The Economic Burden of Patients Seeking Neurosurgical Care at Mulago Hospital, Kampala, Uganda

by

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Duke Global Health Institute
Duke University

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Frank A. Sloan

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: Private healthcare resources, which include private health insurance agencies, households, facility-based NGOs and private firms cover over 75% of the health expenditure in Uganda. Uganda's National Health Accounts for the financial year 2009/2010 reported higher spending from private sources than public sources. Further results showed out of pocket expenditure from households was the largest source of funding, contributing 40% to 46% of total health expenditure. The expenditure of a large fraction of household income on health care results in financial risk for most Ugandans and often leaves families impoverished. Therefore, the goal of this study is to describe in detail the burden of cost of patients, using neurosurgery as a proxy. Methods: The study was carried out in Mulago Hospital, Kampala, Uganda. Eligible patients were patients between the ages of 18-90 years of age who had undergone a neurosurgical procedure at Mulago and were on the neurosurgery ward post-surgery. Ultimately, 144 patients agreed to be part of the study. These patients were recruited three nurses who worked on the neurosurgery ward. The data were collected via the use of questionnaires to interview the patients and/or caregivers. We defined catastrophic expenditure as 10% of the household income, while impoverishment was defined as patients living on less than $1 a day. Our analysis was mainly descriptive; however, we ran several regressions to determine predictors of catastrophic expenditure, and impoverishment. Results: 59% of the patients are living below the

poverty line. An additional 12% were impoverished by expenditure on healthcare. 93% of the patients experienced financial catastrophe due to the direct costs they incurred in seeking care at the hospital. The patients pay, on average, 27% of the hospital costs incurred in treating the patients. Conclusions: The majority of the patients in our study experienced financial catastrophe in seeking neurosurgical care. Furthermore, most of the patients who sought surgical care were already impoverished. These data underscore the fact that the costs associated with accessing neurosurgical care at Mulago Hospital often result financial hardship on the patients, despite the fact that care in Mulago Hospital is supposed to be free.

Dedication

I dedicate this thesis to every single human being I have encountered in this life. In some way shape or form, I am who I am because I met you, and I am confident I am better for our interaction(s). To my family, I say: "Wanyala nabi! Were akwongere gikabi!" and "Eyalama noi. Idari lokasuban"

Finally, I would like to dedicate this thesis to the patients at Mulago Hospital who accepted to take part in the study and share their personal information; and to all the citizens of the Pearl of Africa. We will surely make it someday.

Contents

List of Tables

List of Figures

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1. Introduction

1.1 Burden of Surgery in Low- and Middle-Income Countries.

The Disease Control Priorities Project , which is a joint enterprise of a number of groups (University of Washington Department of Global Health, the World Bank, National Institutes of Health, the World Health Organization, Population Reference Bureau, Gates Foundation, and the International Decision Support Initiative.), defines surgical disease as conditions requiring suture, incision, excision, manipulation, or other invasive procedures that usually requires local, regional, or general anesthesia (1). Surgery is essential in treating a broad range of diseases in the alleviation of human ailment (2). Surgery is necessary across all age groups: from newly born babies with congenital defects to cataracts in the elderly (3). Surgery can prevent illness, such as reducing HIV transmission via circumcision, or curative, as in many traumatic brain injuries, or cancers (3). Furthermore, surgical care is salient in the diagnosis of numerous conditions, such as renal failure (3). Owing to this apparent significance of surgery in global health care, researchers and economists now acknowledge that surgery is crucial to overall social and economic development (2).

Despite the above demonstrated importance of surgical care, the integration of surgical services into global health care is not yet commensurate with the global

surgical need (2). Most of the efforts to incorporate surgical services into global health have been more disease-specific and in support of largely vertical interventions to address deficiencies in low resource settings of the world (2). Vertical interventions in the aforementioned case refer to programs within a health system that have specific defined objectives-usually quantitative, and often relate to a single condition or a small group of health problems (4). In 2010, approximately 16.9 million lives were lost due to conditions requiring surgical care (2). This statistic far exceeded the number of deaths due to HIV/AIDS, tuberculosis, and malaria; however, these infectious diseases still receive more attention and funding than surgical care (2). Yearly, 77.2 million disability-adjusted life-years (DALYs) could be averted via basic surgical care (2). Furthermore, as with most global heath challenges, the brunt of untreated surgical conditions falls disproportionately heaviest on people living in low income and middle income countries (LMICs) (2). Although the necessity for surgery extends across countries at all stages of development, the largest unmet need exists within LMICs (2). In LMICs, the poorest individuals, and/ or those living in rural areas experience the direst circumstances (2). Without adequate surgical care, common treatable diseases become increasingly fatal (2). However, due to the diversity of the causes of the conditions needing surgical care, such as cancer, and injury, the impact of these conditions is not captured adequately due to the existent epidemiological frameworks focused mainly on disease causes rather than treatment requirements (2).

Consequently, death and disability due to conditions needing surgical care in LMICs are substantially unreported (2). Owing to this negligence of the high DALYs due to unmet surgical need in LMICs, the progress of overall health and development goals in LMICs is hampered (2). In the past decade, the interest in bolstering surgical capacity at first-level hospitals in LMICs has increased (5). The increased interest in first-level hospitals is due to the fact that the majority of the world's population accesses emergency care at first-level hospitals (5). More so, many surgical conditions such as life-threatening injuries, necessitate immediate appropriate care in order to save lives (6). The World Health Organization (WHO) responded by launching two complementary initiatives: The Emergency and Essential Surgical Care (EESC) program in 2004 and the Global Initiative for Emergency and Essential Surgical Care (GIEESC) in 2005 (7). The goals of these two initiatives were: (i) the development and implementation of training infrastructure to improve care for surgical conditions at first-level hospitals in LMICs; and (ii) to encourage collaboration among governments and organizations devoted to alleviating death and disability due to surgically treatable conditions (7).

1.2 Burden of Surgery in Uganda

Despite Uganda's commitment to dedicate 15% of its annual budget to the health sector as per the Abuja Declaration in April 2001 (8); over ten years later, Uganda's government health expenditure hovers around 7% of the annual budget (8).

With a population of about 35 million and increased development, Uganda is undergoing an epidemiological transition related to the surging prevalence of non-communicable diseases (NCDs) (8). This increase in NCDs will necessitate the employment of surgical care to treat most of these conditions (9); however, Uganda is still lacking in surgical capacity and accessibility to care (10). There are limited data on the provision of surgical interventions in Uganda. Most of the available data have been derived via extrapolations using health facility registries, and partially through surgical capacity assessments (10). A cross-sectional survey of 29 hospitals in South-Western Uganda demonstrated that the operative rate on children under 15 was only 3% of England's rate of provision of surgical interventions to children under 15 (6). The comparison shows a subpar corrective rate in Uganda (6). The corrective rate refers to number of surgical interventions performed to treat certain conditions or illnesses that require surgery over a particular period of time (11). The majority of operated conditions from the aforementioned study were: trauma and injuries (30.2%), general pediatric surgery and urology (25%), and surgical infections (15%) (6). Galukande and colleagues investigated capacity at four hospitals and found a low surgical intervention rate of 5-45 per 10,000, with the majority of the operations treating obstetric complications or wounds (6). The conditions that did not receive surgery in the aforementioned study were mostly elective procedures, such as hernia repairs and appendectomies (6). As a 2011 national survey of public sector hospitals showed,

Uganda's healthcare system has a shortage of human resources, material resources and the required infrastructure necessary for adequate surgical care (12). The results of the aforementioned studies should have some bearing on the Ministry of Health bolstering surgical care capacity; however, there is still a need for more studies outlining the capacity of health facilities in the country for the provision of surgical interventions (12). These studies provide data that are not representative of the entire country's situation. Owing to these deficiencies in the body of research pertaining to the capacity for surgical interventions and the unmet surgical need in Uganda, the Surgeons Overseas Assessment of Surgical Need (SOSAS) study carried out by Haglund and colleagues in 2014 aimed to quantify Uganda's surgical need. Overall, the limited data in the literature show that there are significant gaps in Uganda's capacity for the provision of surgical interventions, which translates to a large unmet need (10).

The conversation about the unmet need for surgical interventions in Uganda can be well complemented by looking at the healthcare workforce issues in Uganda. There are approximately 0.67 physicians per 100,000 people and 0.1 surgeons per 100,000 people in Uganda (10). The majority of the physicians in Uganda, approximately 90%, reside in the capital, Kampala, while the remaining 10% serve the 83% of Ugandans living in the remote areas of the country (10). Additionally, in the context of this paper, Uganda has only seven neurosurgeons, and all of them are

located at either Mulago National Referral Hospital (MNRH) or Mbarara Regional Referral Hospital (MRRH) (10). Based on these data, it is clear that Uganda has a surgical capacity that is not commensurate with the unmet surgical care need in the country.

1.3 Patient Costs Associated with Accessing Care.

As we consider the substantial unmet need of surgical care in LMICs and more specifically in Uganda, high healthcare costs are a major barrier to the utilization of hospital-based care, as people are compelled to pay out-of-pocket at the point of care (3). The Lancet Commission for Global Surgery estimated that approximately 32.8 million cases of catastrophic expenditure occur due to the medical cost of accessing surgical services annually (2). The aforementioned estimation represents roughly 22% of an estimated 150 million people who experience catastrophic expenditure from accessing all types of healthcare (2). The commission further mentions that the aforementioned estimations preclude non-medical costs, which also cause significant impoverishment (2). When non-medical costs are added to medical expenses incurred when seeking surgical care, the estimate for cases of catastrophic expenditure shoots up to approximately 81.2 million (2). The Lancet commission surmised that approximately half of the world's population, 3.7 billion, are at risk of catastrophic expenditure in the event that they need surgery, because they do not have insurance (2). Most of the aforementioned at risk individuals live in sub-Saharan Africa and south and southeast

Asia (2). Additionally, the Lancet commission intimates that the financial burden induced by out of pocket (OOP) payments for care falls mainly on individuals living in LMICs (2). Furthermore, the Lancet commission's calculations showed that the poorest patients globally were 61 times more likely to experience catastrophic expenditure and/ or impoverishment compared to the wealthiest patients (2). Due to the salience of the costs incurred by patients when accessing healthcare, there has been an increased interest in household level economic effects of illness and OOP payments on healthcare in LMICs (3). The combination of the costs in seeking and accessing care and the costs of being unable to carry out normal activities, or work due to poor health, there can be dire economic consequences for the families (3). In most LMICs, these costs often cause the families to fall into poverty or sink deeper into poverty (2). The increased consideration of user fees has informed several health sector reforms in LMICs over the past decades (13). More in depth analysis of OOP payments and their economic consequences has caused several organizations and countries to rethink policies concerning healthcare financing (14). For example: The World Bank, which was a former proponent of OOP for health services conceded that OOP for health care services in many cases can be a major determinant of a family's level of impoverishment (13). With the acknowledgment of disadvantages of OOP for health services, organizations and nations began to consider a variety of different health financing schemes, such as insurance, in order to provide some financial risk protection

(13). However, in order to better understand the challenge of user fees within the context of household impoverishment, and to devise apt solutions, the costs incurred by the patients must be fully understood. For instance, in most LMICs user fees may be charged at public hospitals for care otherwise deemed free by the government (15). Additionally, most people in LMICs end up visiting private for-profit hospitals, which are significantly more expensive than public hospitals, because most of the public hospitals are derelict (14).

In the discussion of the costs incurred by patients seeking care, the literature usually refers mainly to direct costs and indirect costs (16). The direct costs are those costs borne by the healthcare system, community and patients' families in treating an illness (16). Direct costs, in the context health expenditure, include not only the costs of the surgical services or procedures, but also any other costs incurred across the care continuum (16). Examples of direct costs are: medical costs- procedure costs, drugs, diagnostic tests; non-medical costs-travel costs, meals, lodging, and many others (16). Indirect costs refer to productivity losses to society (or patients' family) caused by an illness (16). Indirect costs can be measured via loss of earnings or wages due to an illness (16). Considering that in most LMICs OOP payments for healthcare remain the main form of health financing (17), and surgical care tends to be more expensive than

other methods of disease treatment (3) it has become increasingly salient to analyze the effects of the OOP payments on the welfare of households in LMICs.

1.3.1 Catastrophic Expenditure

In the study of OOP health financing in LMICs in the literature, we often encounter the terms: catastrophic expenditure and impoverishment (14). Catastrophic expenditure and impoverishment are important for gauging the extent to which households are affected economically by the OOP payments for healthcare (15). A challenge; however, lies in the definition of catastrophic expenditure and impoverishment, as the definitions vary among different health economists (14).

Catastrophic expenditure can be defined differently depending on the key variables used to calculate it (14). For example: total household OOP payments for health care and a measure of household resources, such as income, expenditure, or consumption could be utilized (14). Since income is not directly affected by medical spending, it is advantageous to use it to calculate catastrophic expenditure (14). However, the relationship between health payments and income is not responsive to the means of financing healthcare and that is considered a demerit (14). For example, a household with a saving culture and one without a saving culture are indistinguishable when using a health payment to income calculation of catastrophic expenditure (14). A saving culture in this case refers to the tendency to set some income acquired from

earnings aside, after consumption expenditure is deducted, and dedicate it towards savings for future projects or pursuits (18).

If household income is not used as the denominator, other economists' theories suggest using total household expenditure as the denominator (14). In the case of household expenditure as the denominator, the catastrophic payments are described in relation to the health payments budget share (14). The severity of budget constraint implies that most resources are consumed by items needed for survival, such as food, hence leaving barely anything for healthcare expenditure (14). Therefore, households that are unable to afford catastrophic payments are excluded from the calculation of catastrophic expenditure due to OOP payments for care. A possible solution to this omission is to define catastrophic payments or expenditure not with regard to the health payments budget share, but with regard to the health payments as a portion of expenditure net of spending on basic requirements for sustenance (14). This latter possible solution has been termed nondiscretionary expenditure (14) or capacity to pay (14). There is; however, a challenge in defining what, or when expenditure is nondiscretionary (14).

One method that attempts to define nondiscretionary expenditure is the utilization of household expenditure less food expenditure as an indicator of living standards (14). Even though not all food expenditure is nondiscretionary, non-food

expenditure would better differentiate the rich and the poor than total expenditure (14). Bearing all this in mind, a household is said to have incurred catastrophic expenditure if the ratio of OOP payments to income, or OOP to total expenditure; or OOP payments to total expenditure less nondiscretionary expenditure surpasses a specified threshold value (14).

The threshold value reflects the critical point at which consumption of household resources by spending on healthcare proves disruptive to the household's living standards (14). The determination of this threshold is a subjective issue. Since the threshold is subjective, it is considered good practice by researchers to offer a range of threshold values and let the reader choose rather than imposing their own judgements on the readers (cite). In the literature, when total expenditure is used as the denominator, 10% is the most common threshold used, with the justification that 10% represents an approximate threshold when the household is compelled to forego other basic necessities or become fall into poverty (14). Alternatively, the World Health Organization (WHO) has utilized 40% as the threshold value when utilizing the aforementioned capacity to pay (non-food expenditure) as the denominator (3). The WHO estimated that based on the usage of non-food expenditure as the denominator, 40% was a more accurate threshold value when calculating catastrophic expenditure (3).

Although catastrophic expenditure is a useful tool for quantifying the economic damage healthcare expenses inflict on households, the lack of a standard universal threshold value across the board makes it a consistently contentious topic.

1.3.2 Impoverishment

Another metric when considering the effect of OOP payments for healthcare on households is impoverishment. A household is rendered impoverished by healthcare payments when its available income falls below the poverty line (19).

National poverty lines are based on population-weighted subgroup estimates from household surveys (20). In order to determine the poverty line in developing countries, information is collected on people's consumption goods, as well as their income (20). The collection of consumption goods aims to derive a measure of well-being, which shows the differences in the quality of life across a general population in a country (21). Well-being includes several aspects, such as: income level, place of residence, daily diet, diet expenditures, and so on. While consumption and income do not show all the dimensions of poverty, they provide good indicators of well-being, or quality of life (20). The poverty line is defined as the amount of income required to satisfy an individual's basic needs for survival. These basic needs include: food, water, and shelter; however, in some modern literature, sanitation, education and healthcare are added to the list of basic needs (21).

The international poverty (IPL) line factors in the state of absolute poverty in the poorest countries, as well as the same real level of well-being in all countries (21). Consequently, the IPL is both tied to national poverty lines of the poorest countries, and uses purchasing power parity exchange rates (PPPs) to convert the line into the US dollar, and into the other currencies of each developing country (21). Absolute poverty is defined as a condition characterized by severe deprivation of basic human needs (21). PPP is a measure that enables us to understand exchange rates of currencies between countries, by comparing the price of a set of goods in one country to the price of a similar bundle of goods in another country (21).

Overall, the current World Bank international poverty line is $1.90, while Uganda's national poverty line is $1(22).

1.4 Implications for Out-Of-Pocket Costs and Surgical Care.

Considering both the unmet need for surgical interventions in LMICs and Uganda, and the implications of the high prevalence of OOP payments for healthcare, a more concrete picture of the issue at hand can be drawn. Investments in surgical capacity and increasing patient access to surgical care can result in better health outcomes (5). Better health outcomes for the patients are good for the economy of a country, as they result in a wider work force that can contribute to the economic growth and productivity of the country (2). Furthermore, government expenditure on

surgical capacity and access saves a lot more money that would be lost due to loss of productivity on the part of both patients and caregivers (2). However, while several recent studies have shown that increased investment in surgical care as a means of addressing several conditions in LMICs is cost-effective at the population level (2, 5), individual payment for surgical care can still cause impoverishment to households (2). Worldwide, surgical interventions tend to be more expensive than other non-invasive treatment options (17). Therefore, barring some form of financial risk protection, accessing surgical care could be financially catastrophic to a household. More often than not, in the case of the poorest of the poor, recovery from the subsequent impoverishment induced by OOP payments on healthcare is highly unlikely (5). These patients will in all likelihood remain in poverty. Furthermore, the need for surgical care is a challenge to plan or save for due to its unpredictability, resource-intensity and occasional time-sensitivity (2, 3, 5). Additionally, while some form of financial risk protection would help to insulate patients in LMICs against catastrophic expenditure and impoverishment, there are substantial barriers to pooling of funds, or setting up insurance schemes (2, 3, 5). Human resource shortages, material and facility shortages; and a large informal sector that is difficult tax are some of the main barriers to establishing useful financial risk protection in LMICs, such as Uganda (3, 23).

In the context of Uganda, private healthcare resources, which include private health insurance agencies, such as AAR insurance; households, facility-based NGOs and private firms, cover over 75% of health expenditure in Uganda (8, 24). Private firms in Uganda are companies or organizations that are owned by individuals or groups of individuals, and not by the government. Some of these organizations may be strictly local, but a good number of them are multinational organizations or companies (25). These private firms usually provide insurance coverage for their employees in Uganda. While financing and expenditure reviews are conducted annually for public funds, there is limited documentation of private funding and expenditure (24). Uganda's National Health Accounts for the financial year 2009/2010 reported higher spending from private sources than public sources (2,3). Further, results showed OOP expenditure from households was the largest source of funding, contributing 40% to 46% of total health expenditure (3).

On a related note, approximately 19.7% of Uganda's population is below the poverty line (26). Bearing the aforementioned statistic in mind, the high percentage of OOP payments for healthcare in Uganda combined with the demonstrated high cost of surgical interventions indicates a high likelihood of financial catastrophe and impoverishment experienced by households.

When we distill the information on the substantial unmet need for surgical interventions for surgical conditions in Uganda, the cost of accessing surgical care and juxtapose that information with the high percentage of OOP payments for healthcare in Uganda, we anticipate that the cost of surgical care causes financial catastrophe and impoverishment for a large number of households in Uganda.

The purpose of this study is to describe the burden of cost on patients seeking neurosurgical care at MNRH in Kampala, Uganda. There are limited data on the burden of cost of accessing care at government health facilities in Uganda, let alone at MNRH. This study is very salient in providing insight into the effect of cost on the patients seeking care at MNRH in the neurosurgery ward. Future studies can build on the work of this study, by looking at patient costs in other departments within MNRH and other government health facilities in Uganda.

Therefore, the two major aims of the study are:

- Describe catastrophic expenditure and impoverishment of the patients due to OOP payments for healthcare.

- Compare the cost borne by the patients to the cost borne by the hospital when neurosurgical interventions are provided.

2. Methods

2.1 Setting

The study was carried out at the neurosurgery ward in MNRH in Kampala, Uganda. MNRH is the main national referral hospital in Uganda, and is at the top of a complex tiered referral based healthcare system. The tiered system includes health centres I through IV, then followed by hospitals in ascending order of capacity (8).

Health Centre I (HCI)

Level I health centres include village health teams (VHT) or community medicine distributors. These are the first contact for residents in rural areas. Each village is supposed to have a VHT and have the capacity to provide basic drugs for diseases, such as malaria (8).

Health Centre II (HCII)

Level II facilities have a catchment population of a few thousand people, and should be able to treat diseases, such as malaria. These facilities are also supposed to be led by an enrolled nurse, working with a midwife, two nursing assistants and a health assistant. HCII runs an outpatient clinic, which treats common diseases and offers antenatal care (8).

Health Centre III (HCIII)

A level III facility should be found in every sub-county in Uganda. HCIII have a catchment population of about 20,000 people with about 18 staff, led by a senior clinical officer, who are in charge of a general outpatient clinic, a functioning laboratory and a maternity ward (8). HCIII act as referral centres for HCII facilities (8).

Health Centre IV (HCIV)

Level IV facilities have a catchment population of approximately 100,000 persons and provide preventative and curative outpatient services (8). A HCIV should have similar services as a HCIII, but additionally, they should have wards for men, women and children; and should be able to admit patients. HCIV should have a senior medical officer and another doctor, as well as a theatre for performing emergency operations (8). HCIV facilities act as referral centres for HCIII facilities (8).

District Hospitals (DHs)

District hospitals take referrals from health centres and have a catchment population of approximately 500,000 persons (8). DHs should provide similar services as HCIV in addition to specialized clinics, such as clinics for mental health, dentistry, and consultant physicians (8).

Regional Referral Hospitals (RRHs)

RRHs take referral from DHs, and have a larger catchment population than DHs (8). RRHs provide a full range of preventive and curative outpatient services, inpatient care, obstetrics and gynaecology, laboratory services, a subset of specialty services (psychiatry, pathology, radiology), higher level surgical and medical care than what is found at DHs (8).

National Referral Hospitals (NRHs)

These hospitals are intended to serve all Ugandans, and act as referral centres for RRHs; and offer similar services as RRHs, in addition to teaching and research (8).

Overall, there are 155 hospitals in Uganda (both public and private). Of these, 2 are NRHs (MNRH and Butabika hospital), 14 are RRHs and 139 are general hospitals. Of the 155 hospitals, 65 are government-owned, 63- private not-for-profit and 27 are private for-profit (8).

2.2 Participants

2.2.1 Inclusion Criteria

We based our definition of a neurosurgical procedure on the definition of surgical disease posited by the Disease Control Priorities Project (1). We therefore defined a neurosurgical procedure as any suture, incision, excision, manipulation, or other invasive procedure performed on any portion of the nervous system that usually requires local, regional, or general anesthesia (1, 27). Patients were considered eligible

for inclusion in the study if they were present on the neurosurgery ward and had undergone a surgical intervention for a head injury. Data collection was restricted to the neurosurgery ward, which meant that we would miss patients who went to the casualty ward, or emergency room and either left, or passed away. While this restriction might create some bias, the data collected strictly from neurosurgery ward would still provide useful insight on the patients' burden of cost. We decided to focus on head injuries because of the limited time and resources available to carry out the study within ten weeks. With the limited time within which to carry out the study, and the small budget, we were not able to focus on a wider spectrum of neurosurgical conditions. The budget allowed us to hire at most three nurses to help with data collection, and these nurses were all located on the neurosurgery ward. After consulting with some of the physicians at MNRH, focusing on patients who had a neurosurgical intervention for treatment of a head injury would give us a good sense of the burden of cost on the patients seeking neurosurgical care, based on the high volume and frequency of patients visiting MNRH with head injuries.

2.2.2 Exclusion Criteria

We excluded patients that underwent other neurosurgical procedures other than head injuries, such as spinal surgeries. We excluded these patients because of the limited time and resources available over the ten weeks for data collection as mentioned above in inclusion criteria.

Due to the ongoing renovation at MNRH at the time of the study, we decided to limit the study to patients at the neurosurgery ward. In 2014, the renovation of MNRH was commissioned by President Yoweri Museveni (27). The upgrades were slated to start November 2014 after the African Development Bank gave out a $50m loan for the upgrade of MNRH. As part of the upgrade, a new women's hospital is being constructed within MNRH to treat most female health conditions and decongest the current female wing at MNRH (27). The hospital is also going to have a new intensive care unit (ICU), a children's ward and the current wards will be partitioned into cubicles and water fountains will also be added around the hospital, as part of the renovations (27). Under the upgrade, MNRH will also procure medical equipment, such as CT and MRI scans and the renovation of theaters halls (27). The current bed capacity of the ICU ward will be increased to 40 up from 12 (27).

MNRH serves as the NRH for the entire country, and a general hospital, as well as HCIV, HCIII for the Kampala metropolitan area (27). Owing to the instrumental role MNRH plays in Uganda's healthcare system, the renovations are very welcomed, as most Ugandans prefer to travel to neighboring countries to seek healthcare services, such as major surgeries (27). While the renovations were scheduled to be done in 2015, they were far from done during the time of our study.

Due to the renovations, patients, wards and staff were all constantly being moved around within MNRH as construction was ongoing. Owing to this, it was not possible to interview patients from both the casualty (emergency room) and neurosurgery wards. Additionally, due to the renovations, different departments or wards were not necessarily located where they were designated on paper. This made it significantly difficult to track down patients, let alone staff, who were helping with data collection.

The failure to collect data on patients from the emergency room, in addition to the neurosurgery ward, and the restriction to only head injuries slightly biases our sample. However, the data we capture is still very useful in providing information about the burden of cost on patients seeking neurosurgical care at MNRH.

2.2.3 Study Population

Factoring in all my inclusion and exclusion criteria and patients who declined to participate in the study, we ended up interviewing 144 patients who each underwent a neurosurgical procedure for a head injury and were hospitalized in the neurosurgery ward at MNRH.

Ethical approval for the study was secured from the Research and Ethics Committee of Mulago hospital and Duke Medicine Institutional Review Board for

Clinical Investigations. Verbal consent was obtained from each study participant prior to each interview.

2.3 Procedures

Structured closed-ended and partially open-ended questionnaires were used. The questionnaires were created by incorporating information from The MacArthur Research Network on Socioeconomic Status and Health (28), and the Center for Disease Control and Protection (CDC)'s Susan G. Queen's presentation at the 2012 National Conference on Health Statistics on Accessing the Potential for Standardization of Socioeconomic Status in HHS Surveys (29). The first draft questionnaires were written in English and then translated to Luganda, and then translated back to English to ensure consistency. The questionnaires included general socio-demographic characteristics, direct medical costs (drugs and diagnostic tests), direct non- medical costs (travel costs, meals while in the hospital, and other recurrent costs while hospitalized); indirect costs (opportunity cost of lost working time to the caregiver) and socioeconomic characteristics of households.

Three nurses, who had previous data collection experience, were deployed after three days of training to interview the patients as they presented on the neurosurgery ward. The nurses were supervised as they conducted the interviews for three consecutive weeks, before they were allowed to collect the data unsupervised. The questionnaires were administered via face-to-face interviews. The nurses also reviewed

the patients' medical records to extract information related to surgical procedure undergone by the pertinent patients. The first week of data collection was a trial run to test the questionnaire and the ability of the nurses to obtain the desired information. After the first week, the questionnaire was finalized and data collection proceeded for the next nine weeks.

2.4 Measures

2.4.1 Direct Costs

Direct costs were broken down into direct medical costs and direct non-medical costs. Direct medical costs included costs patients incurred when purchasing drugs (both prescribed and non-prescribed), and paying for diagnostic tests, such as CT scans. There were no operational CT scans at MNRH, and therefore patients were sent out to private for-profit hospitals to obtain the necessary scans before treatment could be provided. This referral to outside private for-profit hospitals for CT scans further inflated the cost estimates, such as the transportation costs. Direct non-medical costs included travel costs, meals while hospitalized, and miscellaneous recurrent costs during the hospitalization. The travel or transportation costs were estimated by asking the patients what means of transportation they used to get to the hospital and how much they paid to utilize the means of transportation, where applicable. The miscellaneous recurrent costs while hospitalized included cell phone airtime costs, snacks, and personal hygiene items, such as soap.

2.4.2 Indirect Costs and Daily Wages

As mentioned previously, indirect costs refer to loss of productivity due to an illness. In the case of our study, we collected indirect costs for the caregivers, who were present in the hospital taking care of the patients. We estimated the caregivers' indirect costs using their daily earnings. By computing the daily earnings, we were able to deduce that the indirect costs were equivalent to the earnings foregone by the caregivers as they took care of the patient in the hospital. The daily wage rate of monthly paid patients and caregivers was determined by dividing their net monthly salary by 30 days.

2.4.3 Total Direct Costs

Total direct medical costs were obtained by summing up costs of drugs and diagnostic tests. Total direct non-medical costs were obtained by summing up travel costs, meals while hospitalized, and any miscellaneous recurrent costs, such as airtime, while hospitalized. All costs were measured in Uganda Shillings (UGX) and then converted to US Dollar using the prevailing exchange rate during the time of the study (1US Dollar = 3600 UGX.

2.5 Analysis

2.5.1 Definition of Variables

The data were entered, cleaned and analyzed using Stata Version 14 for Windows, SAS and Microsoft Office Excel 2016. Descriptive statistics were obtained in Stata, such as means, standard deviations, medians, interquartile ranges, frequencies

and percentages for all the 40 different variables we collected data on. Out of the 40 variables, only the variable 'age' was normally distributed. The rest of the continuous variables: number contributing to household income, number of children in the household, number of adults in the household, patient estimated net wealth, patient estimated wealth, patient wages, patient's number of dependents, caregiver foregone earnings, caregiver's daily earnings, caregiver's daily hours of work, patient earnings, patient daily hours worked, miscellaneous costs, meals costs, diagnostic tests costs, drugs and medical consumables costs, length of stay, and transportation costs are all indicative of a count or Poisson distribution with long right tails. For each of the aforementioned continuous variables, we obtained totals (n), means, standard deviations, ranges, interquartile ranges, and medians.

Marital Status was categorized as: 0-single, 1-married, and 2-other. The category, 'other' included patients that were divorced, separated, widowed, or couples that were living together but not married.

Mode of Injury was classified as 0-non-road traffic incident (NRTI) and 1-road traffic incidents (RTI). Non-road traffic accidents that necessitated neurosurgical intervention included mainly falls and cases of assault.

The categorical variable(s) for patient/caregiver employment status was defined as: 0- unemployed, 1- self-employed, and 2-employed. Unemployed meant that the patient was without a paid job or occupation. Employed meant the patient was hired by

another person, or company, or organization to do a particular. In this study employed patients will be referred to as 'formally employed'. Self-employed meant patients ran their own business, such as shop keeping, food vending, clothes vending, market vending; or commercial farming. Subsistence farmers were also included among the self-employed, as they occasionally sold farm produce in the event of surplus.

The categorical variable for patients' education level was defined as: 0-primary/lower, 1- secondary, and 2-university. The Ugandan education system is similar to the British education system. Students typically start formal education at nursery level at the age of 3 years (30). Nursery school lasts three years before students join primary school. Primary school is 7 years long and the students are typically 6 years in primary 1 and 12 years in primary 7 (30). Students sit a national primary leaving examination (PLE) in primary 7 in order to proceed to secondary school (30). Secondary school is divided in two levels: Ordinary (O) and Advanced (A) level. O-level is 4 years long and the students are typically 13 years in senior 1(S.1) to 16 years in senior 4(S.4). In S.4, the students sit another national examination to obtain their Uganda Certificate of Education (UCE) and proceed to A-level. A stark difference between the American education system and Uganda's is observed at S.4, when students are typically 16 years. At this stage, in the American system, students graduate from high school and proceed to college (30). However, in Uganda's education system, students, who pass the UCE examinations, proceed to A-level (30). A-level is from S.5 to S.6 and the students

typically sit for the Uganda Advanced Certificate of Education (UACE) examinations in S.6 at the age of 18 years (30). In A-level, students select subject combinations tailored to prepare them for their desired degrees at the university level. For example: students interested in going to medical school at university must take Biology and Chemistry in S.6 (30). If the students pass the UACE examinations, and plan on attending a government tertiary institution, they take an approximately six-month vacation, as they await the government selection and placement process which determines which government tertiary or university they will attend. Once in university, students typically initially pursue Bachelor's degrees in some chosen field (30).

The variable for patient wealth referred to the patient's total estimated liquidated wealth (total assets). The variable for patient net worth referred to the patient's total estimated liquidated wealth less all debt owed by the patient (net assets). These variables were elicited from the patients by asking them to value all the fixed assets they owned monetarily.

The dichotomous variable for patient residual income indicates whether or not the patient has multiple sources of income.

The dichotomous variable, impoverishment, which was discussed in more depth previously, was defined as whether or not the household, or individual, was living on less than $1 a day, which is Uganda's national poverty line (20).

The dichotomous variable, catastrophic expenditure, which was discussed in more depth previously was defined as whether or not the household spent more than 10 % on their income on OOP payments for the neurosurgical care. The 10% threshold value of catastrophic expenditure is commonly used in the literature (3).

For the patient's occupations, we only emphasized the two main occupations: peasant farmer and a motorcyclist. A peasant farmer, also known as a subsistence farmer, and these farmers grow food and/or raise animals for domestic use. A motorcyclist in the context of Uganda refers to boda bodas. Boda bodas are bicycle and motorcycle taxis commonly found in East Africa. While motorcycle taxis like boda bodas are present throughout Africa and beyond, the term boda boda is specific to East Africa (31). The rest of the occupations: truck driver, teacher, clothes washer, taxi driver, taxi conductor, security guard, potter, policeman, nursing assistant, mechanic, housemaid, hairdresser, fish monger, farm manager, crime preventer, company driver, commercial farmer, cleaner, catering chef, casual laborer, carpenter, business woman, business man, builder, barber, Uganda People's Defense Forces (UPDF) soldier, and brick layer were all combined into the category, "Other". Our rationale for doing this was we wanted to focus on the major occupations of the patients in our sample. The occurrences of the occupations in "Other" category were minimal, so we decided to combine all of them together. Furthermore, we did not intend to check for any statistical differences between the various occupations in the "Other" category

The complete primary data codebook can be found in Appendix A.

2.5.2 Missing Values and Multiple Imputations.

Our most important variables for the estimation of the burden of cost were the total direct costs borne by the patient, which we have already defined in the previous sections, indirect costs borne by the caregivers, and the patient's income in the past year. These important cost and income variables were affected by 'missingness' and necessitated the use of multiple imputations to estimate them accordingly. The missing data was missing at random (MAR). The percentage of missing in the cost and income variables was as follows: Out of 144 participants in the dataset: meal costs (4.86%), transportation costs (6.94%), drugs and medical consumables cost (15.28%), diagnostic tests costs (11.11%), miscellaneous recurrent costs (29.17%), caregiver earnings foregone (21.53%), patient income in the past year (35.20 %), patient estimated wealth (69.44%), patient estimated net wealth (70.14%). Based on this amount of 'missingness', and on consultation with the literature (32), we elected to utilize multiple imputations to estimate the missing values in the cost and income variables. A percentage of missing greater than 10% on a variable necessitated the use of multiple imputations in lieu of single imputations to estimate the missing variables with minimal error (32).

Imputations can be perceived as a replacement. Statistically speaking, conclusions drawn from any study should not depend on the sample that is involved in the study (32). Provided the study is repeated with a different sample, similar results should be

obtained. Therefore, the conclusions are not dependent on the given set of subjects in the sample (32). This means that any subject or participant in the randomly chosen sample can be replaced with another subject that is randomly selected from the source population as the original subject, without compromising the conclusions. Imputation techniques operate based on this statistical assumption (32). Complete and available case analyses result in inefficient though valid results when data are missing completely at random (MCAR), but biased results when missing data are MNAR, which is common in epidemiological research (32). Since there is no statistical way to test for MNAR, MAR, or MCAR, we simply try to look at the data and deduce what kind of missing is present. Based on the study sample, and the process of administration of the questionnaire, we were able to conclude, with confidence that the missing data were most likely MAR. There was no identifiable pattern in the 'missingness' of our data and patients did not seem to be deliberately refusing to answer the questions.

After deducing that our missing data were most likely MAR, and establishing that imputations were a better approach to handling the missing data than complete case analysis (32), we were then tasked with obtaining more accurate estimates for the missing values. When performing imputations, we should account for the imprecision that results from estimating missing values in the given distribution of variables (32). We try to account for this implicit error by utilizing multiple imputations instead of single imputations (32).

A single imputation represents a singular set of plausible values for missing data, while multiple imputations utilize multiple datasets to predict missing values (32). Multiple imputation is a flexible statistical technique that uses simulation to handle missing data. Multiple imputation follows three steps:

I) Imputation- a designated number of imputations or complete datasets are generated based on some chosen model, such as a linear regression.

II) Completed-data analysis (estimation) step- the desired analysis is ran separately on each imputation (depending on number on imputations chosen in the imputation stage).

III) Pooling step- The results from the complete data analysis step are pooled or combined into a single multiple imputation result.

Since it was computationally feasible to obtain more imputations, we utilized 10 imputations, which is deemed sufficient in the literature (32), to minimize sampling error caused by imputations.

In order to impute the cost variables mentioned in the previous section, multiple linear regressions were employed in STATA to identify the predictors of cost variability. In the regression models, the independent variables with a P-value <0.1 and/or R-squared value >0.1 were included the imputation of the cost variables. Based on these criteria, we determined that the 'length of stay' variable was a predictor of cost

variability. Subsequently, we used length of stay to impute all the missing cost variables in SAS. In order to impute the patient income, which was an ordinal categorical variable, we utilized SAS. By running multiple regressions to determine predictors of patient income, and using the same criteria (P-value<0.1 and/or R-squared value >0.1), we established the variables household size, and education as predictors of patient income. Consequently, we input education into SAS and imputed income via the proc mi command in SAS. See Appendix A for the SAS code used to perform the multiple imputations.

After the imputations were completed in SAS, the new dataset with multiple (10) imputed datasets were exported into a Microsoft Excel Spreadsheet. The Microsoft Excel spreadsheet with the imputed data was then imported into STATA. In order to handle the imputed datasets in STATA, we downloaded a "misum" packet from a website recommended by STATA. Misum calculates summary statistics in multiple imputation (MI) datasets, by generating summary statistics for each dataset. The returned results from the summary statistics of each dataset are added up and divided by M, which is the number of imputed datasets. Standard deviation is calculated as the square root of the variance (32). Therefore, we used the "misum" command, to derive descriptive statistics for the direct and indirect costs (mean, median, interquartile range, standard deviation).

2.5.3. Catastrophic Expenditure and Impoverishment Estimates.

Catastrophic expenditure and Impoverishment were calculated using the patient's income. Income was an ordinal categorical variable collected UGX and defined as: 0-less than 100,000, 1- between 100,000 -300,000, 2-between 300,000-500,000, and 3-greater than 500,000. For the purposes of calculating catastrophic expenditure and impoverishment, we used the less conservative upper limits of the four categories of income. That is to say, we used 100,000, 300,000, and 500,000 for categories 0, 1 and 2 respectively. For the fourth income category, 3- greater than 500,000, we designated the upper limit of this category as 2,000,000 UGX. The basis for the designation of 2,000,000 UGX as the upper limit of category 3 of income was due to an observation during data collection. We collected income as a categorical variable because it is common practice in the literature (28); however, the patients would offer a numerical estimate of their income, and based on this feedback from the patients, it was clear that none of the patient's income in the past year exceeded 2,000,000. Unfortunately, there was no supportive rationale for using the aforementioned 2,000,000. This figure simply made sense to use considering our context, and the feedback from the patients in our sample, as mentioned before. For this reason, we chose to cap category 3 at that amount. This capping of category 3 would be useful when calculating catastrophic expenditure and impoverishment for category 3. For the purpose of this study, we defined catastrophic

expenditure as 10% of the household income, as is common in the literature (3). We defined impoverishment using Uganda's national poverty line: $1/person/day.

Catastrophic expenditure was calculated by dividing each patient's total direct cost by the upper limit of the patient's income category. The expenditure was considered catastrophic if the total direct cost was greater than or equal to 10% of the upper limit of the patient's income.

Impoverishment was calculated by dividing the upper limit of the patient's income category by the exchange rate, to convert it into dollars, then dividing the result by 365 days. An impoverished patient was classified as one living on less than $1 a day (20). That is to say: (Upper limit of patient income category)/3600 UGX/ 365 days.

Impoverishment due to OOP payments for healthcare was obtained by:

(Upper limit of patient income category-total direct costs)/3600 UGX/365 days.

2.5.4 Comparing the Patient Costs Associated with a Procedure to the Hospital Costs Associated with that Same Procedure

The analysis and comparison of patient and hospital costs was performed in Microsoft Office Excel 2016. Utilizing data from the 2015 study by Jihad and colleagues, who looked at the supply-side costs of neurosurgical procedures at Mulago hospital, we were able to match the procedures undergone by the patients in our study with the procedures documented in the study by Jihad and colleagues (33). The neurosurgical procedures we matched with the aforementioned study by Jihad and colleagues that

were performed to treat head injuries included burr holes for Subdural hematoma (SDH), Chiari decompression, craniotomy, craniectomy, Cranioplasty, elevation of skull fracture, excision of brain tumor, incision and debridement, removal of brain abscess or lesion, Subdural hematoma (SDH) or epidural hematoma (EDH) evacuation, and Ventriculoperitoneal shunting (VPS). We also combined the procedure: dermatoid cyst removal and ventriculosotomy into the category of procedures called: "Other". The hospital or supply-side costs of the aforementioned procedures were derived from the study by Jihad and colleagues and juxtaposed with the total costs incurred by patients in our study. The goal of this juxtaposition was to compare these costs together and demonstrate more clearly, the patient's burden of cost.

3. Results

3.1 Descriptive Statistics

A total of 85.4% of the patients in the sample were men, as shown in Table 1. About 52.8% of the patients were married, 35.4% were single; while about 6.9% were either divorced, separated or widowed as shown in Table 1. The most common occupation of the patients in the sample was a peasant farmer (18.1%), followed by a motorcyclist or boda boda driver at 16.0% as shown in Table 1. About 41.7% of the patients were self-employed, 17.4% were employed formally, and about 39.6% of the patients were unemployed as shown in Table 1. The proportion of patients who received at most a primary education was 47.2%, at most a secondary education was 44.4%, while only 4.2% were university educated as shown in Table 1. About 56.9% of the patients in the study sustained the injury that necessitated surgery in a road traffic incident as shown in Table 1. The proportion of the patients who were home owners was about 52.1% as shown in Table 1. In the case of patient income in the past year, 27.3% of the time, the patient income in the past year was less than 100,000 UGX ($27.78) as shown in Table 1. About 23.6% of the patients made more than 500,000 UGX ($138.89) in the past year as shown in Table 1. About 73.6% of the patients reported not having any alternative or multiple sources of income as shown in Table 1. Approximately 57.6% of the patients were the sole bread winner in their households as shown in table 1. About 75.7% of the caregivers would be working if they were not looking after the patient in

the hospital as shown in Table 1. About 50.0% of the patients had children in school as shown in Table 1. About 93.1% of the patients experienced financial catastrophe due to OOP payments for healthcare as shown in Table 1. About 58.9% of the patients were already impoverished before OOP payments for healthcare, as shown in Table 1. The proportion of patients who were not impoverished prior to healthcare expenditure was 41.1% as shown in Table 1. Out of the 41.1% that were not impoverished, 11.9% of these patients became impoverished due to health expenditure. The aforementioned, 58.9%, who were already impoverished, were plunged further into poverty due to health expenditure. (The calculation for impoverishment due to health expenditure is described in the methods section, and was obtained by performing the necessary calculations using Microsoft Office Excel. Since impoverishment due to health expenditure was calculated using Microsoft Office Excel, it was not possible to place the figure, 11.9% in Table 1. The sample characteristics in Table 1 were obtained from STATA.)

The mean age of our study participants was 33.2 years (IQR: 23-41 years), as shown in Table 2. The mean length of stay for the patients after surgery was 5 .0 days (IQR: 2-6.5 days) as shown in Table 2. The mean household size in the patients' homes was 5.4 (IQR: 4-7 people) as shown in Table 2. The mean number of children living in the patients' households was 3.0 (IQR: 1-4) as shown in Table 2. On average, the patients in the sample had about 3.1 dependents (IQR: 0-5 dependents) as shown in Table 2. The mean number of adults living in the household was 2.3 (IQR: 2-3) as shown in Table 2.

The mean number of individuals in the household contributing to household income was 1.54 (1-2) as shown in Table 2.

Of the people living above the poverty line, 88.1% were male, while 83.5% of the impoverished were male, as shown in Table 3. Of the patients that were not impoverished, 37.3% were single, 55.9% were married and 6.8% were either divorced, widowed or separated, as shown in Table 3. Of the impoverished patients, 42.4% were single, 50.6% were married, and 7.1% were either divorced, widowed or separated, as shown in Table 3. Of the patient caregivers that were not impoverished, 42.4% were unemployed, 22.0% were self-employed, and 33.9% were employed formally, as shown in Table 3. Of the impoverished patient caregivers, 27.1% were unemployed, 51.8% were self-employed, and 14.1% were employed formally, as shown in Table 3. Of the patients that were not impoverished, 52.5% were unemployed, 22.0% were self-employed and 25.4% were employed formally as shown in Table 3. Of the impoverished patients, 30.6% were unemployed, 55.2% were self-employed, and 11.8% were employed formally as shown in Table 3. Of the patients that were not impoverished, 62.1% obtained at most a primary education, 36.2% obtained at most a secondary education, and 1.7% obtained at most a university education, as shown in Table 3. Of the impoverished patients, 40% obtained at most a primary education, 53.8% obtained at most a secondary education and 6.3% obtained at most a university education, as shown in Table 3.

Of the patients that did not experience catastrophic expenditure due to OOP payments for healthcare, 90.0% were men, as shown in Table 4. Of the patients that experienced catastrophic expenditure 85.1% were male, as shown in Table 4. Of the patients that did not experience catastrophic expenditure 70.0% were single, and 30.0% were married, as shown in Table 4. Of the patients that experienced catastrophic expenditure38.1% were single, 54.5% were married, and 7.5% were either divorced, separated, or widowed, as shown in Table 4. Of the patient caregivers that did not experience catastrophic expenditure, 30.0% were self-employed, as shown in Table 4. Of the patient caregivers who experienced catastrophic expenditure, 35.8% were unemployed, 40.3% were self-employed, 23.9% were employed formally, as shown in Table 4. Of the patients who did not experience catastrophic expenditure, 80% were self-employed as shown in Table 4. Of the patients who experienced catastrophic expenditure, 42.5% were unemployed, 38.8% were self-employed, and 18.7% were employed formally, as shown in Table 4. Of the patients who did not experience catastrophic expenditure, 40.0% obtained at most a primary education, as shown in Table 4. Of the patients who experienced catastrophic expenditure, 47.8% obtained at most a primary education, 47.8% obtained at most a secondary education and 4.5% obtained a university education, as shown in Table 4.

3.1.2 Patient Wealth, Direct Costs, Earnings and Earnings Foregone by Caregiver

The breakdown of the mean costs incurred by the patients in seeking neurosurgical care was as follows: transportation costs: $27.9 (IQR: 0.8-33.3), Drugs and medical consumables costs: $87.0 (IQR: 38.3-83.3), diagnostic tests costs: $84.1 (IQR: 66.7-84.7), meals costs: $23.1 (IQR: 11.1-26.7), and miscellaneous recurrent costs: $5.5 (IQR: 1.9-4.9) as shown in Table 5.

The mean direct medical costs incurred by the patients was $162.4 (IQR: 105-163.9) as shown in Table 6. The mean direct non-medical costs incurred by the patients was $42.9 (IQR: 30-43.6) as shown in Table 6. The mean earnings foregone by the caregiver while looking after the patient in the hospital was $27.4 (IQR: 5.6-33.3) as shown in Table 6. The mean direct costs paid by patients was $166.1 (IQR: 135.3-196.9) as shown in Table 6. The mean percentage of the total cost of care (hospital costs and patient costs) paid by the patient was 27.5% (IQR: 20.5-33.1) as shown in Table 6. The mean daily earnings by the patient was $6.3 (IQR: 0-11.1) as shown in Table 6. The mean daily earnings by the caregiver was $5.8 (IQR: 1.39-8.3) as shown in Table 6. The average estimated liquidated wealth of the patients was $402.2 (IQR: 111.1-215.3). The average estimated net liquidated wealth of the patients was $230.2 (IQR: 41.7-97.2) as shown in Table 6.

The mean amount of money spent by each patient (summing both direct medical and direct non-medical costs) was $166.14 (IQR:135.28-196.94), as shown in Table 6, compared to an average of $456.85 that would have been spent by the hospital to treat each patient (obtained from data from Jihad and colleagues) (33).

3.1.3 Comparing Hospital Costs to Patient Costs

The hospital costs referenced in Table 7 are extracted from the study of Jihad and colleagues, which aimed to estimate the cost of neurosurgery at MNRH on the hospital side (33). The most commonly performed procedure in our study sample was a SDH or EDH (27.78%), and the total cost to the patients in our study for undergoing SDH/EDH evacuation was approximately $5,575, as shown in Table 7. The hospital would have spent approximately $12,640 to treat the patients who underwent a SDH/EDH evacuation as shown in Table 7. In the particular case of SDH/EDH evacuation, the patients covered approximately 31% of the total cost of care as shown in Table 7.

The proportion of patients that underwent a burr hole for SDH was 4.2%, and these patients paid $1156.1, compared to $1748.8 by the hospital, as shown in Table 7. In the case of burr holes for SDH, the patients covered approximately 40% of the total cost of care, as shown in Table 7.

The proportion of patients that underwent a Chiari Decompression was 6.9%, and these patients paid $970.6, compared to $5013.4 by the hospital, as shown in Table

7. In the case of Chiari Decompressions, the patients covered approximately 16% of the total cost of care, as shown in Table 7.

The proportion of patients that underwent a Craniotomy/Craniectomy was 9.0%, and these patients paid $1644.2, compared to $5737.42 by the hospital, as shown in Table 7. In the case of Craniotomy/Craniectomy, the patients covered approximately 22% of the total cost of care, as shown in Table 7.

The proportion of patients that underwent a Cranioplasty was 9.0%, and these patients paid $1476.8, compared to $5248.0 by the hospital, as shown in Table 7. In the case of Cranioplasty, the patients covered approximately 22% of the total cost of care, as shown in Table 7.

The proportion of patients that underwent an Elevation of skull fracture was 5.6%, and these patients paid $897.5, compared to $2713.6 by the hospital, as shown in Table 7. In the case of Elevation of skull fracture, the patients covered approximately 25% of the total cost of care, as shown in Table 7.

The proportion of patients that underwent Excision of a brain tumor was 0.7%, and these patients paid $113.6, compared to $1220.6 by the hospital, as shown in Table 7. In the case of Excision of a brain tumor, the patients covered approximately 9% of the total cost of care, as shown in Table 7.

The proportion of patients that underwent an Incision and debridement was 6.9%, and these patients paid $1239.2, compared to $5824.4 by the hospital, as shown in

Table 7. In the case of Incision and debridement, the patients covered approximately 18% of the total cost of care, as shown in Table 7.

The proportion of patients that underwent a Removal of brain abscess/lesion was 1.4%, and these patients paid $189.2, compared to $1787.34 by the hospital, as shown in Table 7. In the case of Removal of brain abscess/lesion, the patients covered approximately 10% of the total cost of care, as shown in Table 7.

The proportion of patients that underwent a VPS was 3.5%, and these patients paid $662.64, compared to $3079.2 by the hospital, as shown in Table 7. In the case of VPS, the patients covered approximately 18% of the total cost of care, as shown in Table 7.

The proportion of patients that underwent either a Dermatoid cyst removal, or a ventriculosotomy, which are categorized as 'Other' was 25%, and these patients paid $4292.1, compared to $20,773.8 by the hospital, as shown in Table 7. In the case of dermatoid cyst removal or ventriculosotomy (Other), the patients covered approximately 21% of the total cost of care, as shown in Table 7.

The mean amount of money spent on the respective neurosurgical procedures by the patients was $1,401.36, compared to an average of $5,060.50 that would have been spent by the hospital, as shown in Table 7. Based on the surgical procedures in Table 8, the mean percentage of the total cost of the procedures paid by the patient was 21%.

Table 1: Sample Characteristics of Categorical Variables from Patients in the Neurosurgery Ward at MNRH who Participated in our Study

Categorical Variable	*Characteristics*			*Chi-Squared P-value*
Gender		N	%	<0.001
	Male	123	85.42	
	Female	21	14.58	
Marital Status	Single	51	35.42	<0.001
	Married	76	52.78	
	Other	10	6.94	
Mode of Injury	RTI	82	56.94	<0.001
	NRTI	61	42.36	
Patient Employment Status	Unemployed	57	39.58	<0.001
	Self-employed	60	41.67	
	Employed	25	17.36	
Patient Occupation	Peasant Farmer	26	18.06	<0.001
	Motorcyclist	23	15.97	
	Other	93	65.97	
Caretaker in Absentia	None	30	20.83	<0.001
	Close Relative	53	36.81	
	Distant Relative	12	8.33	
	Non-relative	13	9.03	
Patient Education Level	Primary/Lower	68	47.22	<0.001
	Secondary	64	44.44	
	University	6	4.17	
Patient Income in Past Year[a]	Less than 100,000	39	27.29	<0.001
	100,000-300,000	11	7.74	
	300,000-500,000	9	6.15	
	Greater than 500,000	34	23.62	
Patient Residual Income?	Yes	3	2.08	<0.001
	No	106	73.61	
Patient Home ownership?	Yes	75	52.08	<0.001
	No	62	43.06	
Caregiver Works?	Yes	109	75.69	<0.001
	No	32	22.22	
Patient Sole Breadwinner?	Yes	83	57.64	<0.001
	No	56	38.89	
Patient's Children in School?	Yes	72	50	<0.001
	No	58	40.28	
Impoverishment	Yes	85	58.86	<0.001
	No	59	41.14	
Catastrophic Expenditure	Yes	134	93.06	<0.001
	No	10	6.94	

a- Values in levels of income categorical variable are in UGX ($1=3600 UGX)

Table 2: Sample characteristics of Continuous Variables from Patients in the Neurosurgery Ward at MNRH who Participated in our Study

Variable	*N*	*Missing*	*Mean*	*Standard Deviation*	*Median (IQR)*
Age	142	2	33.19	15.82	30 (23-41)
Length of Stay	144	0	5	5.03	3(2-6.5)
Number of Patient Dependents	127	17	3.09	3.23	3(0-5)
Household size	133	11	5.36	3.15	5(4-7)
Number of Children in Household	133	11	3	2.6	3(1-4)
Number of Adults in Household	133	11	2.34	1.36	2(2-3)
Number of individuals contributing to household income	127	17	1.54	1.02	1(1-2)

Table 3: Descriptive Statistics from Patients in the Neurosurgery Ward at MNRH who Participated in our Study Stratified by Impoverishment.

		All Subjects		*Above Poverty Line*		*Below Poverty Line*		*Chi²* *P-Value*
		N	%	N	%	N	%	
Gender	Male	123	85.42	52	88.14	71	83.53	<0.001
	Female	21	14.58	7	11.86	14	16.47	
Marital Status	Single	51	35.42	22	37.29	36	42.35	<0.001
	Married	76	52.78	33	55.93	43	50.59	
	Other	10	6.94	4	6.78	6	7.06	
Caregiver Employment Status	Unemployed	48	33.33	25	42.37	23	27.06	<0.001
	Self employed	57	39.58	13	22.03	44	51.76	
	Employed	32	22.22	20	33.9	12	14.12	
	Missing	7	4.86	2	3.39	5	5.88	
Patient Employment Status	Unemployed	57	39.58	31	52.54	26	30.59	<0.001
	Self employed	60	41.67	13	22.03	47	55.29	
	Employed	25	17.36	15	25.42	10	11.76	
	Missing	2	1.39	0	0	2	2.35	
Education	Primary/lower	68	47.22	36	62.07	32	40	<0.001
	Secondary	64	44.44	21	36.21	43	53.75	
	University	6	4.17	1	1.72	5	6.25	
	Missing	6	4.17	0	0	0	0	

Table 4: Descriptive Statistics from Patients in the Neurosurgery Ward at MNRH who Participated in our Study Stratified by Catastrophic Expenditure

		All Subjects		*No Catastrophe*		*Catastrophe*		*Chi² P-Value*
		N	%	N	%	N	%	
Gender	Male	123	85.42	9	90	114	85.07	<0.001
	Female	21	14.58	1	10	20	14.93	
Marital Status	Single	51	35.42	7	70	51	38.06	
	Married	76	52.78	3	30	73	54.48	<0.001
	Other	10	6.94	0	0	10	7.46	
Caregiver Employment Status	Unemployed	48	33.33	0	0	48	35.82	
	Self employed	57	39.58	3	30	54	40.3	
	Employed	32	22.22	0	0	32	23.88	
	Missing	7	4.86	7	70	0	0	<0.001
Patient Employment Status	Unemployed	57	39.58	0	0	57	42.54	
	Self employed	60	41.67	8	80	52	38.81	
	Employed	25	17.36	0	0	25	18.66	<0.001
	Missing	2	1.39	2	20	0	0	
Education	Primary/lower	68	47.22	4	40	64	47.76	
	Secondary	64	44.44	0	0	64	47.76	
	University	6	4.17	0	0	6	4.48	<0.001
	Missing	6	4.17	6	60	0	0	

Table 5: Average Direct Costs in Dollars Incurred by Patients in the Neurosurgery Ward at MNRH who Participated in our Study

Costs Associated with Care					
Direct Medical Costs	**Total**	**Mean**	**Median**	**(IQR)**	**SD**
Drugs and Medical Consumables	**122**	**87**	55.56	(38.33-83.33)	128.88
Diagnostic Tests	128	84.08	73.61	(66.67-84.72)	50.49
Direct Non- Medical Costs	**Total**	**Mean**	**Median**	**(IQR)**	**SD**
Transportation	134	27.87	13.19	(0.83-33.33)	41.79
Meals	137	23.05	16.67	(11.11-26.67)	26.48
Miscellaneous Expenses	**102**	5.53	11.81	(1.94-4.86)	11.81

Table 6: Summary of Direct and Indirect Costs in dollars to the Patients and Caregivers Respectively Who Were in the Neurosurgery Ward at MNRH and Participated in our Study

Cost	*Mean*	*SD*	*(IQR)*	*Median*
Direct Medical Cost	162.37	145.95	(105-163.89)	127.78
Direct Non-Medical Cost	42.91	28.96	(30-43.61)	34.79
Overall Average Direct Cost	166.14	43.79	(135.28-196.94)	152.64
Caregiver Foregone Earnings	27.43	45.18	(5.56-33.33)	15.56
Average % of total cost paid by patient	27.49	8.03	(20.45-33.06)	26.93
Patient Daily Earnings	6.34	6.87	(0-11.11)	4.58
Caregiver Daily Earnings	5.78	5.29	(1.39-8.33)	4.86
Patient Estimated Liquidated Wealth	402.15	917.29	(111.11-215.28)	138.89
Patient Estimated Net Liquidated Wealth	230.2	673.73	(41.67-97.22)	69.44

Table 7: Total Costs Per Procedure Incurred by the Patients in the Neurosurgery Ward at MNRH Who Participated in our Study and the Total Cost Incurred by MNRH to Perform the Same Procedures

Procedure	*Frequency (%)*	*Patient Costs$*	*Hospital Costs$*	*Total$*	*% paid by Patient*
Burr holes for SDH	4.17	1156.11	1748.76	2904.87	40%
Chiari Decompression	6.94	970.56	5013.4	5983.96	16%
Craniotomy/Craniectomy	9.03	1644.17	5737.42	7381.59	22%
Cranioplasty	9.03	1476.81	5247.97	6724.78	22%
Elevation of skull fracture	5.56	897.5	2713.6	3611.1	25%
Excision of brain tumor	0.69	113.61	1220.63	1334.24	9%
Incision & debridement	6.94	1239.17	5824.4	7063.57	18%
Removal of brain abscess/lesion	1.39	189.17	1787.34	1976.51	10%
SDH/EDH evacuation	27.78	5575.83	12640	18215.83	31%
VPS	3.47	662.64	3079.2	3741.84	18%
Other	25	4292.14	20773.8	25065.94	17%
Average		1401.36	5060.5	6461.86	21%

$-Costs in US Dollars (1US Dollar = 3600 UGX)

Other-Dermoid cysts and Ventriculosotomy

SDH-Subdural Hematoma

EDH- Epidural Hematoma

VPS- Ventriculoperitoneal Shunting

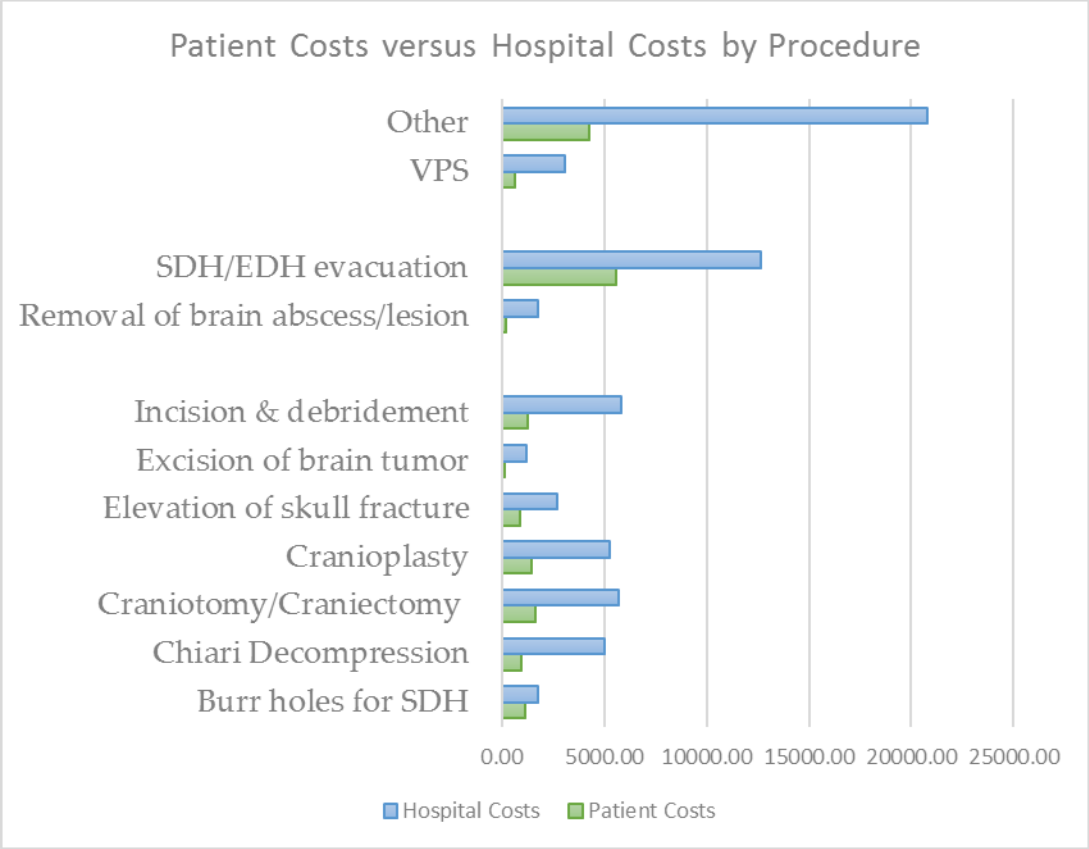

Figure 1: Comparison of Patient Costs versus Hospital Costs by Neurosurgical Procedure at MNRH

4. Discussion

The primary aims of this study were to describe catastrophic expenditure and impoverishment in relation to the patients with head injuries seeking neurosurgical care at MNRH, and compare the costs incurred by the patients when accessing neurosurgical care at MNRH to the costs incurred by MNRH to provide neurosurgical care to the patients. The combination of these two aims enabled us to attempt to describe the economic burden of patients seeking neurosurgical care at MNRH. From our data, we deduced that OOP payments for the healthcare posed a substantial financial burden on the patients, as approximately 93.1% of the patients in our sample experienced catastrophic expenditure, and approximately 70% were impoverished due to OOP payments for healthcare. Furthermore, on average, the patients covered a substantial fraction of the total cost of neurosurgical care at MNRH, even though the majority of the patients were already poor (58.9%). Our findings align well with the literature, and show us that surgical care is very expensive and often impoverishes not only the individuals that receive surgical care, but also the households they live in (5). While accessing surgical care is expensive almost everywhere in the world, the exorbitance of surgery disproportionately impoverishes individuals living in LMICs. Furthermore, as is the case within other LMICs (2), we see that the poorest of the poor in our study at MNRH in Uganda are the most financially affected by OOP payments for healthcare.

Several characteristics of the patients were highly correlated with an increase in direct costs. The average length of stay post-surgery for the patients was about 5 days. Unsurprisingly, from the data, length of stay was directly proportional to some of the direct non-medical costs, such as: meals, and the recurrent miscellaneous costs. However, this burden was also borne by the hospital, as prolonged hospitalization results in increased resource consumption (5). Factors that cause prolonged length of stay can be preoperative, intraoperative and postoperative (5). However, in MNRH, the biggest contributor to length of stay is preoperative, as patients can potentially wait for several days before undergoing surgery (6). In order to address the issue of extended patient stays, or inefficiency, it would be helpful to utilize the Critical Path Method (CPM) to analyze the entire continuum of care from the time the patients arrive for treatment at the hospital to the moment of discharge, in order to identify rate limiting steps and increase efficiency (34). CPM is a step-wise project management technique for process planning that defines critical and non-critical tasks within a project with the goal of preventing time-frame problems and process bottlenecks (34). Complementary to the CPM, several methods in the literature designed to lower the costs due to extended patient stay may be employed, such as: minimization of preoperative, intraoperative and postoperative complications; investing in more training of hospital staff, new techniques, and equipment for the attending medical staff (5). The employment of the aforementioned methods should result in cost reduction. However, since we estimated

costs incurred while the patients were hospitalized post-surgery, the direct non-medical costs were likely higher than we were able to compute within our study scope.

The large number of men in the study reinforces the theory that men tend to engage in high risk behavior more than women (7). Several studies show several gender differences pertaining to risk taking (35). Some theories posit that men are more likely to indulge in a risk if the risk would enable them to acquire more resources, such as money (36). The large number of able bodied men getting injured or dying at a high rate is not good for the economy of Uganda. Especially since Uganda is a largely patriarchal society (8), the loss of several economically productive men places a considerable strain on the economy and on most households' income (4). Consequently, it is important to invest in education and stricter road traffic rules in order to reduce the number of men experiencing traumatic brain injuries (TBI) (7) mainly due to road traffic incidents.

From our data, we also see a correlation between level of education and impoverishment, financial catastrophe, and the likelihood of getting a traumatic brain injury (TBI). This is a trend we see in the literature as well (3, 7). From the study, the injuries were experienced mostly by patients who did not have more than a primary education. Furthermore, from our data, approximately 95% of our patients, who live below the poverty line and experience financial catastrophe, did not attain more than a secondary education. This is important because several studies show that uneducated people are vulnerable to high risk/dangerous situations with higher frequency than the

educated (3, 7). A good way to address this issue would be for the government of Uganda, via the Ministry of Education to implement policies focused on incorporating empowerment education into health education and formal education countrywide (37). In empowerment education, the participation of people in group dialogue and activities designed to achieve particular community goals or targets enhances the participants' control and belief in their own ability to make changes in their lives (37).

RTIs were the main cause of the head injuries in our patient sample with 57% of the patients sustaining the injuries that necessitated surgery via a road traffic incident. The burden of TBI is very high in Sub- Saharan Africa and Uganda largely contributes to this statistic (10). This high burden of TBI due to RTIs has a huge economic effect, as many productive lives are lost and a lot of resources are consumed in the effort to treat the victims (7). Furthermore, this study shows us that these patients spend a lot more than they can afford to seek surgery due to TBI. Consequently, the investment in better and stricter cost effective road traffic policies, as seen in the literature (36) could help curb RTIs and save a lot of money for the not only the government, but also individuals.

A very important predictor of financial catastrophe from our data was patient employment status. About 80% of our patients were either unemployed or self-employed. In the context of our particular sample, self-employment usually referred to employment in the informal sector, which is a large undocumented group in Uganda (17). While it is clear how much out of pocket costs can be catastrophic for the

unemployed, the plight of the patients in informal employment is salient. As is common in most LMICs in the literature, most of the informally employed in our study reported being subsistence farmers, vendors or shopkeepers. The earnings from the informally employed patients were highly irregular and very erratic; varying by season and other factors (25). Irregular earnings render these patients vulnerable to financial catastrophe and therefore there is a need for the government to develop and/or support small-to-medium enterprises (SMEs) (38). Small to medium enterprises employ a limited number of people and generate relatively low income in comparison to larger corporations or companies (25). The development of these enterprises by the government could help provide some financial security for people which might protect the people against catastrophic expenditure and/or impoverishment due to OOP payments for healthcare.

4.1 Implications for policy and practice

It is imperative that the government of Uganda work to implement a national health insurance scheme that can provide some financial risk protection for the poor who face impoverishment each time they seek surgical care. Furthermore, considering Uganda's large burden of road traffic incidents that cause TBI, there is also an urgent need for the government to strengthen road traffic policies to curb the occurrence of these road incidents. The national insurance scheme should be complementary to the government's increased support for SMEs that would promote financial sustainability for the people and consequently improve health outcomes.

4.2 Implications for further research

There are very few data in the literature on the cost of healthcare in LMICs. Most of the existent data, such as the data in the Lancet Commission for global surgery is based off of modeling of data from health facilities. Our study provides actual empirical cost data from Uganda, an LMIC, which provides useful information to add to the body of work on the cost of seeking healthcare in LMICs. However, future studies should investigate the indirect costs borne by both the patients and the caregivers, and also the effect on society, in order to get a better picture of the overall burden of cost of neurosurgical care. Furthermore, the scope of my study was limited to neurosurgery. Further investigations into the cost of care in other departments at MNRH, such as oncology, gynecology, cardiology and so on, as well as at other public and private health facilities in Uganda would provide a better idea about the economic burden of patients seeking care at hospitals in Uganda. It is also very important to investigate the patients after they leave the hospital and explore the capacity of the healthcare providers for offering transitional care to the patients. On another note, post discharge care needs to be studied more in order to not only ensure the proper recovery of the patient(s), but to also improve the cost effectiveness of surgical procedures (39).

4.3 Study strengths and limitations

4.3.1 Strengths

The study collects information on direct non-medical costs, which were difficult to obtain in the case of most other studies (3).

The study also utilized nurses, who worked on the neurosurgery ward to collect data from the patients. This method likely enabled the patients to be more candid with the nurses and hence provide us with more quality information, as is evident in the literature (cite).

4.3.2 Limitations

Our definition of catastrophic expenditure as 10% of household expenditure was extracted from the literature (3, 14). However, this is by no means a universal measure of catastrophic expenditure, and therefore, this issue is debatable among health economists, as I mention in detail in earlier sections of this paper. Moreover, catastrophic expenditure only considers the patients who pay for the health services. Catastrophic expenditure does not include: indirect costs such as lost wages, those who might need services but cannot afford them, or the effect on family members who might donate money towards the treatment of another family member (3, 14). This deficiency of catastrophic expenditure is inherent in most measures of financial burden of health services (3, 14).

Furthermore, our calculation of catastrophic expenditure and impoverishment was heavily dependent on the data we collected for the patients' income in the past year. However, owing to the large amount of 'missingness', in the income variable, we had to use multiple imputations to estimate values for the missing values. While multiple imputation statistically better to use than complete case analysis, there is still some inherent sampling error in the multiple imputation method, which affects the accuracy of our data (32).

5. Conclusion

Several mentions in the literature indicate that the investment in surgical care capacity is cost effective (2). However, this is at the population level. For an individual, it is still very expensive to access high quality surgical care almost anywhere in the world. On this note, LMICs bear a greater disproportionate burden of the cost of surgical care compared to high income countries. Additionally, within the individual LMICs, such as Uganda, the burden of OOP payments for healthcare impoverishes the poor more than any other demographic (2). This study focused on the economic burden of patients seeking neurosurgical care at MNRH. We found that despite the fact that the care at MNRH is supposed to be free, the patients incur several medical and non-medical costs when seeking care at MNRH. These medical and non-medical costs create a significant financial burden on the patients, and/or plunge the patients into poverty. This study adds value to the limited body of research on cost studies in LMICs, and provides data that might be used to model cost data in LMICs. However, future studies should investigate both the direct and indirect costs of care in not only other departments at MNRH, but also other government and private facilities in Uganda to get a better sense of the economic burden of patients seeking healthcare at the hospitals in Uganda. Finally, in order to improve Uganda's healthcare system, the conversation about how

the system is financed is extremely critical, and this study helps to push this very important conversation forward.

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