients on average a year, although it still faces similar issues of overcrowding and lack of resources from the government.

Kampala is the second most populated district in Uganda, with a population of just over 1.5 million people with the highest population density in the country [96]. Within this urban setting, Mulago Hospital sits in the heart of the capital servicing the most critical cases from the city and entire country leading to overburdening of healthcare services, even with five other general hospitals and multiple private facilities located within the district. Individuals at MNRH are more likely to come from higher socioeconomic status and more urban or suburban settings.

Conversely, Jinja is the seventeenth most populated district in Uganda, with a population of approximately 76,000 [96]. Nearly forty percent of the population within the district is within the municipality of Jinja where the regional referral hospital is located. Jinja RRH services much of the southeast of Uganda and is often a gateway in referral to Mulago when services are not available within the hospital. Its smaller bed capacity often creates issues for patients, having to wait and sleep outdoors or in corridors while they wait to be treated or admitted. The population in this area of Uganda tend to come from more rural backgrounds and lower socioeconomic status.

Mulago has specific surgical wards for different types of procedures, allowing for some organization after triage and initial admittance of the patients. All surgical

patients at JRRH are referred to the general surgical ward where there is no separation based on specific procedure.

## ***2.2 Mixed-Method Design***

The mixed-method design utilized a three-part data collection tool utilizing concurrent triangulation. The first two parts consisted of a quantitative demographic survey and a ranking and rating exercise, which was followed by an in-depth interview. The design benefitted from utilizing the qualitative methodology to expand upon the quantitative data collected. Therefore, the interviews could supplement and explain the findings of the demographic survey and ranking and rating exercise. Specifically, the ratings and rankings were indicated by the participant were the focus of the interview, aligning with the goals of the study to fully investigate the barriers to accessing surgical care within the study population.

## ***2.3 Quantitative Methods***

### ***2.3.1 Participants***

Participants were recruited in similar fashions at both study sites. Data was collected on 214 total patients among the two sites, 101 at MNRH and 113 at JRRH. Patients were recruited from a convenience sample within each of the nine different surgical wards at MNRH and from the general surgical ward at JRRH. Further recruitment was done at general inpatient and outpatient wards when necessary provided that the individuals were there to receive or already received surgical care.



Eligibility criteria included that all participants that were either a patient receiving a surgical procedure or a representative family member or attendant that was with the patient throughout the time the patient was in the hospital. Patients could either be waiting for a surgical procedure or already had a surgical procedure completed. Attendants had the same criteria regarding surgery status. All patients needed to be within the designated wards and collection areas to be considered for inclusion. Further, all participants needed to be proficient in either English or Luganda, languages that would be comprehensible to the surveyor.

Potential participants were excluded if they were identified as incapable of understanding and answering the questions or were very ill and unable to provide answers to the survey or interview questions.

### **2.3.2 Procedures**

Multiple research assistants were recruited to aid with the administration of a quantitative demographic and informative survey. All research assistants were nurses with prior research experience and formal training in administering quantitative surveys to hospital patients as part of Makerere University research projects. A one week training period and initial piloting of the survey for understanding among the data collectors was conducted. During this time, nurses first practiced the survey on each other and other medical professionals to assess understandability and provide input on potential changes to the survey. Further piloting occurred on a select group of general

surgery ward patients to again assess for completeness of the survey, understanding of both the research assistant and the patient, and potential changes.

Following completion of piloting the participants were recruited and data collection began. The research nurses were responsible for conducting as many interviews as feasible per data collection day. After identifying potential participants within the surgical wards, the research assistant approached the patients and their families to gauge interest in participating in the study. At this point, the facilitator and the participant underwent the informed consent process. Written informed consent was required by participants prior to starting the survey. If the individual could not read the informed consent document was audibly read to the participant. If the individual could not write, a thumb print was used to grant consent, as this method is an accepted form of signature by the Ugandan National IRB.

Once written consent was obtained, the facilitator led the participant through the process of completing the questionnaire, which has four distinct parts. The facilitator asked the questions of the participant and mark their answers on the paper document. The participant could look on with the facilitator and inquire further if any questions were not fully understood. Questionnaires were either conducted in English or Luganda, depending on the desired language of the participant.

The first part of the questionnaire was a basic demographic survey, pertaining to information about the individual, their household, and their background. Next, the

participant was asked about their surgical experience and what caused them to be in the hospital for the procedure that they either already had or were scheduled to receive. A third section inquired about transportation to the hospital and any prior experiences with going to alternative medical facilities or local healers regarding their current condition. Finally, the questionnaire concluded with a ranking and rating exercise.

In the ranking exercise, the participant ranked variables that represented barriers to seeking surgical care. They ranked them numerically from 1, being the most significant barrier, to 10, being the least significant barrier. The rating exercise asked the participant to individually indicate the significance of the same barriers one at a time using a Likert scale. The participant ranked each barrier individually from 1, being the least significant, to 5, being the most significant.

### **2.3.3 Measures**

The study utilized a thirty-two-question survey, sixteen of which focused on demographic variables, seven about surgical care, seven regarding transportation to the healthcare facility, and two care seeking questions. The survey also included a ranking and rating exercise. These measures were adapted from the literature. The Surgeon Overseas Assessment of Surgical Need Version (SOSAS) 3.0 was adapted for demographic and transportation questions [20]. The remaining questions and ranking and rating exercise were adapted from a structured questionnaire instrumented by Gulack et al. [97], with two additional barriers developed with local input from key

informants at Makerere University in Kampala, Uganda (Table 1). The full survey tool can be referenced in Appendix A.

**Table 1: Access to surgical care barrier origin and model association**

Barrier	Main Dimension of Access	External Healthcare Barrier Factor Type	Patient Level Healthcare Barrier Factor Type	Reference
Cost of Surgery	Affordability	Health System	Enabling	12, 14, 57, 97, 98,
Distance to the Hospital	Availability	Environmental	Enabling	12, 14, 57, 97
Waiting Time	Availability	Provider / Health System	Need	12, 14, 57, 97
Language Barrier	Acceptability	Provider	Predisposing	12, 14, 57, 97, 99
Transportation to the Hospital	Availability	Health System	Enabling	12, 14, 57, 97
Ability to Take Time Off Work to Travel	Availability	Environmental	Predisposing	12, 14, 57, 97
Quality of Care	Acceptability	Health System	Predisposing	12, 14, 57, 97
Lack of Available Hospital	Availability	Environmental / Health System	Enabling	12, 14, 57, 97
No Caretaker Available**	Acceptability	Health System	Predisposing	14
Unable to Make Decision for Self**	Acceptability	Environmental	Predisposing	14

\*\* indicates Ugandan specific barrier

### **2.3.3.1 Surgeon Overseas Assessment of Surgical Need**

The Surgeon Overseas Assessment of Surgical Assessment of Surgical Need (SOSAS) Version 3.0 was adapted to collect demographic and transportation information [20]. The demographic variables allowed us to understand the patients that were recruited for the study based on income, location within Uganda, age, occupation, religion, and literacy. Transportation questions helped determine how the participants got to the hospital with participants having the option to report up to seven different types of transportation modes along with the time waiting, time traveling, distance traveled, cost of the transportation, and whether the transportation could always be provided. Cost, distance, and time were reported as totals for the individual participants. Further care seeking questions about seeking surgical care at other outlets were included from SOSAS, as well and general information regarding when their surgery was and what type of surgery it was.

### **2.3.3.2 Ranking and Rating Exercise**

The ranking and rating exercise utilized business-analysis tools to assess how individuals perceive barriers to accessing surgical care. This model has been used in the literature successfully, and offers insight into which barriers are more significant than others [14, 57, 83, 97, 100]. A Likert scale was used for the rating portion to determine how significant each barrier was, from 1 (least significant) to 5 (most significant) [100]. For the ranking section of the questionnaire, each participant was asked to rank the

same ten obstacles in order of significance. The scale for this part was from 1 (most significant) to 10 (least significant).

### **2.3.4 Analysis**

The quantitative data was imported directly from Lighthouse Studio (Version 9; Orem, UT, USA) into an Excel (Redmond, WA, USA) spreadsheet. Data cleaning involved coding open-ended text answers into numerical categories based upon the specific variables. Surgical procedures were assessed by a surgeon at Mulago National Referral Hospital to determine their proper coding. Cost data was converted from Ugandan Shillings (UGX) to United States Dollars (USD) to be better understood in context to American monetary terms.

The data was imported into Stata statistical software (Version 14.2; College Station, TX, USA) for analysis. Descriptive statistics were used to describe the demographic and other characteristics of the data. All parametric continuous data were summarized as means and standard deviations. Non-parametric continuous data were summarized as medians and interquartile ranges (IQR). Median ranks and rates for each of the barriers to surgical care were calculated along with IQR. The medians of the barriers to surgical care were used to rank each obstacle from most to least significant for both exercises. The medians were also compared between hospital sites and reported to show trends based upon location of where the population was surveyed.

## **2.4 Qualitative Methods**

### **2.4.1 Participants**

Qualitative interviews were only conducted on individuals that had already completed the quantitative survey. Finally, participants also needed to be able to adequately answer the survey questions and interview questions, with the help of a parent/guardian or surrogate, if applicable. All participants needed to be proficient in either English or Luganda, languages that would be comprehensible to the interviewer.

Potential participants were excluded if they had not previously taken a quantitative survey.

### **2.4.2 Procedures**

After the questionnaires were conducted by the facilitators, the questionnaires were checked for completion and errors and then screened for potential interview participants. Individuals were chosen to interview based on convenience upon completion of the questionnaire. If chosen to interview the participant was taken to a secluded area and a 30 to 45-minute interview was conducted. All interviews were conducted by an interviewer with previous experience in health care research. While both the quantitative and qualitative pieces of the survey were conducted in a mutually understood language, usually either English or Luganda, all interviews happened to be conducted in Luganda as those participants and the interviewer shared Luganda as their common language. The questions in the interview pertained to their individual



experience with the different barriers to seeking surgical care to better understand their questionnaire answers. A question guide was utilized to make the interviews semi-structured and the interviews were recorded.

Following the interview, the recordings were sent to be translated and transcribed by an individual with prior transcription and translation experience within Makerere University in Kampala, Uganda. The recordings were first transcribed in Luganda, translated into English, and then back translated into Luganda to determine consistency within the translations. The final English transcriptions were used for analysis of the qualitative data. Overall, 214 questionnaires and 13 interviews were conducted.

### **2.4.3 Analysis**

Interviews with patients and/or caretakers were transcribed and translated from Luganda to English. The translated transcripts were coded and analyzed for emergent themes using NVivo (Version 11.4.0; Doncaster, VCT, AUS). The emergent themes were catalogued and summarized in a memo and quotes representing the themes were chosen for the qualitative analysis. The interview guide and questions used in the interviews are in Appendix B.

## **3. Results**

### ***3.1 Description of the Sample***

The sample population was evenly split between two surgical sites within Uganda, with 47% (n = 101) from Mulago National Referral Hospital and 53% (n = 113) from Jinja Regional Referral Hospital (Table 2). Almost half of patients were located within the general surgery wards of the hospitals (48.6%, n = 104). Pediatrics contained the second highest percentage of patients, with 16.8% (n = 36), representing the breadth of ages included in the study. Notably, 38.8% (n = 83) of respondents reported that an injury was the reason for which they were there to receive surgery, while 49% (n = 105) cited a pre-existing medical condition as being the reason why there were there for surgery. The rest of the participants (n = 16) were either unsure or did not report a reason for needing surgery. We noted several differences in household size between patients at MNRH and patients at Jinja JRRH, with average household size being 7 and 5 people, respectively.

**Table 2: Sample demographic characteristics**

Characteristic	Overall (n= 214)	Mulago National Referral Hospital (n = 101)	Jinja Regional Referral Hospital (n= 113)	P value
Age (yrs.)				
Mean (SD)	30.8 (20.4)	29.2 (21.9)	32.2 (18.8)	0.282
Gender				
Female, n (%)	76 (35.5)	42 (41.6)	34 (30.1)	0.080
Ward				
Outpatient, n (%)	20 (9.3)	20 (19.8)	0 (0)	
General Surgery, n (%)	104 (48.6)	21 (20.8)	83 (73.4)	
Neurosurgery, n (%)	12 (5.6)	12 (11.88)	0 (0)	
Cardiothoracic, n (%)	4 (1.8)	4 (4.0)	0 (0)	
ENT, n (%)	9 (4.2)	7 (6.9)	2 (1.8)	
Pediatrics, n (%)	36 (16.8)	17 (16.8)	19 (16.8)	
Orthopedic, n (%)	23 (10.8)	14 (13.8)	9 (8.0)	
Uganda Heart Institute, n (%)	6 (2.8)	6 (5.9)	0 (0)	
Patient Highest Education Achieved				
None (including Nursery), n (%)	54 (15.2)	33 (32.6)	21 (18.6)	
Primary, n (%)	92 (44.9)	43 (42.6)	49 (43.4)	
Secondary, n (%)	50 (23.4)	20 (19.8)	30 (26.6)	
Tertiary, n (%)	16 (7.4)	4 (3.9)	12 (10.6)	
Graduate, n (%)	2 (0.9)	1 (0.9)	1 (0.8)	
Home Classification				
Urban, n (%)	53 (24.8)	12 (11.8)	41 (36.2)	
Suburban, n (%)	82 (38.3)	31 (30.6)	51 (45.1)	
Rural, n (%)	79 (36.9)	58 (57.4)	21 (18.6)	
Household Size				
Median (IQR)	6 (4 , 9)	6 (5 , 10)	5 (4 , 8)	0.001**
Religion				
Catholic, n (%)	61 (28.5)	36 (37.1)	25 (22.1)	
Protestant, n (%)	56 (26.2)	21 (21.6)	35 (31.0)	
Born Again Christian, n (%)	24 (11.2)	14 (14.4)	10 (8.8)	
Muslim, n (%)	48 (22.4)	16 (16.4)	32 (28.3)	
Anglican, n (%)	13 (6.0)	2 (2.0)	11 (9.7)	
7 <sup>th</sup> Day Adventist, n (%)	1 (0.4)	1 (1.0)	0 (0)	
Other, n (%)	7 (3.2)	7 (7.21)	0 (0)	
Injury				
Yes, n (%)	83 (38.8)	34 (33.6)	49 (43.4)	0.054
Medical Condition				
Yes, n (%)	105 (49.0)	53 (52.4)	52 (46.0)	0.348

\*\* Indicates statistical significance

### **3.2 Economic Demographics**

Patients seen for surgery at the two sites primarily self-reported that they were unemployed, which was 36% (n = 77) of the participants (Table 3s). The breadwinner of the family was often the individual at the hospital, whether that be the patient (35.1%, n = 75), the patient's parent (29.4%, n = 63), or the patient's partner (20.6%, n = 44). The median income for participants in the study was 5.56 USD (20000 UGX) per week and 288.88 USD (1000000 UGX) per year. Comparatively, the average total cost incurred by participants was 10.20 USD (36713.50 UGX). The highest cost that an individual incurred during their time to reach the hospital was 691.66 USD (2490000 UGX). Between the two hospitals, the total cost incurred was statistically significant with patients at MNRH incurring a higher average cost on their way to the hospital.

**Table 3: Population economic characteristics**

Characteristic	Overall (n= 214)	Mulago National Referral Hospital (n = 101)	Jinja Regional Referral Hospital (n= 113)	<i>P</i> value
<b>Weekly Income</b>				
Median (IQR), in UGX	20000 (10000 , 50000)	20000 (10000 , 50000)	20000 (10000 , 42500)	0.974
Median (IQR), in USD	5.56 (2.78 , 13.88)	5.56 (2.78 , 13.88)	5.56 (2.78 , 11.80)	0.974
<b>Yearly Income</b>				
Median (IQR), in UGX	1000000 (520000 , 2600000)	1000000 (520000 , 2600000)	1000000 (520000 , 2200000)	0.974
Median (IQR), in USD	288.88 (144.44 , 722.22)	288.88 (144.44 , 722.22)	288.88 (144.44 , 613.88)	0.974
<b>Patient Occupation</b>				
Unemployed, n (%)	77 (36.0)	45 (44.6)	32 (28.3)	
Home maker, n (%)	8 (3.7)	4 (4.0)	4 (3.5)	
Domestic Helper, n (%)	7 (3.2)	4 (4.0)	3 (2.6)	
Farmer, n (%)	44 (20.6)	20 (19.8)	24 (21.2)	
Self-employed, n (%)	62 (29.0)	23 (22.8)	39 (34.5)	
Government Employee, n (%)	6 (2.8)	4 (4.0)	2 (1.8)	
Non-government Employee, n (%)	5 (2.3)	1 (1.0)	4 (3.5)	
Private Sector Employee, n (%)	5 (2.3)	0 (0)	5 (4.4)	
<b>Breadwinner</b>				
Partner, n (%)	44 (20.6)	21 (21.6)	23 (22.1)	
Sibling, n (%)	8 (3.7)	6 (6.2)	2 (1.9)	
Child, n (%)	6 (2.8)	4 (4.1)	2 (1.9)	
Parent, n (%)	63 (29.4)	35 (36.0)	28 (26.9)	
Aunt / Uncle, n (%)	2 (0.9)	1 (1.0)	1 (1.0)	
Grandchild, n (%)	1 (0.4)	1 (1.0)	0 (0)	
Grandparent, n (%)	1 (0.4)	0 (0)	1 (1.0)	
Patient, n (%)	75 (35.1)	28 (28.8)	47 (45.2)	
Other, n (%)	1 (0.4)	1 (1.0)	0 (0)	
<b>Total Cost Incurred</b>				
Mean (SD), in UGX	36713.50 (5.51)	73438.24 (5.34)	19026.91 (4.46)	<0.001**
Mean (SD), in USD	10.20 (5.51)	20.40 (5.34)	5.28 (4.46)	<0.001**

\*\* Indicates statistical significance

### **3.3 Care-Seeking Description of the Population**

The care-seeking characteristics of the subjects showed a high rate of prior interaction with the healthcare system (Table 4). Overall, most patients had previously visited medical facilities of any kind twice per year. For the condition that they currently had, 73.4% (n = 157) of participants sought care at an alternative facility than the one at which they were surveyed. The average cost for a visit to an alternative medical facility was 17.02 USD (61267.20 UGX). Both visits to alternative facilities and the cost of those facilities were statistically significant between MNRH (24.76 USD, 89161.09 UGX) and JRRH (9.82 USD, 35383.46 UGX), with both having p-values less than 0.001 and 0.002, respectively.

Of respondents that sought care at an alternative medical facility, 78.3% (n = 123) were referred to the current hospital by that facility. Only 8.4% (n = 18) participants saw a traditional healer prior to coming to the hospital, and the average cost for the healer was 11.69 USD (42095.66 UGX). This average cost was significant between MNRH (37.48 USD, 134940.60 UGX) and JRRH (4.30 USD, 15510.86 UGX) with a p-value of less than 0.001. The maximum an individual paid for a traditional healer's services was 638.88 USD (2300000 UGX).

Time from arrival at the hospital to surgery was significantly different between MNRH and JRRH. Median time from arrival to surgery was 3 days at MNRH and 2 days

at JRRH. The results were significant for time from arrival to surgery with p-values of 0.029.

**Table 4: Sample care-seeking characteristics**

Characteristic	Overall (n= 214)	Mulago National Referral Hospital (n = 101)	Jinja Regional Referral Hospital (n= 113)	<i>P</i> value
Number of Medical Visits				
Median (IQR)	2 (1 , 4)	3 (1 , 6)	2 (1 , 3)	<0.001**
Alternative Medical Facility				
Yes, n (%)	157 (73.4)	84 (83.2)	73 (64.6)	0.002**
Alternative Medical Cost				
Mean (SD), in UGX	61267.20 (3.58)	89161.08 (3.28)	35383.46 (3.37)	<0.001**
Mean (SD), in USD	17.02 (3.58)	24.76 (3.28)	9.82 (3.37)	<0.001**
Referral				
Yes, n (%)	123 (78.3)	70 (83.33)	53 (72.6)	0.104
Traditional Healer				
Yes, n (%)	18 (8.4)	9 (8.9)	9 (8.0)	0.804
Traditional Healer Cost				
Mean (SD), in UGX	42095.66 (8.27)	134940.60 (8.89)	15510.86 (4.75)	0.062
Mean (SD), in USD	11.69 (8.27)	37.48 (8.89)	4.30 (4.75)	0.062
Time to Admittance (days)				
Median (IQR)	0 (0 , 0)	0 (0 , 0)	0 (0 , 0)	<0.001**
Time to Surgery (days)				
Median (IQR)	2 (1 , 5)	3 (1 , 12)	2 (1 , 4)	0.029**

\*\* Indicates statistical significance



### **3.4 Transportation Description of the Populations**

The median number of transportation modes used by subjects was 1 (IQR 1, 2), and ranged from 1 to 7 types of transportation per route to the hospital and was significantly different between the two study sites with a p-value of 0.048. MNRH had a median number of transportation modes used of 2 (IQR 1, 2) and JRRH had a median of 1 (1, 2). (Table 5) The most common modes of transportation were by motorcycle, locally referred to as bodas (or boda bodas), and public transport with a taxi known as a mutatu. Of all the participants, 37.2% (n = 132) reported using motorcycles and 31.0% (n = 110) stated use of public transportation. Only 7.9% (n = 28) of participants cited being taken to the hospital by an ambulance. Most participants (55.6%, n = 119) of respondents indicated that their preferred method of transportation to the hospital would be an ambulance.

Overall, participants travel to the hospital an average of 20.6 kilometers, this number being higher (31.2 km) for those at MNRH than those at JRRH (14.2 km) (p-value < 0.001). Similarly, total travel time and total wait time for transportation to arrive were higher at Mulago than at Jinja (p-values < 0.001 for both). When the time waiting for transportation was subtracted from the total travel time to reach the hospital, there was a decrease of nearly 1 hour overall - 2.9 hours with waiting and 2 hours without waiting.

In terms of cost of transportation, the average amount of money spent on transportation for all respondents was 4.00 USD (14406.58 UGX), and this number was again significantly higher for MNRH than JRRH. At MNRH the patients on average spent 8.26 USD (297768.32 UGX) on transportation compared to 2.04 USD (7359.44 UGX) at JRRH, significant with a p-value less than 0.001.

**Table 5: Sample transportation characteristics**

Characteristic	Overall (n= 214)	Mulago National Referral Hospital (n = 101)	Jinja Regional Referral Hospital (n= 113)	P value
<b>Transportation Mode</b>				
Ambulance, n (%)	28 (7.9)			
Motorcycle, n (%)	132 (37.2)			
Public Transport, n (%)	110 (31.0)			
Bus, n (%)	13 (3.6)			
Private Hire, n (%)	57 (16.1)			
Boat, n (%)	6 (1.6)			
Police Car, n (%)	5 (1.4)			
On Foot, n (%)	2 (0.6)			
Other, n (%)	1 (0.2)			
<b>Number of Transportation Modes</b>				
Median (IQR)	1 (1 , 2)	2 (1 , 2)	1 (1 , 2)	0.048**
<b>Preferred Transportation</b>				
Public Transport, n (%)	24 (11.2)	20 (19.8)	4 (3.5)	
Car, n (%)	57 (26.6)	44 (43.6)	13 (11.5)	
Motorcycle, n (%)	12 (5.6)	8 (7.9)	4 (3.5)	
Boat, n (%)	1 (0.4)	0 (0)	1 (1.0)	
On Foot, n (%)	1 (0.4)	1 (0.8)	0 (0)	
Ambulance, n (%)	119 (55.6)	28 (27.7)	91 (80.5)	
<b>Distance Away</b>				
Mean (SD)	20.6 (4.6)	31.2 (5.6)	14.2 (3.4)	<0.001**
<b>Total Travel Distance (km)</b>				
Mean (SD)	22.4 (4.5)	38.2 (4.9)	14.2 (3.6)	<0.001**
<b>Total Travel Time (hr)</b>				
Median (IQR)	2.9 (1.2 , 6)	5.5 (2.6 , 9.1)	1.5 (0.8 , 3)	<0.001**
<b>Total Travel Wait Time (hr)</b>				
Mean (SD)	0.7 (4.9)	2.1 (3.4)	0.3 (3.8)	<0.001**
<b>Total Travel Time Without Wait (hr)</b>				
Median (IQR)	2 (0.8 , 4)	3 (1 , 5.5)	1 (0.5 , 2.2)	<0.001**
<b>Total Transportation Cost</b>				
Mean (SD), in UGX	14406.58 (4.64)	29768.32 (4.57)	7359.44 (3.36)	<0.001**
Mean (SD), in USD	4.00 (4.64)	8.26 (1.38 , 22.08)	2.04 (0.56 , 3.33)	<0.001**

\*\* Indicates statistical significance

### **3.5 Overall Barrier Trends**

The rating and ranking exercise demonstrated differences between the most significant barriers (Fig 3). The rating exercise revealed that cost of surgery (median 4, IQR: 3 – 5), distance to the hospital (median 4, IQR: 2 – 5), and transportation to the hospital (median 4, IQR: 2 – 4) were the most significant barriers to seeking and reaching care. Language barrier (median 1, IQR: 1 – 2) and no control over decision making (median 1, IQR: 1 – 3) were the least significant barriers during the rating assessment.

The ranking exercise revealed that cost of surgery (median 1, IQR: 1 – 3) was the most significant barrier to care (Fig 4). Second was transportation to the hospital (median 3, IQR: 2 - 5). No control over decision making was elucidated as the least significant barrier to surgery (median 9, IQR: 6.25 – 10).

Comparison of the rating and ranking exercises shows similarities in which barriers were the most and least significant, yet there were differences between the two exercises (Fig 5). Cost of surgery was the most significant barrier to care in both exercises. Distance to the hospital and transportation to the hospital were second and third in the rating exercise, but third and second in the ranking exercise. Also of note, language barrier was the least significant in the rating exercise, but eighth out of ten in the ranking exercise.

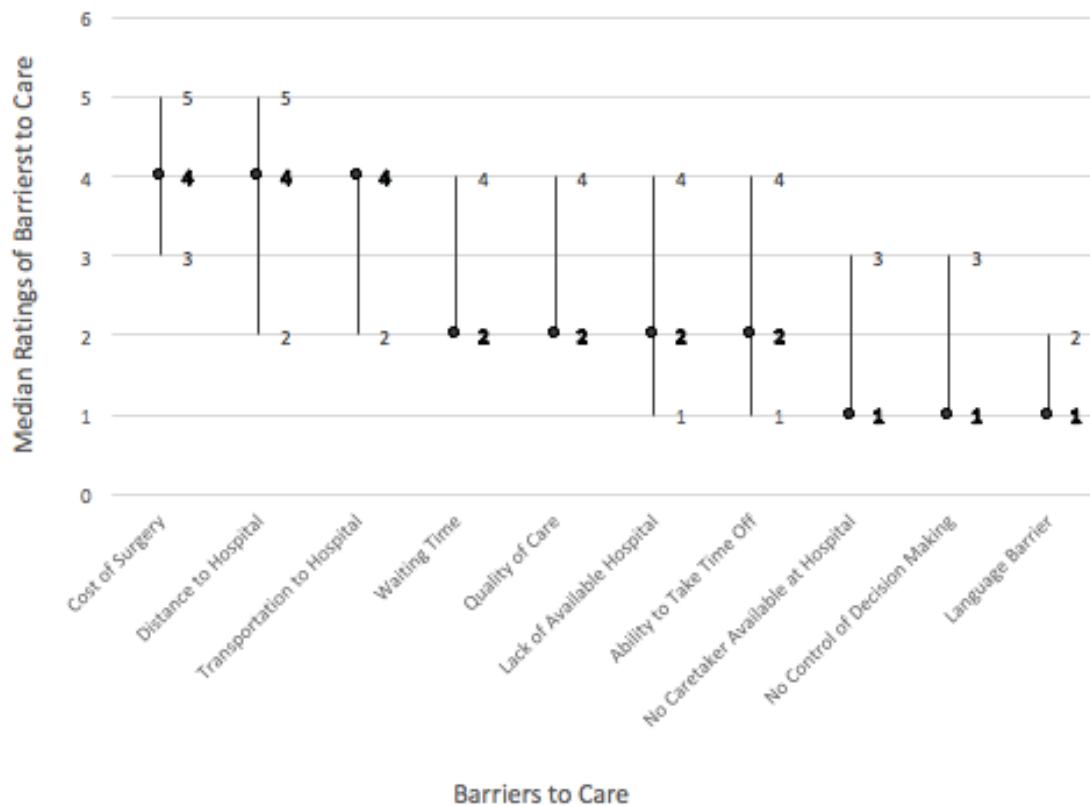


Figure 3: Median rating for each barrier to surgical care along with interquartile range for all participants. Variables are ordered from highest median ranking (5) to lowest(1).

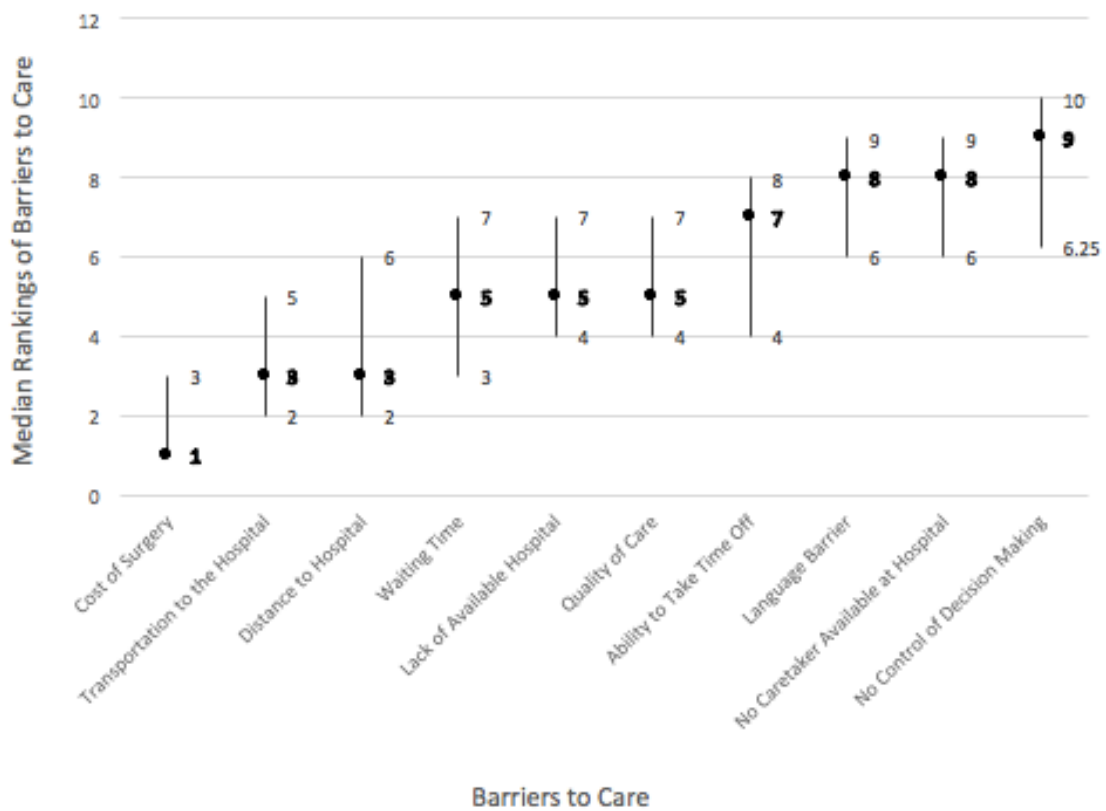


Figure 4: Median ranking for each barrier to surgical care along with interquartile range for all participants. Variables are ordered from most significant median ranking (1) to least (10).

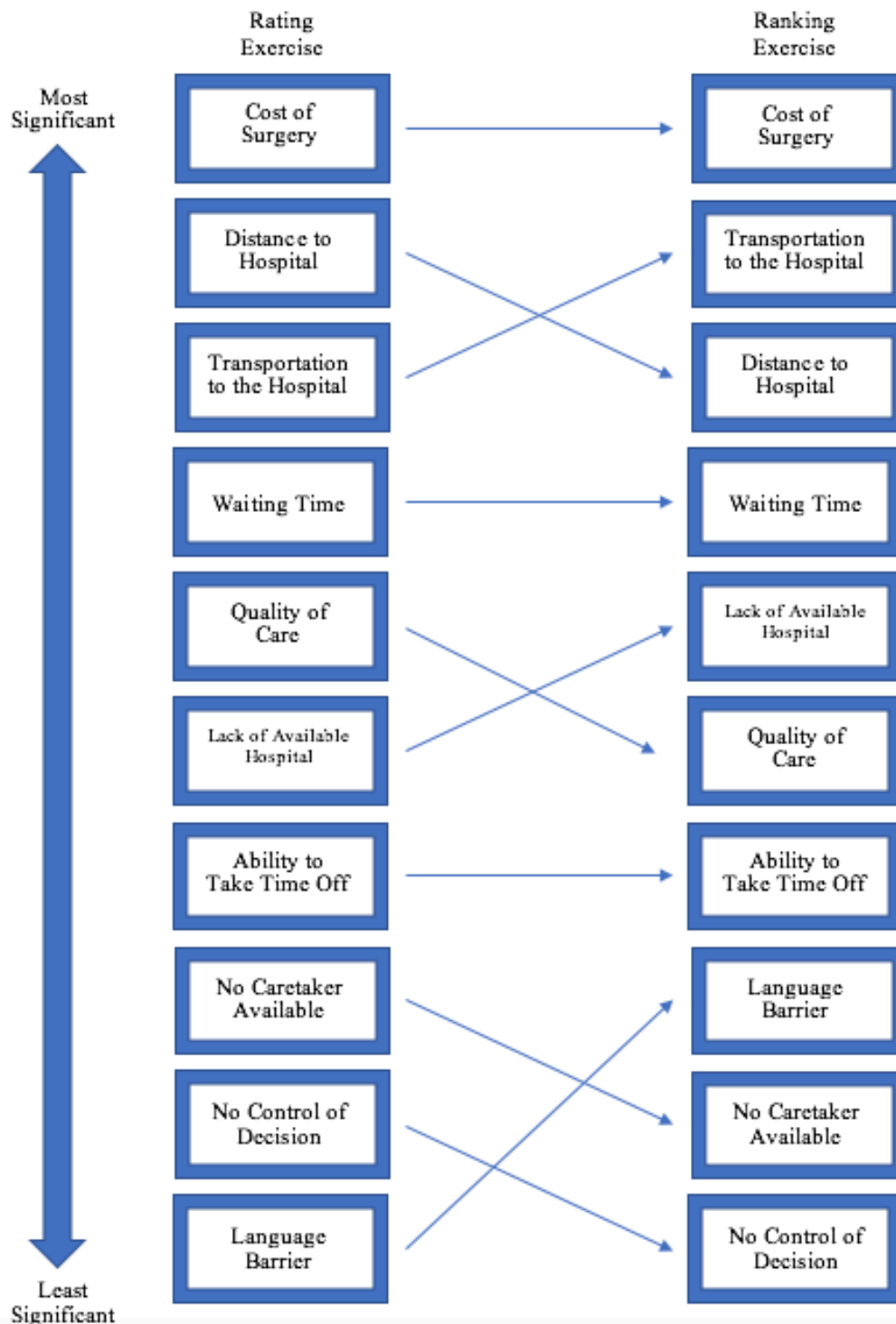


Figure 5: Comparison of ranking and rating analysis of barriers to surgical care listed in order from most significant to least significant by median and interquartile range. Arrows represent the differences between the findings of the two types of analysis.

### ***3.6 Qualitative Interviews: Respondent's Accounts of Barriers***

Transcripts to semi-structured interviews were analyzed for emergent themes around three topics as derived from McIntyre's categories of accessibility, affordability, and acceptability. Sub-themes emerged as they related to the ten barriers assessed in this study. All respondents to the interviews were caretakers of patients as patient interviews were not feasible given the severity of patient conditions and inability to move patients from the ward to secluded areas for the interview. The main categories are explored through different quotes from the participants that were interviewed. Coding for the interviews was conducted by recognizing first order and higher order themes from McIntyre's dimensions of access to care. This is outlined in Table 6 and then fully demonstrated with excerpts below.



**Table 6: Categories and themes of qualitative data**

Categories	First Order Themes	Higher Order Themes
Availability	Provision of Service	Waiting Time ( <i>B</i> ) Ability to Take Time Off Work to Travel ( <i>B</i> )
	Infrastructure and Resources	Lack of Available Hospital ( <i>B</i> )
	Transportation and Location	Distance to the Hospital ( <i>B</i> ) Transportation to the Hospital ( <i>B</i> )
Affordability	Direct Cost	Cost of Surgery ( <i>B</i> )
	Indirect Cost	Cost of Services and Transportation
	Socioeconomic Status	Income and Wage
Acceptability	Provider-Patient Interaction	Language Barrier ( <i>B</i> ) Caretaker Behavior
	Quality of Care	Quality of Care ( <i>B</i> ) No Caretaker Available ( <i>B</i> ) Condition of Hospital
	Understanding of Health and Community Support	Unable to Make Decision for Self ( <i>B</i> ) Decision Making
		Fear

(*B*) indicates barrier assessed in the study

### 3.6.1 Availability

The lack of a surgical center near the patient is one of the biggest barriers to availability that the patients and their caretakers had to overcome to get the surgical care that they required. One individual responded: *“Where I stay there are hospitals but the clinics that are there are not good enough and they don’t take care very well and the government facilities for city council they sometimes don’t have drugs so we have to get help from here in Mulago.”* The fact that there are clinics and lower level hospitals scattered around Uganda was cited in many interviews, but the participants viewed them as insufficient to getting the surgical care they need. The lack of high-quality centers was particularly important for pediatric care, as one mother said: *“The one that can treat my baby is not there.”* She was referring to her home, where she had traveled from.

For many patients, the distance from the hospital was a large barrier, often cited as the second or third highest barrier among the ten presented to the participants. For example, one respondent stated: *“To be the most important one, the hospital being far from where you live, it’s a very big problem because you cannot reach there on time to access the services because you stay far especially when the distance is very far.... I see it as a big problem.”* Yet, while the problem of distance is an important, there were participants that, while acknowledging distance is a barrier, would travel any length to get treatment. Another participant responded in the following manner: *“I am willing to go any distance as long as my patient gets fine.”*

Often difficulties with transportation is linked to how far the individual needs to travel to access care. Often transportation is not accessible, and even when it is, it may not be the safest mode of transportation possible, putting the patient and caretakers at risk when traveling to the hospital: *“The journey is difficult, it is simply because in most cases we use bodas since there is a lot of jam so we can’t use taxis and yet you are with a patient.”*

Bodas are the motorcycle taxis that populate the roads and are one of the most common forms of transportation in Uganda. Many road traffic injuries occur on bodas and then patients attempt to get to the hospital on another boda. This bodes for some issues, but even travel by safer means and the majority preferred mode of transportation (55.6% n = 119) by participants in the study, an ambulance, provides a unique set of challenges to the patients and their families: *“At first they told us that the ambulance is not around and later they told us that it is around but we should pay for the fuel. I later asked a doctor how much money they needed for the fuel, they were not telling us until when my son in law came, its him who asked and they told him to pay 120,000 UGX. He paid for the ambulance as well the fee for the hospital.”*

### **3.6.2 Affordability**

Cost was overwhelmingly cited as the greatest barrier to surgical care in the surveyed population. Money was cited multiple times throughout the interviews as well. The last example above hinted at the juxtaposition of many of the barriers to care cited in this study with cost and financial burden. Money is a great hindrance and cause

of delay of care. One respondent spoke of how care was being delayed because of insufficient funds: *"We are waiting and at the same time back in the village we are collecting the money."* Patients also have issues with being able to afford the indirect costs of surgical care, like the medications and drugs they need prior to or following surgical intervention: *"Sometimes they prescribe for us drugs and yet they don't have them so they tell us to out there and buy the drugs. When you reach you find the drugs very expensive and that is kind of hard and sometimes the drugs are hard to find so you have to really look harder and when you find them they are so expensive."*

Further, long stays at the hospital lead to financial hardships: *"I have even run out of money to use because I have spent one and a half months here and they have not yet worked on him. They put him on the list and later remove him on the list and it has been like that for a while."* Running out of funds while waiting for care and incurring indirect and direct costs are issues, and respondents cite that this financial burden trickles back to their home: *"My husband has spent some good months without working. He used to sell oranges and mangoes although me I was not working. The problem I have now is that I also have children now they don't go to school, we owe them rent for the house."*

Finally, regarding finances, patients were asked to how much money they would be able to provide without an issue versus what would be too much to bear. The responses were as followed:

Respondent 1: *"I think we can look for 200,000 UGX" ; "More than 500,000 and above, that is very high"*

Respondent 2: *"If they ask me for 10.000 UGX I can afford that since my earning is very small." ; "If they ask for 500.000 UGX, that is a lot of money."*

Respondent 3: *"If they tell me to pay like 200.000/=, I can pay that." ; "More than 1 million [would be too much]"*

Respondent 4: *"I think I can get 100, 000 UGX" ; "If they exceed more than 100,000/= I can't afford that according to me."*

Financial burden manifests itself through the many costs that apply to the hospital and the costs cited above through willingness-to-pay speak only to the cost of the surgery, not the indirect costs and costs of getting to the hospital.

### **3.6.3 Acceptability**

Acceptability refers to patient attitudes towards hospital staff and each other within the hospital and can relate to the quality of care, the time they spend waiting within the hospital, interactions they and caretakers have with each other and staff. Participants did not always feel as though the services provided were of the highest standard of care: *"The most important thing that weighs off some burden from the people as in providing good services is by upgrading it, the instruments used, they should be of high standard."* Even when the care can be provided, it is often difficult for the patients and caregivers to wait patiently for the intervention that is needed, putting burdens on both

the providers and the patients/caretakers: *"It has been a while now coming to 3 weeks, they put you on a list and when they get an emergency they remove you from the list. Of course you feel bad about being in hospital and yet there are things that need their attention. That is not good. You feel bad."*

It is often hard for the patients to be accepted within the hospital as well because of language barriers that may exist between the providers and the individuals there to receive the care. One patient had this to say about language barriers: *"I tell them that I have not understood what they are trying to tell me although they don't know Luganda, they were trying to speak it in a way that I understand so that I get to know what he is trying to say because I can understand it."* Although there is an attempt to bridge the language gap, it is difficult for communication between parties, often leading to other patients or caretakers having to interpret for their peers. This proves to be difficult as the patients' attendants (caretakers) are responsible for providing the day-to-day bedside care for their loved ones: *"They tell us that in the morning, you bath the patient, dress him up, lay the bed, brush his teeth and then sleeps again, arrange the bed and clean it so that the doctors/nurses find him when he is clean. After you wash his dirty clothes."* The amount of care provided from non-medical staff is immense, and does not come without its own indirect costs and delays.

## 4. Discussion

This study demonstrated that individuals seeking surgical care face catastrophic expenditure, are required to travel unthinkably large distances for basic surgical care, and face numerous significant obstacles to care prior to even being admitted for surgery, which many already cannot afford. Nearly half of all patients surveyed (48.6%) received unspecialized, general surgical care. Thirty-six (36) percent of all patients were unemployed. Median weekly income of participants was 5.56 USD compared to an average 10.20 USD total cost incurred on the way to the hospital. Cost incurred was significantly larger at MNRH than JRRH (p-value of <0.001). Most respondents, 73.4%, reported that they sought care at an alternative medical facility prior to arriving at the hospital they were surveyed at, with an average cost of 17.02 USD (61627.20 UGX) charged for that visit. Finally, a dichotomy between transportation types taken and preferred transport type was discovered, as 37.2% of participants traveled on a motorcycle and 31% of participants traveled on public transportation to the hospital. This is compared to 55.6% of all participants that preferred an ambulance as their main means of travel – only 7.9% of participants were transported via ambulance to the hospital.

Qualitatively, McIntyre's themes of accessibility, affordability, and acceptability were used to categorized the healthcare-seeking behavior described as important in the interviews. This supported the findings of the ranking and rating exercises. We found

that cost of surgery, distance to the hospital, and transportation to the hospital were the largest barriers to accessing surgical care, with language barriers, not having a caretaker at the hospital, and having no control over the decision-making process being the least significant barriers to care. Some variation existed between the two tools. For example, distance and transportation were often interchanged between the ranking and rating exercise, nevertheless still presenting large barriers to care according to the participants.

#### ***4.1 Sample Characteristics and Hospital Comparison***

Comparison of quantitative hospital data and qualitative data confirmed that cost and transportation are major issues for families. Our demographic characteristics echo that of the literature surrounding accessing barriers to surgical care [24, 67, 101]. Mulago National Referral Hospital had much greater costs, travel distances, and transportation barriers associated with it. Representative in the data between JRRH and MNRH was a difference in total costs incurred, with MNRH having higher costs. This is consistent with findings in the literature, as distance is often seen as a proxy for not only severity of disease but also incurred cost [102]. Welch and colleagues showed that patients traveling from large distances to the hospital incur more financial burden than those that are local [102]. This is consistent with what can be seen at Mulago, as being the national referral hospital creates a much larger catchment area than JRRH [26].

Further, catastrophic expenditure for surgical patients is recognized as very important in Lancet Commission on Global Surgery's main barriers to care [12]. This is



shown in our data by comparing median income for participants with average total cost incurred. Median weekly income came out to 5.56 USD per week and 288.88 USD per year, while total cost incurred was on average 10.20 USD overall, 20.40 USD at Mulago, and 5.28 USD at Jinja. We see over two weeks of income required on average to pay for the cost incurred to get to the hospital overall, rising to around a month of income required to pay for the cost incurred on the way to Mulago. Xu and colleagues defined catastrophic expenditure to represent healthcare costs that exceed 40% of income remaining after sustenance has been met [103]. Our data supports that prior to even getting estimates for costs associated with surgical care, on average patients are already spending approximately 183% of their weekly income just to get to the hospital. This further supports findings of catastrophic expenditure across the globe in LMICs [104, 105, 106, 107].

The three delays framework aligns with many of the findings in this study [12]. However, this study primarily focused on the first two delays, which becomes apparent when looking at the data. An important piece found in the analysis was comparing the time spent traveling with and without having to wait for transportation. Median travel time was 2.9 hours when having to wait for transportation; if that wait time could be removed, the median travel time drops by nearly one hour to 2 hours. This is even more significant for MNRH. At this facility, the median travel time was 5.5 hours, and dropped to 3 hours when waiting for transportation was taken out of the equation. This

is imperative because being able to save 2.5 hours in the transport of patients could make the difference between life and death, especially for more severe injuries and more complicated surgical interventions like neurosurgery and cardiothoracic surgery [12, 102]

## ***4.2 Ranking and Rating Analysis***

Our findings for the ranking and rating analysis support the main barriers to surgical care in the literature. These barriers, primarily reported under the umbrella of both McIntyre and Irfan's theoretical frameworks, are founded on the basis on individuals not being able to access, afford, and accept surgical care [28, 30]. Studies have indicated that these categories of barriers to care inform the decision-making process and can prevent individuals from receiving the care that they need [14, 57]. Systematic reviews that looked at barriers to care support the ten barriers chosen for this study, as well as the supporting empirical literature [14, 28]. Further these barriers used were previously utilized in studies in Guatemala, to similar results [57, 97].

Our study reflects the literature for other sub-Saharan Africa studies. Lin and colleagues found that cost was reported as the most significant barrier to surgical care in the Republic of Congo by 73% of their respondents [67]. A study utilizing SOSAS in Nepal found similar results as well, citing accessibility and affordability as the largest self-reported barriers to care, which supplements the findings by Fuller and colleagues in Uganda preceding this study [24, 26]. One way in which our data differs from these

studies is that our qualitative interviews, which were used to assess more in-depth reasons for not seeking care, did not elucidate fear as a large barrier to care, as seen in previous SOSAS studies [24, 26]. This may reflect the patient population that we surveyed, which already were at the hospital and many of which already had received a surgical intervention.

This study highlights the importance of utilizing the tandem pair of both ranking and rating analyses, as the two tools complement each other. Although the rating exercise afforded us the ability to determine the order of importance that the patients placed on specific barriers, the ranking exercise made respondents choose between two different variables [83]. However, the issue with the latter exercise is that we are unable to determine how significantly different the barriers are in the mind of the respondent; we are only able to see how they rank in relation to one another. Further comparisons between other demographic barriers and the results of the ranking and rating exercises could elucidate more important delineations between the specific barriers.

### ***4.3 Implications for policy and practice***

In tandem with the recommendations from the Lancet Commission on Global Surgery, this study has important implications for policy. Elucidating the means in which individuals travel to the hospital and the barriers and financial loss incurred during that process is invaluable to a Ministry of Health and to administrative personnel within hospitals. To better determine how to decrease the barriers associated with delay

in seeking and delay in reaching care, our study could be used to understand where patients are having the most problems as they attempt to get to the hospital.

With catastrophic expenditure already occurring before the patient gets to the hospital, revisiting health financing schemes should be made a priority. Whether it be by providing better access and transportation to surgical centers to mitigate the cost of reaching care or by making indirect costs within the hospital less, there needs to be a restructuring of what patients need to spend out-of-pocket for. If this can be addressed, then there would be less stress on patients to be able to get to the hospital and many more people would be able to receive the care that they need.

The findings of this research indicate that governments and healthcare providers need to value the input, opinions, and preferences of the patients and caretakers that consume the healthcare. This is important for all healthcare settings, regardless of country economic classification. Within the three dimensions utilized as the lens for this study, acceptability is incredibly important to determining the effectiveness of the healthcare system [28]. If patients and providers, administrators, and governments do not see eye to eye on expectations for healthcare provision, then the system will fail those who need it most. This study elucidates the preferences and opinions of patients within the Ugandan healthcare system, which should be utilized to influence proper investigations into mitigating the barriers seen by the Ugandan people. These lessons

should be able to be applied across settings within Uganda, and ideally throughout many developing countries worldwide.

However, mitigation of barriers to seeking care is not the only answer. Service provision needs to continue to be invested in as barriers are reduced. Greater accessibility leads to greater demand, and it is the responsibility of the healthcare system to provide the necessary capacity to address the demand. The Lancet Commission on Global Surgery is a great beginning to understanding how to address these issues across the three-delay framework and should be utilized moving forward to help create and invest in quality surgical care for all [12].

#### ***4.4 Implications for further research***

Further research should address reasons for which individuals cite specific barriers to care and determining how complex decisions are made about seeking care. Behavioral economics research could be a way to help understand this gap in the literature, but is scarcely used to address issues in surgical settings. While business analytic tools such as the ranking and rating exercises used in this study are in the literature, the dearth of use of business and economic tools to understand the decision-making process makes it difficult to predict and understand how the consumer of healthcare interacts with the system they are trying to access. In high-income countries, discrete choice experiments, which are utilized to determine how individuals make complex decisions, have been used to address healthcare providers and the way they

provide care [59]. In LMICs, the use of such tools has been limited and primarily revolve around specific types of care or how to incentivize physicians to move from urban areas to rural areas [62]. The use of behavioral economics can be critical to understanding how barriers influence the individual decision to seek care or not, and where to seek care.

Further research can also be done to address the context of catastrophic expenditure within the first two delays to care. Cost to surgery is a large barrier to care as seen as a priority by the Lancet Commission [12], however, all the indirect costs that lead up to accessing the hospital should be looked at more in depth.

#### ***4.5 Study strengths and limitations***

The main strength of this study is the utilization of a mixed-method approach. While the quantitative tools were useful in measuring, the study aims the complementary data shown in the qualitative interviews helps provide context to the data. This allows for a better understanding of why certain barriers are cited more often than others and within what context those barriers are the main obstacles. The utilization of both ranking and rating exercises allowed this study the barriers to surgical care against each other and overall. While the results were expectedly similar, it provided the basis for the qualitative aspects of the study, which we could elucidate specific instances in which barriers had significant impacts on individuals attempting to reach care.

Another strength of the study is that it effectively assessed specific barriers in depth, instead of just identifying barriers. We determined the ordinal significance of barriers to care and give weight to which barriers had the largest impact on care-seeking individuals. This allows us to inform future, more in-depth research that could target specific barriers, rather than just assessing overall trends. Overall frameworks of accessing healthcare and describing barriers to care do not provide the depth in understanding of specific barriers, in which this study is able to do.

Our study has several limitations. The most important limitation is the short time of data collection and small sample size, leading to selection bias. Further, a limit of the business analytics used is that, as mentioned previously, while they are good to use in tandem they individually cannot fully measure significant differences between citing specific barriers over others.

Another limitation is the convenience sample utilized in this study. All participants could reach the hospital and therefore may be biased towards which obstacles and barriers they faced to reach care. That, coupled with self-reporting, which at times can be unreliable, makes it difficult to generalize the data to the entire country of Uganda. However, despite these limitations, we are confident in our results and the associations that we could draw.

## 5. Conclusion

Catastrophic expenditure is not only relevant regarding to direct costs of surgical care. Indirect costs provide equally large barriers preventing individuals from accessing the surgical care that they need. Our ranking and rating exercise confirmed that cost is the most significant barrier to surgical care, yet all types of cost need to be considered to fully understand the economic burden that surgical patients face as they attempt to seek care. Distance to the hospital is another significant factor that needs to be addressed, as it manifests not only in large travel costs and delays in initial care-seeking behavior, but also represents the need for proximal surgical sites that can provide surgical care to the most remote patients.

Language barriers and not having control over decision making were the least significant barriers to surgical care, yet still need to be taken into consideration when assessing healthcare system acceptability. Healthcare facilities need to be attuned to the needs of the individuals and support those that may be unable to effectively communicate about and understand the decisions that are required to ensure successful surgical care.

Future research should explore the connections between barriers to fully determine the impact each barrier has on the care-seeking individual. Overall, efforts to reduce the cost of surgery and shortening the delay in seeking and delay in reaching care should be prioritized to impact the most individuals, especially those in poverty or



in rural parts of developing countries. Further studies regarding these barriers are necessary to influence the progression of policies around surgical care, ensuring that surgical provision and quality becomes a priority for governments and healthcare administrators.

## Appendix A: Quantitative Survey

Informed consent has been obtained (Please circle one):

YES                      NO

Time and Date of Informed Consent: \_\_\_\_\_ AM / PM (Circle) \_\_\_\_/\_\_\_\_/\_\_\_\_  
(DD/MM/YYYY)

Unique Participant ID Number: \_\_\_\_\_

### Demographics:

1. Are you here to receive medical care?                      YES                      NO
- a. Is a family member here to receive surgery?                      YES                      NO
- b. What is your relation to the family member?                      \_\_\_\_\_

2. Patient Gender:      Male \_\_\_\_                      Female \_\_\_\_

3. Age of Patient: \_\_\_\_

[Age for babies:

<3 months = 0

3- <6 months = 0.25

6- <9 months = 0.5

9- <12 months = 0.75

12-24 months = 1 etc.]

4. What is the highest educational level that you and the patient has achieved or are currently following?

You

\_\_\_\_ None (includes nursery)

\_\_\_\_ Primary school

\_\_\_\_ Secondary school (junior / senior)

\_\_\_\_ Tertiary (diploma, colleges, bachelors)

\_\_\_\_ Graduate degree (Master degree, PhD)

Patient

\_\_\_\_ None (includes nursery)

\_\_\_\_ Primary school

\_\_\_\_ Secondary school (junior / senior)

\_\_\_\_ Tertiary (diploma, colleges, bachelors)

\_\_\_\_ Graduate degree (Master degree, PhD)

5. Are you and the patient able to read and write in any language?

[For adults and children who are currently learning how to read and write answer: 'No']

You

\_\_\_\_ Yes

\_\_\_\_ No

Patient

\_\_\_\_ Yes

\_\_\_\_ No

6. Where are you from? \_\_\_\_\_ District \_\_\_\_\_ Town

7. What is your primary occupation?

- Unemployed [*Currently looking for jobs, retiree's, students*]
- Home maker [*Housewives*]
- Domestic helpers [*Cleaners, housekeepers, watch guards*]
- Farmer [*Herders, agriculture, pastoralist*]
- Self-employed / small-business [*Small business owners like: shops, kiosks, food traders*]
- Government employee [*Police officer, accountant, teachers, health care workers*]
- Non-government employee [*Cooperation managers, NGO-staff*]
- Private sector employee [*Company manager, employee*]

8. What is the patient's primary occupation?

- Unemployed [*Currently looking for jobs, retiree's, students*]
- Home maker [*Housewives*]
- Domestic helpers [*Cleaners, housekeepers, watch guards*]
- Farmer [*Herders, agriculture, pastoralist*]
- Self-employed / small-business [*Small business owners like: shops, kiosks, food traders*]
- Government employee [*Police officer, accountant, teachers, health care workers*]
- Non-government employee [*Cooperation managers, NGO-staff*]

9. What is you and the patient's ethnic background? [*In case of refusal to answer, ask whether the person was born in Uganda*]

- Native to the Area
- Native to another District of Uganda                      Which one? \_\_\_\_\_
- Non-Ugandan    What country? \_\_\_\_\_

10. Do you live in an urban/suburban/rural area? (Please Circle One)

Urban                      Suburban                      Rural

11. What is the average weekly income in your household? \_\_\_\_\_

12. What is the primary source of income for your family? \_\_\_\_\_

a. Who is the primary breadwinner of the family? \_\_\_\_\_

13. What is the primary language your family speaks?

- Luganda
- English
- Swahili

Other: \_\_\_\_\_

14. What is the primary religion/spiritual faith your family practices?

\_\_\_\_\_

15. In total how many people live in your household? \_\_\_\_\_

a. How many dependents do you have? \_\_\_\_\_

i. Is the patient one of them? YES NO

b. How many dependents does the patient have? \_\_\_\_\_

16. How many times have you visited a clinic or hospital, or nurse / medical doctor in the past year? \_\_\_\_\_

**Surgery Specific:**

17. On what date did you/your family member get here? \_\_\_/\_\_\_/\_\_\_ (DD/MM/YYYY)

18. On what date were you/your family member admitted? \_\_\_/\_\_\_/\_\_\_ (DD/MM/YYYY)

19. On what date is/was your/your family member's surgery scheduled?  
\_\_\_/\_\_\_/\_\_\_ (DD/MM/YYYY)

20. What type of surgery is/was it?  
\_\_\_\_\_

21. Did the problem start after an injury or accident? What kind of accident?  
*[Pick the one that best describes the injury / accident. Pedestrian and bicycle crash definition: there was no motorized vehicle involved. All can be intentional or unintentional.]*

- \_\_\_ No, it was not due to an injury / accident
- \_\_\_ Car, truck, bus crash
- \_\_\_ Motorcycle crash
- \_\_\_ Pedestrian, bicycle crash
- \_\_\_ Gunshot
- \_\_\_ Stab / slash / cut / crush
- \_\_\_ Bite or animal attack
- \_\_\_ Fall
- \_\_\_ Open fire / explosion
- \_\_\_ Hot liquid / hot object

22. Did the problem start from having a disease?

YES NO What disease? \_\_\_\_\_

23. When did this problem start?  
 \_\_\_\_\_ days / weeks / months ago (circle one)

**Transportation Specific:**

24. How far away do you live from this clinic (specify units of measurement)?  
 \_\_\_\_\_ km

25. How did you get to this facility today? Please list all stages of transport.

	Transport Type	Cost	Distance Traveled	Time of Travel	Time Waiting
1.	_____	_____ UGX	_____ km	_____ hours	_____ hours
2.	_____	_____ UGX	_____ km	_____ hours	_____ hours
3.	_____	_____ UGX	_____ km	_____ hours	_____ hours
4.	_____	_____ UGX	_____ km	_____ hours	_____ hours
5.	_____	_____ UGX	_____ km	_____ hours	_____ hours
6.	_____	_____ UGX	_____ km	_____ hours	_____ hours
7.	_____	_____ UGX	_____ km	_____ hours	_____ hours

26. Are you always able to provide these means for transport of a sick household member?

	Transport Type
1.	YES _____ NO _____
2.	YES _____ NO _____
3.	YES _____ NO _____
4.	YES _____ NO _____
5.	YES _____ NO _____
6.	YES _____ NO _____
7.	YES _____ NO _____

**SKIP TO QUESTION 30**

27. How long did it take you in total to get here? (hours)  
 \_\_\_\_\_

28. How long did you have to wait for transportation to here, in total? (hours)  
 \_\_\_\_\_

29. How long does it take you in total to get to your primary health facility if you don't have to wait for transportation? (hours)  
 \_\_\_\_\_

30. What type of transportation would you prefer that you or your household members got for transport to a primary health facility?

- Public transport (Mutatu)
- Car
- Motorcycle (Boda)
- Bicycle
- Boat
- On foot
- Ambulance

**Healthcare Seeking Specific:**

31. Did you go to a different health facility or see a doctor/nurse for this problem prior to coming here?      YES                      NO

31a:    What was the name of the facility? \_\_\_\_\_

31b:    What kind of treatment did you receive? \_\_\_\_\_

31c:    How much did this treatment cost? \_\_\_\_\_

31d:    Were you referred here by this individual or facility?      YES                      NO

32. Did you go to a herbalist, traditional doctor, or bone setter for this problem?

YES                      NO

32a:    What kind of treatment did you receive? \_\_\_\_\_

32b:    What did this service cost (money, property, favors, etc.) \_\_\_\_\_

It did not cost anything: \_\_\_\_\_

32bi: If money, how much? \_\_\_\_\_ UGX

**RANKING TEST:**

**Please rank in order from 1-10 the most significant barrier to care that prevented you or your family member from getting surgery before now**

Barrier	Ranking
Cost of Surgery	_____
Distance to the Hospital	_____
Waiting Time	_____
Language Barrier	_____
Transportation to the Hospital	_____
Ability to Take time off of work to travel	_____
Quality of Care	_____
Lack of Available Hospital	_____
No Caretaker Available at Hospital	_____
No Control of Decision Making	_____

**RATING TEST:**

**For the following variables, please rate each in terms of significance for what prevented this specific surgery for you or your family member (1- least significant, 2 – moderately significant, 3 – neutral, 4 – very significant, 5- most significant)**

Barrier	Rating
Cost of Surgery	_____
Distance to the Hospital	_____
Waiting Time	_____
Language Barrier	_____
Transportation to the Hospital	_____
Ability to Take time off of work to travel	_____
Quality of Care	_____
Lack of Available Hospital	_____
No Caretaker Available at Hospital	_____
No Control of Decision Making	_____

## Appendix B: Semi-Structured Interview Guide

### ISC-2: Family Member / Surrogate Interview

**\*\*Please follow the interview script and ask the questions as they are written below.\*\***

**\*\*Utilize the area under each question to take notes and record observations.\*\***

**\*\*For parts with more than one question make sure to ask them one at a time,\*\***

**\*\*allowing the participant to answer each question before\*\***

**\*\*moving on to the next one.\*\***

Hello. Before we start, I would like to confirm that you have consented to this interview and signed the informed consent form, is that correct? Do you have any questions before we begin?

We will now begin the interview. Remember, at any point we can stop and you can choose to no longer continue participating. I will be recording our conversation today to be used in our research. I am now going to turn on the recorder.

#### **PRESS RECORD ON THE VOICE RECORDER NOW**

First, let us talk about the questionnaire you just took. I notice that you listed \_\_\_\_\_ as the most significant barrier to you seeking care. Why is that?

You then listed \_\_\_\_\_ as the least significant barrier to you seeking care. What makes this the least significant?

Finally, I want to know more about why similarly rated obstacles were ranked in the order they were. Both \_\_\_\_\_ (, or and) \_\_\_\_\_ (, or and) \_\_\_\_\_ were rated as a \_\_\_\_\_. Why did you then rank them in the order that you did? (Go through one by one).

Now, I would like to have a conversation about your experience with seeking surgical care here. Why did you make the decision to come get surgery? Why did you decide to come with your family member?

Did you or your family consult anyone to make this decision? If so, what did they tell you?



Why did you decide to come to this facility, rather than another one? (Referred here / Closest?)

Did anyone advise you to come here? If so, who?

Please describe your experience to get here.

What obstacles did you face in acquiring transportation?

Did you provide the transportation for your family member? If not, who did and how do you know them?

What is the furthest that you would be willing to travel if your family member would be ensured to have a successful and safe surgery?

How have your family and friends reacted to your family member needing surgery?

Will you be waiting with your family member until they are discharged? (IF NO: Why not?)

How did you find out that your family member needed surgery? How long have you known?

How do you and your family usually receive health education? From who do you receive it?

How do you get information about surgery?

Do you believe that hospital staff (especially doctors/nurses) explain things to you and your family member well enough in a way that you can understand? (IF NO: Is there a language barrier between you / your family member and the nurses and doctors that prevents you from understanding?)

Do you trust your doctors when they provide you and your family member with medical advice?

What is the maximum amount of time you would be willing to wait if you knew your family member would have a successful and safe surgery?

Do you feel as though you are provided enough information by hospital staff while you are waiting? What information do you wish you could know?

What is waiting for care in the hospital like?

Describe your interactions with hospital staff during your wait.

Have the services provided by this hospital been sufficient for your family member?

What do you think could be improved within this hospital in relation to your family member getting surgery?

Do you think your native district has enough public / government hospitals? (IF NO: Do you think that should be changed?)

What reservations do you have about going to the hospital?

Is there anything that frightens you specifically about surgery?

What have you heard about complications from surgery? How did that impact your decision to come get surgery?

Did you expect to incur any costs when coming to this facility when seeking treatment? (IF YES: How did you know about them ; IF NO: When did you find out you would have to pay for them?)

Who provides the majority of the income for your household? How has needing surgery affected the their/your ability to provide for your family?

What are you and your family member losing because you are here rather than working? (School being missed?)

How much would you be willing to pay if it meant that your family member would have a successful and safe surgery? Why would that amount be okay with you?

How much do you believe is too much to pay for surgery?

Do you feel you are supported by the healthcare system? Why or why not?

Do your religious or spiritual belief influence the way you have decided to seek out surgery? If so, in what ways?

Did your family member seek a traditional healer prior to coming here? (IF YES: What did they tell you?)

Is there anything else you wish to tell me?

Thank you for your time and for sharing your opinion with me on these topics.

**STOP THE RECORDING AND TURN OFF THE VOICE RECORDER**

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