

Understanding Perceptions of Healthcare Professionals on Delays in Care for Traumatic
Brain Injury Patients at Mulago National Referral Hospital, Kampala, Uganda

by

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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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2018

ABSTRACT

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Abstract

Background: Uganda is experiencing a high rate of Traumatic Brain Injuries (TBI), approximately 170 per 100,000 when compared to the global rate of 106 per 100,000. This may be due to an increasing rate of road traffic incidents (RTIs) and falls. LMICs like Uganda are disproportionately burdened with a higher number of RTI and other risk factors for TBI. One of the foremost reasons for poor outcomes for moderate and severe TBI patients are the delays in seeking, reaching, and receiving care. The aim of this study is to understand the perceptions of pre-hospital and in-hospital delays in seeking, reaching, and receiving care for patients diagnosed with TBI at Mulago National Referral Hospital (MNRH), and obtain perceptions of interventions that could reduce delay for these patients.

Methods: The study is a qualitative research project and will be carried out at Mulago National Referral Hospital, Kampala district, Uganda. The study participants were healthcare professionals in the Neurological ward of this hospital. This study will utilize semi-structured in-depth qualitative interviews, outlined through “The Three Delay Framework”, to understand perceptions of the reasons behind the three delays: seeking, reaching, and receiving care. Additionally, collecting perspectives on what can be done about the delays.

Results: During the study period, fourteen healthcare professionals in the Neurological ward of MNRH were interviewed. Of the fourteen, three were senior neurosurgeons, six were neurosurgical residents, and five were nurses. Four themes were derived from the data, *Transportation, Knowledge and Stigma, Surgical Intervention Preparedness*, and *Financial Burdens*. Nineteen sub-themes or sub-codes were found during analysis and were deductively pre-coded for either delay or solution. *Transportation Means, Physical Distance, Road Conditions, Injury Knowledge, Hospital Knowledge, Hospital Stigma, Communicable Disease Information, Instruments, Resources, Staff, Space, Equipment, Investigations, Cost of Obtaining care, Cost of Transport, Cost of Cheaper Care, Cost of Investigations, Cost of Surgical Equipment, and Cost of Medication* are all found within the four main themes.

Conclusions: Understanding perceptions of delay and methods to reduce them from the perspective of the healthcare professional established confirmation of current issues affecting care at MNRH. The data also demonstrated the issue of understanding the delays but not methods to solve them. Interviews with patients and their families are the next step in understanding these prevalent issues and creating an appropriate intervention to reduce them.

Dedication

I dedicate this thesis to Brianna Pimentel, without whom I would not have been able to accomplish this feat.

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1. Introduction

Delays in the care continuum experienced by traumatic brain injury (TBI) patients transitioning from the incident to final treatment are not well understood in Uganda. Interventions for reducing delay are best created inductively. Patient-centered culturally appropriate solutions are more effective in managing global healthcare deficiencies. To practicing a patient-centered care the provider or researcher must provide care substantiated from a patient's subjective experiences of disease. (Barry, 2012; Suchman, 1994) This study aims to understand perceptions of delay and formulate ways to mitigate them based on Thaddeus's three delays framework. This framework is often used in maternal mortality but was reintroduced into the global surgical setting by the Lancet Commission on Global surgery. (Thaddeus & Maine, 1994; Meara et al., 2016) This framework highlights three key events during the pre-hospital and in-hospital setting that are part of the maternity and childbirth and has been extrapolated for use in surgical care in general. (Thaddeus & Maine, 1994; Meara et al. 2017; Kuo et al. 2017). These three key events are seeking, reaching, and receiving care and serve as the basis for which this study is centered on. (Thaddeus, 1994; Meara, 2016) Due to the time sensitive nature of TBI, understanding perceptions from healthcare professionals of delays in the care continuum for patients with this injury in Uganda is vital to provide improved care and outcomes for patients and their families. (Haddad, 2012; American Association of Neurological Surgeons [AANS], 2014) Exploring potential solutions for

these delays that are patient-centered and culturally appropriate is also important for proposing an intervention that could reduce these delays. (Barry, 2012)

1.1 Traumatic Brain Injury

TBI is defined as a blunt or penetrating head injury that alters or interrupts normal brain function. (Centers for Disease Control and Prevention [CDC], 2016; AANS, 2014) This injury occurs when the head abruptly and forcefully hits an object or when an object penetrates the skull entering the brain tissue. (CDC, 2016; AANS, 2014)

Depending on how extensive the damage to the brain is, the injury severity could be classified as mild, moderate, or severe. (CDC, 2016; AANS, 2014) A systematic review of 29 countries found that the most common outcome of moderate and severe TBI is death. (Li, 2016) The symptoms of TBI also vary based on the severity of damage to the brain and range from vomiting, lethargy, headache, and confusion to cerebrospinal fluid leaking from nose or ears, loss of consciousness, coma, and even death. (CDC, 2016; AANS, 2014) Timely access to care is vital because 50% of mortalities due to TBI occur within the first two hours. (Fual et al., 2010; Bullock et al., 2006^a; Bullock et al., 2006^b; Kong et al., 2014)

TBI is a comprehensive term used to describe many different types of head trauma, but a TBI diagnosis is determined based on clinical symptoms. (Maas et al., 2008; AANS, 2014) The term, mass lesion, is used to describe the damage to the brain and the two most common forms of this are hematomas and contusions. (AANS, 2014)

Contusions are brain bruises typically with swelling. Hematomas are blood collections and can be within the brain or on its surface. The most common hematomas are epidural or subdural, where the blood pools between the skull and the dura matter or between the dura matter and the arachnoid layer respectively. (AANS, 2014) Hemorrhaging can also occur in TBI and is either intracerebral, within the brain tissue, or subarachnoid, diffusely spread around the brain's surface. Diagnosis of these injuries is standardized Minimal time between injury and diagnosis for surgical evacuation is critical for improved outcomes for TBI. (Bullock et al., 2006^a; Bullock et al. 2006^b)

Diagnosis of TBI is methodical, when a patient is admitted to the hospital an evaluation of the patient's injury is conducted. First, cardiac and pulmonary condition is assessed, then a rapid full body examination is conducted. (AANS, 2014) After these steps are performed an initial Glasgow Coma Scale (GCS) is determined and pupil test is administered. The GCS gives a numerical value to the responsiveness of a patient, 15 being the highest score and 3 being totally unresponsive. (Teasdale & Jennett, 1974; AANS, 2014) Eye opening response, verbal response, and motor response evaluations are rated 1 to 5 to complete the GCS. (Teasdale & Jennett, 1974) The score and blown pupils may indicate the patient has high intercranial pressure from their TBI. (AANS, 2014) Based on the results of these evaluations the patient may be recommended to have a CT scan to confirm the diagnosis before surgical intervention is recommended. (AANS, 2014) The principal method of treatment for moderate and severe TBI patients is

surgery. The surgical intervention depends on the cause and location of contusion, hematoma, or hemorrhage. (Maas et al., 2006) Once surgery is performed to remove the hematoma or reduce swelling in the skull, the patient is then taken to the ICU for post-operative care. At 6- months and 12-months post-operation a Glasgow Outcome Scale Extended (GOSE) is then used to determine the level of disability. (Jennett et al., 1981; AANS, 2014) The GOSE scores recovery from 1, death, to 5 a good recovery and return to normal life. (Jennett et al., 1981; AANS, 2014) TBI is complicated and progressively worsens without treatment; timely surgical intervention is vital for optimal outcomes and decreased disability. (Fual et al., 2010; Bullock et al, 2006^a; Bullock et al., 2006^b; AANS, 2014)

1.2 The Global Burden of Traumatic Brain Injury

TBI is a leading cause of death and disability globally and is responsible for the mortality or injury of approximately 10 million people annually. (Maas et al., 2017; Johnson et al., 2017; Bryan-Hancock & Harrison, 2010; Hyder et al., 2007; Huang et al., 2010) Primary causes of TBI are road traffic incidents (RTIs), falls, and violent trauma. (Hyder et al., 2007; Global Burden of Disease [GBD], 2016) RTI was found to cause 60% of TBI related outcomes, making it the leading cause of TBI internationally. (Hyder et al., 2007) Although, many high-income countries (HICs) were found to have falls as the greatest cause of TBI (34.4%), Low and Middle-Income Countries (LMICs) are primarily afflicted with RTI as the number one cause of RTI (42.4%). (Li, 2016; CDC, 2016) While

percentages of global death and disability due to Falls has increased (+0.12%) and RTI has decreased (-0.33%) in HICs over the past decade, they have increased in LMICs (+0.18% and +0.42%). (IHME, 2006 & 2016) LMICs are disproportionately burdened by TBI due to increasing risk factors associated with TBI, rapid urbanization, and limited resources for treatment. (Hyder et al., 2007; Tran et al., 2015, IHME, 2016) This also coincides with the epidemiological transition occurring in LMICs; as the prevalence of communicable diseases decrease, there is an increase in non-communicable disease like injuries. (IHME, 2016)

1.2.1 Traumatic Brain Injury in Sub-Saharan Africa and Uganda

With an incidence rate of 150-170 per 100,000 population compared to the global rate 106 per 100,000, Sub-Saharan Africa (SSA) is suffering from a disproportionate amount of TBI. (Hyder et al., 2007) Current estimates from Global Burden of Disease (GBD) data suggest an even higher global incidence of 200 per 100,000 and is possibly an underestimate. (Bryan-Hancock & Harrison, 2010; Naidoo, 2013; IHME, 2016) For example, in the largest population-based study in SSA, a TBI incidence rate of 316 per 100,000, was found in Johannesburg, South Africa, almost double that of the estimated incidence rate in SSA. (Nell & Brown, 1991) Globally, TBI predominantly affects males in the age groups, 5-14 and 15-49 according to the GBD study in 2015. (Wang, 2016) This is of concern in Africa, where 40% of its population falls into the 0-14 age group and 19%

falls into the 15-24, because over the next 10 years over 60% of the population of Africa will be at a higher risk of TBI. (United Nations Economic Commission for Africa [UNECA], 2016) There is also a disparity in mortality rates from TBIs between LMICs and high-income countries due to a lack of access to surgical care. (Hyder, 2007) This disparity can be explained by delays in receiving definitive medical and surgical care, which have been associated with significant morbidity for many emergency surgical conditions. (Kong et al., 2014; Bullock et al., 2006^a; Bullock et al., 2006^b) In general, there is evidence showing longer wait times (delays) leading to negative health outcomes. (Prentice, 2007)

In Uganda, the third most common admission diagnosis at the national referral hospital is TBI. It is suggested that in the next 12 years RTI will become the fifth leading cause of death internationally and in Kampala, Uganda RTI is the most common cause of mortality and morbidity. (World Health Organization (WHO), 2013; Kwizera et al., 2012; Hsia et al., 2010; Demyttenaere et al., 2009; Tran et al., 2015; Andrews, 1999;) A retrospective review of patient medical records from 2008 to 2009 at the Mulago National Referral Hospital (MNRH), Kampala, determined that 79% of severe TBI was due to RTI. (Tran et al., 2015) A quarter of these patients diagnosed with severe TBI at MNRH died from their injuries. (Tran et al., 2015) The overall mortality rate for TBI of all severities in Uganda is 9.6%, and as suggested earlier is likely an underestimate of the disease burden. (Kuo, 2017)

1.2.2 Burden of TBI at Mulago National Referral Hospital

MNRH admits approximately 130,000-140,000 patients per year, 61,568 of the total patients seen by MNRH were emergent, and a substantial portion of cases treated are TBIs. (MOH Uganda, 2014; Hsia et al., 2010) It has been reported that approximately 10-15% of TBI at MNRH are classified as severe the actual cumulative incidence of severe TBI is 89 cases per 100,000. (Brandkvist, 2013) 79% of these cases were caused by RTI, with the highest rate within the 15 to 20 year-old age group. (Haglund, 2011; Tran, 2015) The cases are managed by four of the countries neurosurgeons, in two neurosurgical operating rooms. The volume of cases this hospital receives is greater than its capacity of 1500 beds.

A study completed at MNRH used novel tool, NeuroPIPES, adapted from the PIPES survey tool to assess surgical capacity at MNRH. In this study they found that MNRH scored higher in both PIPES and NeuroPIPES when compared to the two other hospitals in Uganda performing neurosurgery. (Ploss et al., 2017) At MNRH there are 30 general surgeons, 4 neurosurgeons, 11 anesthesiologists, 50 medical doctors, and 30 nurse anesthetists working at the hospital and are responsible for managing all surgical cases. (Ploss et al., 2017) The lack of reliable access to a ventilator was also noted in this study, while availability of all other necessary surgical tools was “always available”. (Ploss et al., 2017)

The pre-hospital capacity in Kampala, Uganda is limited although some strengths exist. (Balikuddembe et al., 2017) Principal weaknesses in pre-hospital capacity were poor quality first aid, insufficient skills or training of first responders, inadequate EMS resources, and the delays in timely response to the victims. (Balikuddembe et al., 2017) These specific weaknesses indicated that, as a whole, the lack of an organized and efficient EMS system affected pre-hospital care. (Balikuddembe et al., 2017)

1.3 Delay

When discussing the health care continuum, it is important to consider any issues preventing the injured patient from the event or onset of symptoms to obtaining timely care from the necessary healthcare provider a delay or barrier. TBI cases are time-sensitive; meaning the time care is given directly affects the outcome. (Fual et al., 2010; Bullock et al, 2006^a; Bullock et al., 2006^b; Kong et al., 2014) For example, 50% of deaths due to TBI injury occur within the first two hours. (CDC, 2010) Critical patients in developed countries have poor outcomes in care when emergent care is delayed despite access to modern medicine, rapid hospital transport, and plentiful resources. (Ylvisaker et al., 2005, Slomine et al., 2006) In a LMIC, there is limited emergency medical service, resources, and modern medical care may not be available, the delay compounds the rate of poor outcomes.

In this study, delay will be defined as: to postpone, slow down or defer an action. Delay can also be used to describe someone and/or something, physical and/or non-

physical, which caused seeking, reaching, and/or receiving health care to be late, slow, or paused. (Merriam Webster)

1.4 The Three Delays Framework

When describing delay and its effect on care there are time intervals used to describe them concisely; the Three Delays framework, often used in maternal health research, was developed for this purpose. (Thaddeus & Maine, 1994; Meara, 2016) The time intervals can also be described as key events during the healthcare continuum for each patient and are described in detail in the three subsequent sections. The Lancet Commission on Global Surgery uses this framework to explain issues within a referral system for surgical care in the developing world, explaining at different points during healthcare delivery there are specific problems, as well as specific solutions to these delays. In LMICs issues with accessibility and availability of appropriate care are vital in understanding healthcare delivery. (Meara et al., 2016)

In this study, this framework is used to manage the intricacies of delay within the context of TBI in all its severities. It is also used to describe the different solutions that could potentially be used to mitigate delay and create a system for better surgical, and non-surgical outcomes.

1.4.1 The First Delay: Seeking Care

The first delay is in the decision to seek care, described as the time from onset of symptoms or event causing injury up until this decision is made. (Thaddeus & Maine,

1994) Patients will wait to seek care, for many reasons, cost and distance are two primary factors affecting the decision to seek care in the literature, but the relationship is much more complicated. (Meara et al., 2016; Thaddeus & Maine, 1994; Källander et al., 2008)

Depending on which developing country being discussed, the makeup of its healthcare delivery and the ability of patients to seek care vary greatly. This decision can be altered by cultural and moral beliefs, lack of knowledge of disease or availability of care, and even a fear or lack of confidence in these services. (Grimes et al., 2011) The decision to seek care is not inherently available to all patients; if the patient were unconscious they would not be able to make this decision themselves leaving the decision to others. The decision to seek care, if made by others, may be a delay in itself.

1.4.2 The Second Delay: Reaching Care

The second delay, the delay in reaching care, is described as the time between the decision to seek care and the arrival at the appropriate facility to receive care.

(Thaddeus, 1994; Meara, 2016) These delays can vary from lack of transport, to distance between patient and nearest care facility. (Bigdeli et al., 2010; Khorasani-Zavareg, 2011)

Even when a patient can find transport and is a reasonable distance, finances can play a factor in being able to secure transport. (Meara et al., 2016)

1.4.3 The Third Delay: Receiving Care

The third delay, the delay in receiving care, is a category of in-hospital delays and the time begins when the patients arrives at the hospital up until receiving appropriate care. (Thaddeus & Maine, 1994; Meara et al., 2016) This category of delay has the largest variability of reasons why appropriate care is not given, such as investigations, cost, ICU and OR constrictions.

1.5 Problem Statement

Understanding perceptions of delay from healthcare professionals for patients is an initial step in solving an issue with health care delivery in any health system. In the context of MNRH there is limited data on the causes of delays, especially for TBI patients. While spoken generalizations from health systems and hospitals in other LMICs clarify broad themes within a global context, this is the first qualitative study targeting perceptions of delay in SAA. The qualitative data collected at MNRH are needed to guide hospital policy decisions in prioritizing with limited resources and improving healthcare delivery. When expedient healthcare is delivered, some deaths due to TBI are preventable. (Fual et al., 2010; Bullock et al, 2006^a; Bullock et al., 2006^b; Kong et al., 2014) When health care administration is delayed or the time to receiving care is extended due to any issue, the chances of receiving care in the proper timeframe is greatly diminished. Understanding perceptions of these delays through in-depth

interviews will facilitate the integration of an intervention to prevent deaths from delays.

1.6 Objectives

The purpose of this study is to analyze the perceptions of healthcare professionals about the pre-hospital and in-hospital delays in seeking, reaching, and receiving care for patients diagnosed with TBI at MNRH. Additionally, we gathered opinions of healthcare professionals on what can be done about these delays. For the purpose of this study healthcare professionals are senior neurosurgeons, neurosurgical residents, and nurses that work in the Neurological ward at MNRH.

1.6.1 Specific objectives

1. Identify perceptions from healthcare professionals on delays in seeking, reaching, and receiving care for TBI patients.
2. Verify propositions from healthcare professionals on solutions to reduce delays in seeking, reaching, and receiving care for TBI patients.
3. Develop a conceptual framework for delays in seeking, reaching, and receiving care for TBI patients based on perceived delays and solutions from healthcare professionals.

2. Methods

In this study we are reporting results based on the Consolidated criteria for reporting qualitative research (COREQ) guideline, which includes a 32-item checklist for reporting important aspects of a qualitative study. (Tong et al., 2007)

2.1 Study Design

This 10-week qualitative study utilized semi-structured in-depth interviews to understand perceptions of delay in care for TBI patients from health providers at Mulago National Referral Hospital. A total of fourteen interviews were conducted with healthcare professionals, three were senior neurosurgeons, six were neurosurgical residents, and five were neuro-ward nurses. The next step in this study is to collect and analyze interviews from patients and their families in the neuro-ward.

2.2 Setting

Uganda, located in East Africa, has a population of approximately thirty-eight million people. (World Fact Book 2016) There is a total of 2,761 public health service facilities serving this population, of these, there are three national referral hospitals, twelve regional referral hospitals, fifty general hospitals, 166 higher level (level IV) facilities, 868 mid-level (level III) facilities, and 1662 low level (level II) facilities. (MOH Uganda 2014) As of 2018 there are nine neurosurgeons serving a population of 38 million (1:4.2 million), up from five serving 30 million 7 years ago (1:6 million). Across Africa there are 513 surgeons, twenty-seven serving 250 million in East Africa (1:9

million), 486 surgeons serving 174 million in northern Africa countries and zero in 11 other SSA countries. (Khamlichi, 2005; Haglund et al., 2011) The study took place within Mulago National Referral Hospital in Kampala, Uganda. MNRH is home to four of the country's nine neurosurgeons. It is located in Kampala and was founded in 1913. (MOH Uganda, 2014) It is the largest hospital in the country with 1500 beds and they treat approximately 6000 patients daily. (Brandkvist, 2013) MNRH hospital has an approximate catchment area of 1.5 million but serves the entire nation as the hospital with the highest level of medical care and expertise. (Tran et al., 2015)

2.3 Participants

This study included 14 research participants, all were healthcare professionals, of which, 3 were senior neurosurgeons, six were neurosurgical residents, and five were neuro-ward nurses. To participate in this study, the prospective participant must be: (1) a neurosurgeon, neurosurgical resident, or neuro-ward nurse working in the Neurological ward at MNRH, (2) proficient in a language mutually comprehensible to the interviewer and the study participant, (3) able to adequately answer the interview questions. The specific exclusion criteria are if the prospective participant is a child or in another vulnerable population.

The method used to obtain the sample was convenience sampling from the Neurological Ward at Mulago National Referral Hospital. The participants were approached within the hospital setting as they were on break in the meeting room, not

preoccupied with a current task, or after the morning meetings. . They were asked if they would be willing to participate in a study and interviewed on their experiences and observations regarding delay in care for TBI. No participants refused or dropped out of the study and demographic data was not collected to insure an

2.4 Procedures

The ethical review boards at both Duke University and the Mulago Hospital Research and Ethics Committee approved all study procedures. Prior to data collection for this study a relationship had been formed between the neurological healthcare professionals at MNRH and a team of researchers called Duke Global Neurosurgery and Neurology (DGNN). Headed by Dr. Michael Haglund MD, PhD, partnered with the Duke Global Health Institute (DGHI), and a part of Duke Medicine, DGNN seeks to understand and improve neurosurgery in Uganda. DGNN has been working with healthcare professionals at MNRH for over 7 years. Prior to in-depth interviews, participants were found in the neuro-ward at MNRH, the interviewer would then approach the potential participant face-to-face and explain the study, then they would ask them if they would like to participate in the study. Following the verbal consent process using the consent script, the interviewer then proceeded to conduct the interview with the participant when they were not busy caring for patients or doing paperwork. The interviews were audio recorded using a small handheld device in a private room within the neurological ward at MNRH. The interviewer was a male

student for a master's of science in global health degree trained at Duke University, fluent in English, and is the primary author of this thesis. Each participant had a one-on-one interview with the research assistant and lasted anywhere from 30 minutes to 1 hour in length. There were no cost or immediate risks involved to the medical staff that participated. Also, the participants were offered snacks after the interview as compensation for time spent.

2.5 Medical Staff In-depth Interviews

The topics of the semi-structured in-depth interview are related to the three delays in care: seeking, reaching, and receiving. Additionally, the questions sought ways to diminish the effect of delays and barriers on patients. In-depth interviews were divided into sections, first to describe the purpose of the interview and explain the structure of the interview. The second section provides the definitions of delays and barriers in the context of the interview. The third section begins at the first delay, the delay in seeking care, the fourth is the second delay, and the fifth is the third delay. Each of the delay sections are subdivided into a description of the delay, the time period in question and then ways in which the participant feels as though the delays and/or barriers could be managed.

2.6 Analysis

To help insure the privacy of the participants, only audio recording was used in the transcription of the data collected. Each interview was transcribed verbatim, and

then transcribed verbatim a second time by the research assistant; these two copies were then compared for differences. If a difference was found it was discussed by the interviewer and the research assistant until the nature of the difference was resolved. The data collected from the healthcare professionals was all originally recorded in English, allowing for two transcriptions and comparisons. At the completion of each transcription, the data was scrubbed of identifying information and all inaudible or crosstalk events were noted in the transcription. The transcriptions were entered directly into the study laptop and stored in an encrypted drive. These data were coded for themes using the Grounded theory. (Bradley et al., 2007)

A formal system of analyzing qualitative data, coding, is used after the data has been reviewed and many of the concepts are understood by the researcher. (Bradley et al., 2007) These codes are tags or labels, that denote specific parts of the data, they can be a single word or a whole document. (Miles & Huberman, 1994; Bradley et al., 2007) Themes are general perceptions that are found within a dataset, they are typically recurrent and can be connected between interview participants. (Bradley et al., 2007) Many codes and sub-codes can be related to a single theme and can span multiple data sources. (Bradley et al., 2007)

Grounded theory of qualitative analysis is an inductive approach used so that codes are not forced upon a data prematurely. The data are meticulously examined verbatim and then when a concept is defined it becomes a code. (Bradley et al., 2007;

Glaser et al., 1992) The codes are refined to match the data better as the data is analyzed. (Bradley et al., 2007) The themes identified after the analysis are recurring and encompassing ideas or theories, they are terms used to generalize a participant's specific experiences into silos that can be used across multiple people. (Bradley et al. 2007)

Prior to the initial coding process, the lead member of the research team developed a framework master codebook, after a detailed review of the transcribed material and based on the three delays framework to give a base level organization for the codes. A few experts on the topic argue that an individual analyzer can complete all the coding and that it is adequate, even ideal. (Morse, 1994; Morse & Richards, 2002; Janesick, 2003; Bradley et al., 2007) These initial codes were developed deductively and were necessary for creation of an organizational framework. The data was then analyzed inductively utilizing the Grounded theory in NVivo version 11 software package to find themes within the data.

Using the master codebook as guidance the primary researcher completed coding of each transcription. Codes were added to the codebook through this iterative process, until a final codebook was established. At this point it was necessary to refine the codes so they showed the parallels between interviews, this was done to understand the themes within the data. The concept of the three delays framework was added into the codebook to further organize the codes into time intervals so the codes could be better understood.

2.7 Ethical Considerations

2.7.1 Informed Consent

Verbal informed consent will be obtained from all respondents in the study in English. The interviewer will not document consent because this documentation of consent will be the only identifying information in the study, instead verbal consent will be required and was approved by both Duke University Research and Ethics Committee and the Mulago Hospital Research and Ethics Committee. After verbal consent was acquired the audio recorded interview began with the rest of the interview.

2.7.2 Confidentiality Assurance

Privacy and confidentiality of all respondents will be respected. Specific information provided by respondents will not be shared with anyone except persons specifically designated by the respondent and per study protocol. Interviews will be held in as private of a location as possible in the neuro-ward of MNRH. No demographic data was necessary to collect for the purposes of this study. All data will be stored on an encrypted drive, computers will be password protected and stored in a secure location. The primary investigator, interviewer, and author of this thesis was responsible for the safety of the data.

2.7.3 Study Risks

By design, this study poses no greater than minimal risks to participants. There are two main ethical concerns. First, the respondents may perceive that study

interviewer is obtaining information for hospital administration and responses that portray the hospital in a negative way may reflect upon the participants. The interviewer made it clear that no identifying information will be used for the purpose of this study. Once the recorded data is transcribed the recording will be deleted to ensure the identities of participants will remain undisclosed. The interview transcripts will be stored on an encrypted drive, although no identifying information will be in these data. Interviewer will make clear implications to participating in the interview and will obtain informed consent prior to commencing. It was important for the interviewees to have a clear understanding of the study procedures, objectives, aims, and purpose. Any questions the participants had could be directed towards the interviewer and primary investigator of the study. The interviewer explained to the participants that they were free to leave the study or refuse to participate in the study at any time, and that their refusal or exit will not count negatively toward them. They were also informed on the dissemination of the results of the study, and that it could be submitted for publication in a peer-reviewed journal and used in this thesis. There are no conflicts of interest in this study and no identifying information can be found in the data.

3. Results

3.1 Themes

Careful analysis of the data found four main themes, *Transportation, Knowledge and Stigma, Surgical Intervention Preparedness*, and *Financial Burdens*. These results are organized chronologically based on which time interval of the three-delay framework is most associated with the theme, seeking, reaching, then receiving. *Financial Burdens* was a recurrent theme found throughout all delays and is at the end of the results section.

Nineteen sub-themes or sub-codes were found during analysis and were deductively pre-coded for either delay or solution, shown in Figures 1 & 2. *Transportation Means, Physical Distance, and Road Conditions* are all sub-themes within the *Transportation* theme. *Injury Knowledge, Hospital Knowledge, Hospital Stigma, and Communicable Disease Information* are all sub-themes for the *Knowledge and Stigma* theme. *Instruments, Resources, Staff, Space, Equipment, and Investigations* are all sub-themes for the theme, *Surgical Intervention Preparedness*. Finally, *Cost of Obtaining care, Cost of Transport, Cost of Cheaper Care, Cost of Investigations, Cost of Surgical Equipment, and Cost of Medication* are all found in the main theme, *Financial Burdens*. A coding tree is provided in (Table 1) to further explain these codes and sub-codes. For the purpose of this study there is a difference in obtaining transportation delaying seeking and reaching

care and the literal longer distance of travel delay, this is why *Transportation* has a sub-theme of *Distance*.

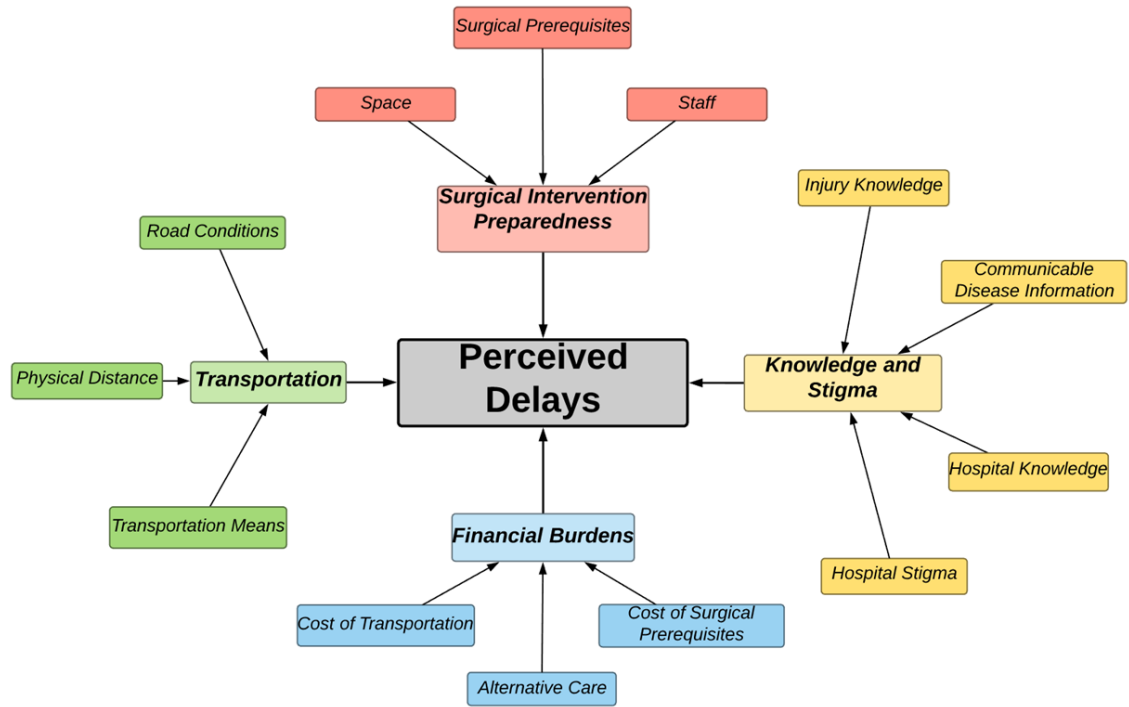


Figure 1: Perceived Delays

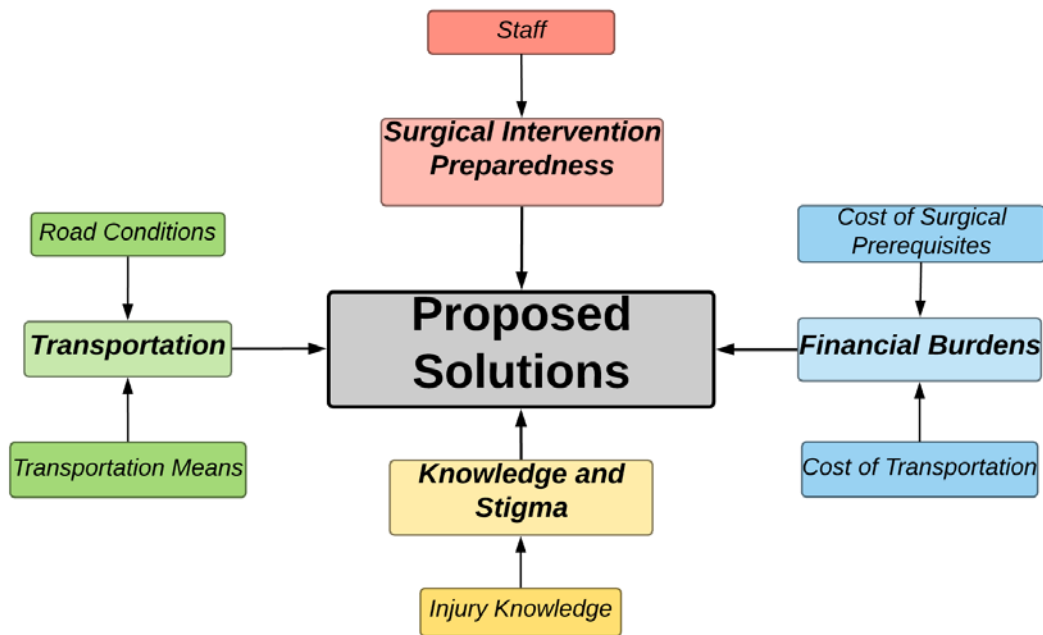


Figure 2: Perceived Solutions

3.2 Delay and Solution Emergent Themes

3.2.1 Theme 1 – Transportation

Emergency care for TBI is time sensitive; therefore, expedient transportation to care is critical. The perception that *Transportation* delay and solutions are a recurrent theme found in all interviews. This theme has three main sub-themes within it, *Transportation Means*, *Physical Distance*, and *Road Conditions*. These are used to specifically identify which problems or solutions for *Transportation* the participant is describing. The burden of finding transportation was of utmost concern in the participant population, observations described by care-providers are on the receiving end of this delay and they deal with consequences of the delayed transport. Depending on the location and severity of the injury transportation to the hospital can vary, and if

mild enough it can be a determinant in the decision to seek care. If severe enough, an unconscious individual from a RTI has no decision and is the decision to seek care is up to bystanders or family, in such cases the participant describes the delay in both seeking and reaching care:

“Most times, for example during road traffic accidents. There is a response team, and the first response team is usually the traffic police, that is on the roadside. [...] A phone call is made to any that is nearby or most times they get to know because they are not usually very far from those accidents, especially on the highways and they could get to the scene usually within less than 30 minutes. [...] Although, of course, there have been instances, where they get there much later. And then I guess they take a bit of time, to ascertain the cause and then, not being medical, they may not of course know the emergency situation the patient might be in. But in most cases, they actually, respond by putting the patients on the van, on the pickup, because of the kind of cares they use, on the pickup and then rush them to Mulago. [...] It takes a long time.” **[Delay: Transportation Means]**

One healthcare professional perceived the acquisition of transport to take longer, which increases the chances of mortality for the patient. That healthcare professional felt as though this delay in transportation ties in with distance from the hospital. Traveling long distances may require different means of transportation and this can delay, and the literal traveling of the distance can also delay. In context, the public means of transportation are often not safe for transport of a critically injured patient, the van, pick-up, or even a boda-boda are extremely unsafe methods of transportation, especially for someone critically injured with a TBI.

“A distant person, people comes from very far. And the owner sees them they have to get this in Mulago only so someone can - they get an accident from 100 kilometers away from Mulago, so they are looking still for

transport and the traveling distance, we are using lots - you know? Lots, it takes time to come this way, hospital." **[Delay: Physical Distance]**.

One healthcare professional described these observations as though she had experienced them herself; it is more of a problem than solely for TBI patients. *Physical Distance* itself is a transportation delay, a delay in reaching care. The care providers also spoke about road and traffic conditions playing a role in delay in care, through transportation.

"Normally reaching is only about transport [...] The way they come to hospital, even if it is a car with traffic because they can't find an ambulance at that time, so it is the result of traffic in Kampala, so reaching is also delayed, but patients agreed to go to Central Lugogo but is bleeding so [...] so they have to go in a, not a special hire, which is also going to make traffic." **[Delay: Road Conditions]**

One healthcare professional attempts to explain an issue that has an even broader range of issues with road conditions, not only traffic patterns but also road infrastructure. Then the professional continued with a method to mitigate this transportation delay.

"I think, if they had everything for emergency care and an ambulance, that it would be settled. But because the patient is has been sent in a special hire, which is expensive to reach to Mulago [...] Getting an ambulance, stabilize, to Mulago, because ambulance will bypass the jam." **[Solution: Road Conditions]**

The healthcare professional was describing an Emergency Medical System for Uganda, or at least Kampala to help bypass road traffic. Another participant also mentions the solution to transportation delay being ambulances.

“Another thing is government to provide means of transport, like ambulances.” **[Solution: Transportation Means]**

Both healthcare professionals felt as though the formation of an EMS system in Kampala could dramatically change outcomes for TBI patients. One healthcare professional gives an example of this.

“For instance, if you got in an accident, you could call a center which coordinates an ambulance, hospital where you should be going. [...] Currently, the police are doing a good job of bringing patients to hospital. I think they also need to get more training. [...] They could get faster training and get proper ambulances or proper vehicles to move the patients. I think that would help a lot for the time being. The fact that I don't know anybody country that's handling this area. There might be some isolated ambulances owned by bodies or persons, but not well organized to cater for the national, the public. [...] c **[Solution: Transportation Means]**

Transportation delay and solutions for these were a reoccurring theme within the study population; this delay concept was mentioned at least briefly in all fourteen interviews.

3.2.2 Theme 2 – Knowledge and Stigma

Seeking care delays are experienced during the decision-making process to obtain care for an injury, this decision is vital for people experiencing mild TBI. According to perceptions of healthcare professionals, for participants, the decision to seek care requires knowledge of the injury, where to go, and also what they can expect at the hospital. This theme of *Knowledge and Stigma* was identified as a delay.

“Yes, that it [decision to seek care] is also dependent on what they understand about the injury for example, if they know that is a severe injury, they will definitely rush. Of course, there are those subtle injuries

where someone may not know that, especially mild head injury, where it might not be very clear cut there is a big injury, for example if someone fell in the bathroom, and old lady or whatever, and she managed to get up and was able to do her work and so on, they are less likely to seek for care, because one, it is expensive of course, getting the care, so they don't want to get into any expenses. Just because they suspect maybe, anything happened, so, lots of people have different views on when to actually start for seeking for care. What I see that if it is something to do with a child, a parents usually rush, even if it was a simple fall or whatever, they always rush. If it is other people, adults, themselves, if they think that it is a simple thing, they won't rush, they won't go, and they will delay it definitely." **[Delay: Injury Knowledge]**

Also, an intervention for the mitigation of this delay is informing the public and educating the public so they are more aware of the problem and their options for care.

"Yes, there is a way, and I think it always comes back to us, the medical personnel. I know we always busy, we have got a lot of things to do all the time in the hospital and so on. But I guess, we also have to have a way of informing the public of certain dangers, yes like, certain things to look out for, either with a brochure, or something like that, or even with programs, because now if you listen to the radio you can also have programs deal with communicable diseases and how to prevent them, but the non-communicable diseases they totally, not really talk about them." **[Solution: Injury Knowledge] [Delay: Communicable Disease Information]**

Another part of this theme is the lack of knowledge about MNRH, the public is unsure what constitutes a visit to Mulago versus a visit to a local clinic.

"Everyone thinks Mulago is a complex place, a complicated place to actually get to where you want, says complicated. Then not really, they may know, but most people think Mulago, rightly so, that it is meant for really very serious cases, so if it is not a very serious case according to them then they won't rush to Mulago. And they may depend on the other hospitals, if they can actually confirm to them that it is something that actually requires higher center. So, one, they may fail to actually judge how bad it is, so they may not go to Mulago because of that initially, or they may delay to go because of that." **[Delay: Hospital Knowledge and Injury Knowledge]**

There is also a stigma associated with knowledge of Mulago hospital; the healthcare professional perceives this knowledge gap is what perpetuates a stigma, and then leads to a delay in the decision to seek care.

“But two they, a few people that have seen me have anxieties about going to Mulago. Mulago has got a good side, good stories about Mulago but there are also many bad stories about Mulago, being tertiary care lots of people die here so some people think well by the time you got to Mulago you are going to die, something like that, so it’s one of the things that out them off. Not that the care is bad but because of course we get very bad cases, most cases, most times they are very bad chances of survival are low, so your end up getting a lot more deaths here, than in a smaller hospital. Because still the smaller hospitals find it is impossible for them to handle, they will always refer to Mulago. Yea, I mean if someone is critical, someone is terminal, they will always end up here. So of course, our death rates are much higher than other places. So, sometimes people associate death with a place and they don’t want to go there because of that.” **[Delay: Hospital Stigma]**

A stigma concentrating on fear was perceived in this excerpt; the healthcare professional observes that patients think Mulago is where they go to die. This stigma about the hospital prevents patients from making the decision to go there for care. This is another example of fear in certain aspects of hospital care:

“First of all is lack of knowledge. [...] And then fear of hospital. [...] Because they have that tendency, that thinking that once they are hospitalized it means they are very sick, it means they are going to die. And I think there's no caretaker, like the medical person's attitude towards them, some are rude. So, they fear to face that professional, the medical people. Bad attitudes. And we say, "When you go to hospital you are not get benefit." There are no drugs. There are no beds.” **[Delay: Hospital Stigma]**

One healthcare professional also mentions ways to educate the public about injuries, a way to intervene in a preventative fashion to avoid RTI and the injury in the first place.

“One of the major ones is first of all to make people aware of the possible causes of injuries to the brain. This could be done through the media, through the newspapers, through talk shows and sometimes little road traffic signs along the way whenever they are passing. I think if those educative facilities I employ, then the patient or the victim may [...] the possible consequences of either misusing the road for instance, overtaking the wrong corner, driving my car, they are not sounding and so forth.”
[Solution: Injury Knowledge]

3.2.3 Theme 3 – Surgical Intervention Preparedness

In-hospital delays, or delays in receiving care, are a very prominent theme within the interviews, delays are caused by a deficiency of these sub-themes, *Resources, Instruments, Equipment, Investigations, Space and Staff*. The healthcare professionals were knowledgeable in this area because they often experienced the problems themselves first-hand and are delayed providing care because of them. All the necessary steps taken for surgical intervention are delays when the care provider must wait, for example:

“If it is for example a subdural hematoma and so on, preparation is basically maybe getting the blood, blood that is necessary, getting the equipment the instruments, you would need in theater ready.” **[Delay: Instruments] [Delay: Resources]**

“Getting theater space, getting an anesthetist or an anesthesiologist. Then maybe if you’re the only surgeon at the A and E at that time, then of course you would need an assistant. So being able to put all those things together can take a bit of time. For example, yesterday, we had one of the kids had an epidural hemorrhage, but we actually didn’t manage to get blood, and we were unable to get blood, and in order to do a craniotomy you need blood.” **[Delay: Space] [Delay: Staff]**

The professional continued to explain give more examples of constraints for providing care, or for the patient, receiving care.

“It took about two hours to look for blood alone. To get an Anesthetist, the anesthetists you find that you got one anesthetist for example, on a call in the evenings, and that one is supposed to handle all cases, general surgery, abdominal surgery, cardiothoracic surgery, and so on. So, by the time you actually put up your list in theatre, you most likely would have already started on other cases and maybe there are other people who have already booked, so at the end of the day you have to wait for other surgeries.”

[Delay: Staff]

“Even if you've got space. Then space, you've got maybe three rooms, three operating rooms, yes, they are not fully equipped, so generally that can also be a problem because if you three rooms in a day, you get more than hundred patients at casualty and maybe more than twenty definitely need emergency surgeries, yes, so three rooms definitely and one surgery you can't guarantee that it will take less than an hour.”

[Delay: Space]

“And then equipment, if for example, yesterday if we had gotten another patient with epidural hemorrhage who had required an emergency craniotomy would not have been able to do because we had one set for that in there, the casualty department.”

[Delay: Equipment] **[Delay: Instruments]**

A specific staff problem was reported multiple times, by separate care providers, “anesthesiologists” are in high demand at Mulago and cause serious delays in care on the back end.

“Not enough nurses employed by the hospital, not enough nurse anesthetists and anesthesiologists that work at the hospital, they are here in Uganda yes. Not enough tools, equipment to use. [...] You still have one anesthetist, even with then a big number of rooms that we originally had we still had one anesthetist, so lacking the human resource. And that is quite common all over the country that you may infrastructure have been put up but you don't have the human resource, and the equipment. Sometimes the drugs, most times, many times the drugs, definitely.”

[Delay: Staff] **[Delay: Resources]**

Another identified issue within the theme of surgical preparedness is the “investigations”; healthcare professionals had observed extreme delays with patients obtaining CT scans.

“There are hurdles in investigations. Yeah. We don't promptly get the investigations ... we don't get them in time. Some investigations we miss to get them, just because the hospital CTs don't work. [...] But there's also the investigations, you're [the patients] not having them. Some investigations are done from outside the hospital and they have to pay for them. And then that delays the surgery, but then that also could make the CAT scan be not accurate anymore because of how long it is between.” **[Delay: Investigations]**

There were limited responses on specific interventions for these delays; primarily all of the solutions were coded and associated with the final theme.

3.2.4 Theme 4 – Financial Burdens

All healthcare professionals in all positions agreed that cost was a source of delay, albeit not directly. Cost was the only multi-delay theme that was identified in all three delays of the framework, seeking, reaching and receiving. Also, there were no solutions given for this problem that creates delay. Examples of healthcare professionals perceiving cost as a seeking delay:

“Of course, there are those subtle injuries where someone may not know that, especially mild head injury, where it might not be very clear cut there is a big injury, for example if someone fell in the bathroom, and old lady or whatever, and she managed to get up and was able to do her work and so on, they are less likely to seek for care, because one, it is expensive of course, getting the care, so they don't want to get into any expenses. Just because they suspect maybe, anything happened, so, lots of people have different views on when to actually start for seeking for care.” **[Delay: Cost of Obtaining Care]**

“And some patients have to first mobilize funds from their relatives before coming to hospital. And that causes delay. [...] And then I think some they don't have [money] ... Provided, they don't have money to come to hospital.” **[Delay: Cost of Transport]**

“Some of our patients or the relatives have some ... like they believe in traditions. They think accidents are caused by witches. [...] Some of them they believe, they can use that tradition medicine. [...] Some of them, they fear going to the hospitals, they think they will ask them to give them money.” **[Delay: Cost of Cheaper Care]**

“Who is the owner? [Of the wrecked car] They first ask [The person finding the RTI victim] ... Then again the money. When you get an accident, that very moment [...] there is no money. [For someone to take them to the hospital] Even what you have they steal it and then they run away, and then you remain casualty. You remain without help. So, from there, if there's someone who is going to come and help, that person will bring the patient to the hospital or the police.” **[Delay: Cost of Transport]**

There was also mention of delay in reaching care due to cost constraints; these cost delays were primarily related to the cost of the transportation:

“There is no money. Even what you have they steal it and then they run away, and then you remain casualty. You remain without help. So, from there, if there's someone who is going to come and help, that person will bring the patient to the hospital or the police. [...] So reaching is also delayed, but patients agreed to go to Central Lugogo but is bleeding so they have to go in a special hire, which is also going to make traffic they say it is very expensive. I think, if they had everything for emergency care and an ambulance, that it would be settled. But because the patient is has been sent in a special hire, which is expensive to reach to Mulago.” **[Delay: Cost of Transport]**

The third delay, the delay in receiving care also had the same theme of financial burdens primarily for “investigations”.

“Yes. There's a knowledge thing there. But there's also the investigations, you're not having them. Some investigations are done from outside the hospital and they have to pay for them. Even when they pay, there is that travel ... the distance thing. Yeah. [...] Materials you need to use intra-op. And you may not have them. They are fairly expensive for the patient, and

they need to produce them really, really fast.” **[Delay: Cost of Investigations]** **[Delay: Cost of Surgical Equipment]**

“If the investigations would be done quickly, that patient would be alive but here that depends. There are physicians [...] Patients are unable raise funds before they operated. Then before you get to know it, 5 days have passed, the patient's condition changes, and it declines.” **[Delay: Cost of Investigations]**

“Yeah, and condition can change at night as we are waiting for them to organize funds to get things to be bought for theater. So, the theater doesn't have things, so patients have to come. So, we find that for a poor person who had a good transport to come here, [...] They have an epidural for bleeding in the brain, but this still can be applied to the wound because in the event of anything to be used in theater. The same goes to ICU. The patient, gasping, can't be put on a vent because they have nothing to sterilize the equipment.” **[Delay: Cost of Surgical Equipment]**

“Supplies run out and before they are reinforced for the patients, relatives or friends go to buy some of the things, the encounter is difficult. Then there is also a challenge of the first aid drugs, which sometimes also may run out or may not be enough. For instance, if the patient comes in convulsing you may not have the anticonvulsant at hand. That may delay to get the service until such a drug is provided.” **[Delay: Cost of Medication]**

“Mulago doesn't have a free CT scan. Even when Mulago had a free CT, it is not free, it is money. They have to pay so they don't have money sometimes to make the CT scan. When Mulago doesn't have it, they have to go outside Mulago. That involves paying for the CT scan, getting transport to go to where they have to do it, it becomes complicated.” **[Delay: Cost of Investigations]**

The data was strongly skewed towards delay rather than solution especially in the themes of *Surgical Intervention Preparedness* and *Financial Burden*. There was also an overall lack of perceptions on delay mitigation versus the actual delays. The most referred to time interval healthcare professionals perceived delays within was receiving

care, followed by seeking care. There was confusion between the time intervals of seeking and reaching care and many of these answers overlapped in the data.

4. Discussion

The purpose of this study is to understand perceptions from healthcare professionals of delays for TBI patients, giving these experiences organization using the three delays framework, and to propose solutions to these delays inductively from the insights of the healthcare professionals. Healthcare professionals at MNRH perceive, *Transportation, Knowledge and Stigma, Surgical Treatment Preparedness, and Financial Burdens* of the healthcare delivery experience as primary themes of delay found within the care continuum for TBI patients. While publications on delays in surgical care are frequently written in LMICs, it seems to be sparse in Uganda, although the themes presented in this study are still represented and supported by the existing literature. A better understanding of these perceived problems and methods of reducing them can benefit patients by improving outcomes and preventing injuries from occurring in the first place. This study is unique because it is the first qualitative study involving TBI to use the three delays framework as a foundation. It also attempts to derive solutions inductively rather than deductively which is often not the case in global health interventions. Also, an objective of this study was to develop a conceptual framework for delays in seeking, reaching, and receiving care for TBI patients based on perceived delays and solutions from healthcare professionals, shown in Figure 3.

Conceptual Framework

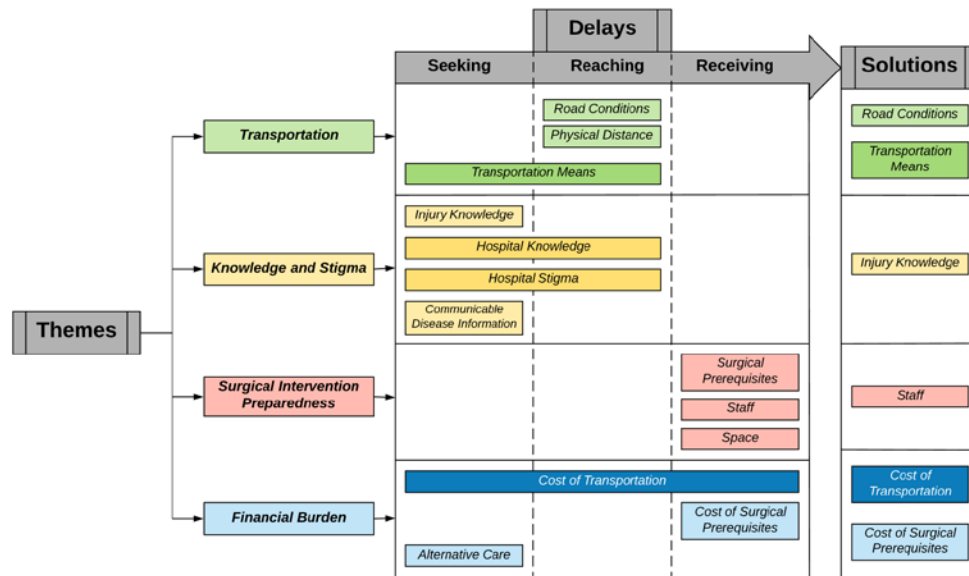


Figure 3: Conceptual Framework

4.1 Seeking Care

The sub-themes identified in this study linked to the first delay, seeking care, such as *Injury Knowledge* and *Hospital Stigma*, are issues effecting the continuum of care in many LMICs over a broad range of illnesses.

Knowing how extensive an injury or strong a disease, based on symptoms, is a determinant in whether a person makes this decision to seek care or not. The sub-theme of *Injury Knowledge* as a delay in care has been shown to be a principal deciding factor in treatment-seeking behaviors for Tuberculosis (TB) patients in Peru and Nigeria, and for myocardial infarction (MI) patients in Egypt and Scotland. (Paz-Soldan, 2014; Baldwin, 2004; Ghazawy, 2015; Leslie 2000) This data backed up the perceived delays due to *Knowledge and Stigma*.

Healthcare professionals alleged a solution to this delay would be to inform the public, that an information campaign focused around symptoms and prevention would mitigate the delay. Although concluding points in these publications agree that health promotion interventions involving information campaigns could work, it is not concurrent with an eighteen month intervention and has not been shown to resolve issues with delay statistically for patients with acute MI. (Luepker, 2000) Also, a systematic review conducted on mass media interventions to reduce help-seeking delay in MI concluded that the majority of interventions did not decrease delay, and more than just symptom awareness is needed. (Kainth, 2004; Caldwell, 2002) The perceptions of the healthcare professionals seem to contradict the literature and it seems like the feasibility of conducting an intervention based on *Injury Knowledge* will not produce fruitful results. A contradicting study, at Duke University, did show that public education campaigns do statistically reduce the delay in seeking care for a different neurological condition, cerebral infarction. (Alberts, 1992) In this intervention, their educational programs included specifications also mentioned by participants in this study, such as: television and radio spots. (Alberts, 1992) This study is older and contradicts many more current publications. This concept of informing the public may be outdated and healthcare professionals might not yet know the futility in attempting these measures to reduce delay.

4.2 Reaching Care

Transportation delay was a reoccurring theme primarily associated with delays in reaching care and a major theme throughout the study. *Transportation Means, Physical Distance, and Road Conditions* play an important role in the ability of the patient to receive care in a timely manner. These were all sub-themes healthcare professionals perceived to be factors causing delay in reaching care. These sub-themes were also found in a systematic review on the topic. This review found that six studies found that distance was a barrier to care, and in nine studies related to mode of travel collectively suggested that for individuals from low income backgrounds lacking access to transportation could be associated with reduced healthcare use. (Syed, 2014) Furthermore, specifically in cases of TBI, pre-hospital delays like these can result in increased mortality. (Rahul, 2013)

Perceived solutions to this delay involved theories of a basic EMS. In developed countries a modern emergency medical system (EMS) with ambulances, paramedics, and emergency medical technicians (EMTs) is expected and often, taken for granted. While in Kampala, participants suppose a basic system of rapid hospital transport could change thousands of people's lives. The literature confirms the effectiveness of a cost-effective ambulance system in Ethiopia for obstetrics and neonatal care, suggesting that it is possible to adapt a system in Uganda. (Accorsi, 2017) Based upon suggestions from the participants in this study another method of mitigation may be used specifically in

Kampala. A motorbike ambulance service has been funded in South Sudan by UNICEF, to provide fast and affordable transportation for pregnant women to hospitals. (Unicef, 2010) The literature supports the effectiveness of motorcycle ambulances in Malawi, Zambia, and Uganda, but for another medical condition. (Hofman et al., 2008; Bhopal, 2013; UNICEF, 2010; Irby, 2010; Mohanty, 2013; Ssebunya et al., 2016) These concurrences in the literature suggest that a motorcycle-based ambulance system in Uganda could be effective to manage the delays in reaching care for TBI patients.

4.3 Receiving Care

The third delay, receiving care, was principally attributed to the lack of *Surgical Intervention Preparedness* for TBIs. *Surgical Intervention Preparedness* delays are perceived as being caused by lacking certain aspects needed to begin surgery. More specifically lack of anesthesiologists, surgical instruments, intensive care unit (ICU) and operating room (OR) space, investigation, and resources such as blood and equipment. The literature confirms that these issues are also apparent in other LMICs and that they effect the speed at which care is delivered.

Kushner and colleagues (2010) reported that across eight African countries more than half of the district hospitals lacked anesthesia machines and almost three quarters of operating rooms had no pulse oximeters according to a study by Funk and team. A study in Nigeria identified a lack of essential medical supplies such as medication, surgical instruments, PPE, and surgery supplies, also 42% of district level hospitals and

24% of regional hospitals had the supplies for the maintenance of a pediatric airway. (Kushner et al., 2010; Wagenaar et al., 2014; Henry et al., 2012) Hospitals in LMICs with limited resources often have equipment that does not work and is difficult and expensive to repair, such as CT scanners; this donated equipment had been shown to be out of service 40% of the time. (Lebrun et al., 2014; Perry & Malkin, 2011) Due to issues with testing of communicable endemic diseases in LMICs, blood supplies are low are many hospitals in SSA have poor blood collection infrastructure and storage. (Tagny et al., 2010) One recent publication in Uganda found that almost a quarter of patients waited at least one day to seek care and 29.8% of patients took longer than 4 hours to reach care. (Kuo, 2017) In this same study delays in receiving care were also quantified, where 33.6% of patients waited more than 4 hours to be seen by neuro staff after arrival and most patients diagnosed with TBI waited for more than a day in the hospital before receiving care due to issues with investigations. (Kuo, 2017) The evidence of surgical issues is so abundant; the Lancet commission released a document on the subject referring to all the issues effecting global surgical care access. (Meara, 2016)

Interventions to solve these issues that will directly reduce the delays they cause have been clear but are not cost-effective. The results suggest that healthcare providers need resources and funds, but this has not been constructive in the identification of solutions to delays. The influx of financial resources does help in the short-term but in long term financial stability, it does not.

4.4 Implications for Policy and Practice

As a result of the qualitative in-depth interviews, care providers want an education campaign to inform the public on symptoms of TBI and when to seek medical intervention, they also think a cost effectively and rapid transport system with trained personnel, this would allow TBI patients to arrive at the hospital in a relatively more stable condition and reduce delay to care. Also, they want to better educate the public on what MNRH is, to reduce the stigma that “Mulago is where you go to die”. Furthermore, an issue effecting care in low income and resource settings globally, the care providers need more resources and funding.

4.5 Implications for Further Research

The findings of this study raise questions about if the same delays effecting MNRH are found in other regional referral hospitals (RRH) around the country such as Mbarara RRH, to the west, and Gulu RRH to the north. Care providers expressed desires to have access to a functional CT scanner at Mulago as well as a knowledge campaign to increase TBI awareness to help with prevention efforts. In order to decrease delays in the TBI Care Continuum through further research may be a pilot study on a TBI Symptom Information campaign, to see if this concept could work to diminish the number of TBI patients in Uganda indirectly leading to less patients experiencing delay. Another important step would be to have patients and their families identify delays they have experience or observed from their perspective, and methods to diminish them.

4.6 Study Strengths and Limitations

The strengths of this study are the sample and the methodology. The sample was a strength because all physicians in the Neuro ward at all levels of training were interviewed as well as most of the experienced nurses. The data from this source was saturated from this perspective. Also, the In-depth interviews were well received, and participants felt as though the questions were adequately targeting the delays in the care continuum.

The main limitations to this study that could have had an impact on the result is focused on the interviewing care providers. The nature of the interview was focused on the negative aspects of the care continuum; some participants may have felt like answers to some questions would have a negative connotation to the hospital that they are employed at. This is particularly concerning at the receiving care delay where the participants needed to describe issues within the hospital that prevent patients from receiving care. The participant's privacy was of great concern, so any information given about the care continuum would not be tied to the individual care provider.

Another limitation is the lack of perspectives. It is important to have actual TBI patients and their care-providers perceptions on delay and solutions in order to create an inductive intervention for delay in Uganda. Also, to have these perspectives extend to the other two regional referral hospitals conducting neurosurgeries for TBI, Mbarara and Gulu. These two locations could have specific delays not perceived by participants from

Kampala using MNRH. This limitation will be mitigated through the continuation of this ongoing study with new data from patients and their families.

5. Conclusion

Understanding perceptions of delay from healthcare professionals for TBI patients can fabricate detail rich information about the care continuum in Kampala, Uganda. Including, but not limited to, interrelated themes of *Transportation, Knowledge and Stigma, Surgical Intervention Preparedness, and Financial Burdens*. Furthermore, deductively collecting perceptions on methods to mitigate delay is critical for the formation of feasible and culturally appropriate interventions. Understanding these two points of interest is particularly useful when organized through the Three-Delays Framework. This created a foundation for which this study was built upon and provided an avenue for detailed responses from the healthcare professionals.

In this thesis, we highlight the thematic relationships of delay from the perspective of healthcare professionals and supported it with data from the literature while also finding support contradictory of a few claims. This understanding of the feasibility of proposed methods to reduce delay are vital in the understanding of the delay landscape in Uganda for TBI patients. This study sought to transform perceived ways of reducing delays to interventions that could work at MNRH, to improve outcomes for moderate and severe TBI patients, effectively creating a solution based on the need.

Appendix A

IDI Guide: Patient

Section A:

Description of interview

Today, I will be asking you questions about delays and barriers that you experienced during the time after the incident that caused your diagnosis of traumatic brain injury and up until receiving care. First, I will ask demographic baseline and incident specific questions. Then I will define delays and barriers. This will be followed by three sections of questions inquiring about the delays and barriers within specific time intervals. The time interval will be described after each question, and then once you feel that you have adequately responded to the question, it will be followed by a question about ways to change these problems.

- *If proper consent is acquired:* Thank you for your time and patience today, let us begin.

Section B:

Relevant Demographic Data

First off, what is your age and gender?

Where do you currently live? *Region/City/Community/etc.*

Could you describe the incident that caused your diagnosis with Traumatic Brain Injury?

➤ *If road traffic incident:* What vehicles were involved in the accident?

Where did the incident occur?

What were you doing when this incident occurred? *Working/Commuting/At Home/etc.*

What form(s) of transportation were used to get to the hospital?

Approximately how much time has elapsed from the time of the incident until you received care at this hospital?

Thank you, we will now continue onto the next section.

Section C:

Definition of Delays and Barriers

The interview being conducted today will address delays and barriers, these will be defined as: to postpone, slow down or defer an action. Also, the general noun used to describe someone and/or something, physical and/or non-physical, which caused seeking, reaching, and/or receiving health care to be late, slow, or paused.

Do you feel like you understand the definitions of delays and/or barriers to care?

Is this definition sufficient and effective in its description? If not, could you describe a more functional definition?

Thank you, we will now continue onto the next section.

Section D:

The First Delay

Immediately following the incident or event associated with the symptoms and later diagnosis of Traumatic Brain Injury, what specific delays and/or barriers did you experience while seeking care?

- Seeking care refers to the time interval between the event, or onset of symptoms in the case that the event is unknown, and the decision that you made to pursue health care for these symptoms.

Now please explain, in detail, why these delay(s) or barrier(s) occurred.

In your opinion, are there any methods to alleviate this/these delay(s) and/or barrier(s) you have just described to me? Please be detailed.

- Methods refer to ways in which these delay(s) and/or barrier(s) can be diminished by you, the community, the hospital, and/or the government.

Section E:

The Second Delay

Once you made the decision to seek medical intervention, what delays and/or barriers did you experience while reaching care?

- Reaching care refers to the time interval after you made the decision that you needed to pursue medical intervention and then ends at the point of first contact with a health care professional.

Now please explain, in detail, why these delay(s) or barrier(s) occurred.

In your opinion, are there any methods to alleviate this/these delay(s) and/or barrier(s) you have just described to me? Please be detailed.

- Methods refer to ways in which these delay(s) and/or barrier(s) can be diminished by you, the community, the hospital, and/or the government.

Section F:

The Third Delay

After initial contact with a health care professional was made, what delay(s) and/or barrier(s) did you experience while receiving care?

- Receiving care refers to the time interval of first contact with a health care professional up until treatment for TBI was received. This includes the time interval of being referred to this hospital from a local health care clinic, if this applies to your situation.

Now please explain, in detail, why these delay(s) or barrier(s) occurred.

In your opinion, are there any methods to alleviate this/these delay(s) and/or barrier(s) you have just described to me? Please be detailed.

- Methods refer to ways in which these delay(s) and/or barrier(s) can be diminished by you, the community, the hospital, and/or the government.

You have now completed all interview questions.

Do you have any questions about the interview or anything you would like to mention on the topic? Thank you for your time and patience.

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