

Evaluating the Influence of Patient Caretakers' Health Literacy on Delays in Care for Traumatic
Brain Injury Patients at Mulago National Referral Hospital, Uganda.

by

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Contents

Abstract	4
Dedication and Acknowledgements.....	6
1. Introduction	8
1.1 Caretaker Health Literacy.....	10
1.2 Caretaker Health Literacy Framework.....	12
1.3 Delays in Care.....	13
1.3.1 The Three Delays Framework	13
1.4 Burden of Traumatic Brain Injury.....	15
2. Objectives.....	16
2.1 Specific objectives.....	16
2.2 Future objectives.....	16
3. Methods.....	17
3.1 Study Design.....	17
3.2 Study Setting.....	17
3.3 Participants.....	17
3.4 Procedures	18
3.5 Caretaker In-depth Interviews.....	18
3.6 Analysis.....	19
3.7 Ethical Considerations	20
3.7.1 Informed Consent.....	20
3.7.2 Confidentiality Assurance.....	19

3.7.3 Study Risks.....	20
4. Results.....	21
4.1 Overview.....	21
4.2 Theme One – Intrinsic Factors.....	26
4.2.1 Navigational Skills.....	26
4.2.2 Understanding of Health Information.....	28
4.2.3 Emotional Challenges.....	29
4.3 Theme Two – Extrinsic Factors.....	30
4.3.1 Government Support.....	30
4.3.2 Community Support.....	31
4.3.3 Financial Burdens.....	32
4.4 Theme Three – Health Systems Factors.....	34
4.4.1 Physician Support.....	34
4.4.2 Lack of Medical Resources.....	36
4.4.3 Access to Health Information.....	38
5. Discussion	39
5.1 Caretaker Health Literacy and Seeking Care.....	40
5.2 Caretaker Health Literacy and Reaching Care	43
5.3 Caretaker Health Literacy Receiving Care.....	45
5.4 Implications for Further Research, Policy and Practice.....	46
5.5 Study Strengths and Limitations.....	48
5. Conclusion	49
References	50

Appendix A.....53

List of Table and Figures

Figure 1: Caretaker health literacy main themes and sub-themes.....23

Figure 2: Conceptual framework of the three delays to care and caretaker health literacy factors.....24

Table 1: Caretaker health literacy factors and key points within each delay framework25

Abstract

Background

Caretakers take on caregiving tasks such as feeding and administering oral medication for patients at Mulago National Referral Hospital (MNRH), Uganda and many Low-Middle Income Countries (LMICs) where nurse shortages are prevalent. They shoulder the burden of caretaking responsibilities with little or no knowledge of the patient care. Studies have shown that caretaker's ability to navigate the healthcare system, find, and use health information to support their patients throughout the care continuum can impact the three delays in care: seeking, reaching and receiving care. With the life-threatening nature of Traumatic Brain Injuries (TBI) in Uganda, caretakers' play an important role in ensuring patients access care in a timely manner. This study seeks to determine the factors that impact TBI patient caretakers' health literacy in MNRH and examine how these factors influence the three delays in care.

Methods

This qualitative research study was carried out in the neurosurgical ward at MNRH, in northern Kampala. The study participants were 27 adult caretakers. Semi-structured in-depth qualitative interviews, outlined through "The Three Delay Framework", was utilized to understand participants' experiences with delays in seeking, reaching and receiving care for moderate to severe TBI patients. Thematic content analysis and manual coding was used to analyze interview transcripts and identify overarching themes in the participant responses.

Results

This study identified three main caretaker health literacy factors, each with three

sub-factors, that impact the three delays to care. The main themes identified were Extrinsic, Intrinsic and Health System Factors. The nine sub-themes were Government Support, Community Support, Financial Burdens, Lack of Medical Resources, Access to Health Information, Physician Support, Emotional Challenges, Navigational Skills and Understanding of Health Information. These components were found to influence the delays to care to varying degrees. More importantly, Financial Burdens, Government Support, Emotional Challenges, Physician Support and Lack of Medical Resources were recurring health literacy factors across the three delays.

Conclusion

The health literacy factors identified in this study work to influence caretakers' functional health literacy and the delays to care in a co-dependent manner. A better understanding of how these factors impact patient outcomes is necessary for the development of context and culturally relevant interventions targeted at improving a caretaker's ability to maneuver the healthcare system and support patients in resource-poor settings. There is a strong need for the state and policy makers to invest in improving health education and communication strategies to support caretakers' health literacy needs and mitigate the delays to care for TBI patients.

Dedication

I dedicate this honors thesis to Almighty God, my parents, Mr. and Mrs. Samuel and Joy Nwosu, and my siblings: Chinenye, Chiamaka, Chijioke, Chisom and Akachukwu, who have been my source of strength and inspiration throughout my academic career at Duke. *A hụrụ m unu nile n'anya.*

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caretakers at Mulago Hospital neurosurgery ward for inspiring this thesis project, your hard work and resilience does not go unnoticed. Your contributions to patient care at Mulago Hospital will always leave a positive impact in the lives of those you have touched, including mine.

1. Introduction

In hospitals across many African countries, family members are the primary caretakers of patients during and after their hospital stay (Söderbäck et al., 2008) (Hoffman et al., 2012). In 2011, there was a 42% shortage of nurses within the public health sector in Uganda, and a 10% shortage in MNRH, which has severely affected health delivery services (Baine and Kasangaki, 2014). With the scarcity of health workers, caretakers are entrusted with tasks which they have little to no knowledge on how to successfully carry out. Such tasks include complex feeding for neurologically altered patients, administering medications on a specific schedule or via IV, turning coma patients to prevent bed sores, wound care, cleaning or maintaining IVs or other ports aseptically and monitoring or responding when patient deteriorates or presents concerning symptoms. These tasks are particularly relevant in a neurosurgical ward where most TBI patients are immobile, unable to speak or comprehend instructions. Improving caretaker health literacy is critical to improving quality of care and ultimately the patients' health outcome.

Holistically addressing the barriers in the health system that pose a threat to patient care is necessary for improving patient outcomes. In a context and setting like MNRH neurosurgery ward, the patient caretaker's health literacy is an important factor to consider when seeking ways to improve patient care due to their direct contact with patients and the medical personnel's reliance on their assistance for patient care. The Patient Protection and Affordable Care Act of 2010, Title V, defines health literacy as the degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions (CDC, 2016). Studies in global health have shown that patients' low health literacy contributes to poor outcomes such as higher death rates, readmissions, medication

errors and higher health care costs (Westlake et al, 2013). The impact of health literacy is usually evaluated based on the patient's understanding while the analysis of a caretaker's health literacy often goes underrepresented in both research and clinical practices particularly in Sub-Saharan African countries indicating a significant gap in literature that needs to be addressed. Healthcare professionals recognize that patients need health information, but are less likely to acknowledge that caretakers also have information needs because they are involved in patient care (Bevan and Pecchioni, 2008). A study conducted in Mozambique about family involvement in care found that lack of adequate knowledge of the patient's illness before and during the admission process, as well as during the care process leads to poor quality in preoperative care by caregivers (Söderbäck et al, 2008).

With the life-threatening nature of TBI, the need for caretakers to assume their responsibilities in a time sensitive manner is important and the delays in the care continuum experienced by TBI patients is also understudied in Uganda and many LMICs. The Thaddeus and Maine three delays framework which highlights the key events in seeking, reaching and receiving care has been adopted in the global surgery settings (Meara et al., 2016). Investigating the factors that influence a caretaker's ability to navigate the healthcare system and assist their TBI patients through each stage of care is a fundamental step needed to design and implement effective interventions tailored towards addressing their health literacy needs, particularly at the initial stages of health care continuum. It is also crucial when designing health communication strategies to ensure greater readability, comprehension and retention of health information, and a helpful resource for physicians and nurses when communicating to patients and their caretakers (Liu et al., 2009). The purpose of this study is to examine which factors influence caretaker

health literacy and how they affect the delays in seeking, reaching and receiving care for TBI patients in MNRH neurosurgical ward.

1.1 Caretaker Health Literacy

Health literacy is defined as an individual's ability to find and comprehend the basic health information necessary to act on medical instructions and make decisions about one's health (AHRQ, 2019). Health literacy exists within a broader framework of general literacy which is content and context specific. There are three main types of health literacy: functional, critical and interactive (Nutbeam et. al, 2018). Functional Health Literacy encompasses the basic skills needed for individuals to obtain relevant health information and apply that knowledge to a range of prescribed activities (Nutbeam et. al, 2018). Interactive health literacy describes more advanced literacy skills that allow people to obtain health information and derive meaning from different forms of communication, to apply new information to differing circumstances, engage in interactions with others to extend the information available and make decisions (Nutbeam et. al, 2018). Critical health literacy describes the most advanced literacy skills which can be used to critically analyse information from a range of sources, and information relating to a greater range of health determinants, and to use this information to exert greater control over life events and situations that impact on health (Sykes et al., 2013). Critical health literacy also encompasses one's ability to use health information for engagement in political and social movements to improve health (Wills, 2009). This study focuses on caretaker's functional health literacy which entails being able to carry out basic caregiving tasks, seek and understand health information.

There are barriers to identifying individuals with inadequate health literacy because educational attainment (i.e., years of schooling), and self-reported literacy skills are not reliable reflections of one's health literacy (Lee et al., 2010). Thus, research studies have worked to develop several health literacy measurement tools for various culturally and linguistically different populations such as the Short Assessment of Health Literacy-English (SAHL-E), Rapid Estimate of Adult Literacy in Medicine (REALM) and Test of Functional Health Literacy in Adults (TOFHLA). However, most of these assessment tests are typically used to measure health literacy of patient populations. Despite the important caregiving roles caretakers are responsible for, studies have continuously reported unmet health education and literacy needs for caretakers (Washington et al., 2011).

Caretakers seek out health information to assist with managing care and supporting patients. Studies have found that they play a significant role in the treatment and care of patients with chronic illnesses (Yuen et. al, 2015). Caretakers, who are typically relatives, are important sources of health information for patients and assist in the health decision-making throughout the care continuum. Depending on the diagnosis and severity of illness, caregivers may engage in a variety of care tasks such as wound care, medication and symptom management, transportation and provision of emotional support (Glajchen, 2004). Unfortunately, the importance of their health literacy is severely understudied in literature even though better understanding of the extent to which caregivers can comprehend the health information they are provided is critical for successful patient outcomes (Bevan and Pecchioni, 2008).

1.2 Caretaker Health Literacy Framework

Studies have shown that inadequate health literacy skills have been linked to misunderstanding of essential health information, poorer medication adherence, high hospital readmission rates, and low rates of compliance with physician recommendations (Yuen et al., 2015, Bevan and Pecchioni, 2008). Most caretaker health literacy frameworks have been developed within cancer care, due to varied and complex nature of cancer treatment and the active role of family members as caretakers throughout the cancer care process (Yuen et. al, 2015). The frameworks can be applied more broadly to illnesses that require long term care management such as TBI. Caretaker health literacy is a multifaceted construct, and there is a need for broader conceptual models that provide sufficient information on the socioeconomic factors that influence their roles and abilities. Examples of such models include Edwards and others' Health Literacy Pathway Model (2012) and Distributed Health Literacy Model (2013). One conceptual model developed by Yuen et al. (2015), described the constituent elements of caretaker health literacy within cancer care and identified themes such as support systems, managing challenges of caregiving, relationship with care providers and care recipients, psychosocial support, self-care and processing health information. These themes were connected to caregiver's capacity to appraise health information and emphasized the importance of support systems (e.g. social, financial and legal) in assisting caregivers in their role. This study will utilize a qualitative approach to craft a similar framework in the context of TBI care in order to identify the broader factors that influence health literacy beyond basic reading and comprehension skills.

1.3 Delays in Care

This study defines delays as when an action does not happen quickly enough or happens at a later time and consequently causes seeking, reaching and receiving health care to be late or postponed. TBI cases are extremely time sensitive and life-threatening. Thus, the ability to seek care immediately for patients, who may not be able to care for themselves, can mean the difference between life and death (Bullock et al, 2014). Patients in critical conditions have poorer health outcomes when their access to emergency care is delayed even with the presence of abundant medical resources and adequate transportation systems (Slomine et al., 2006). Thus, in resource poor settings, with poor referral systems, geographical barriers, financial and infrastructural problems, these delays may be exacerbated and worsen patient outcomes (Vaca et al., 2019)

1.3.1 The Three Delays Framework

The Lancet Global Commission on Surgery Three Delays framework describes the barriers within the healthcare system of many LMICs that prevent patients from obtaining surgical care (Meara et al, 2016). It explains the different problems and solutions to them in each time point in healthcare delivery (seeking, reaching and receiving care). Research studies have used this framework to understand how to mitigate delays and reduce risk of poor patient outcomes. One study found that delays for mild and moderate TBI patients in Uganda were associated with higher mortality and called for timely interventions to improve TBI outcomes (Vaca et al., 2019).

The first delay is in the decision to seek care by the patient or family members or both from the time of the incident or onset of injury till the decision is made (Thaddeus and Maine, 1994). This decision-making is influenced by the illness characteristics, costs of care seeking within that geographical location, distance and transportation factors, past experiences with the healthcare system as well as individual awareness (Meara et al, 2015). The delays in seeking care are also influenced by cultural and religious beliefs that may cause individuals to seek care from other non-medical sources. A 2002 WHO report showed that up to 80% of the population in low-resource settings rely on informal providers not well connected to a health system (Meara et al., 2015). In severe TBI cases, where victims are not typically able to make decisions to seek care, they rely on relatives and community members which may contribute to delays in seeking care.

The second delay is the delay in reaching care, which is typically affected by health system capacity and public transportation. This delay is also influenced by ambulatory services in case of emergency medical cases and financial burdens which are often increased with greater distances to hospitals and clinics for care. The distance to medical facilities is far greater in LMICs than in developed and high income countries, thus increasing the delays to reaching care in many developing countries (Meara et al., 2015). The third delay is the delay in receiving care which encapsulates the barriers to care patients face when they are in the hospital. This category of delay is affected by a wider range of factors such as lack of essential medical supplies, limited access to laboratories, low blood bank supplies, lack of patient beds or surgical equipment and insufficient physician support (Meara et al, 2016).

1.4 Burden of Traumatic Brain Injury

TBI in Uganda and other LMICs present increasing prevalence and has growing impact on morbidity and mortality. This is further compounded by the increased motorization and lack of resources to care for TBI patients in these settings. One study found that 9.6% of all TBI patients in MNRH die from injuries (Kuo et al., 2017) and another approximated that 10-15% of TBI cases in MNRH are classified as severe (Hsia et al, 2010). These injuries cause health loss and disability for individuals and their families and present an immense financial burden to health-care systems and economies through lost productivity and high health-care costs (Thompson et al., 2006). Ninety percent of the 5 million estimated annual global deaths from injury occurs in low-and middle-income countries (Langlois et. al, 2006).

The main causes of TBI for adults globally are falls (51%), and road traffic incidents (RTI) (9%) (Thompson et al, 2006). However, the global incidence of TBI from RTIs is mostly concentrated in LMICs with rates of 150–170 per 100,000 TBI in Sub Saharan Africa compared to the global incidence of 106 per 100,000 (Hyder et. al, 2007). One 2017 study in Mulago Hospital, Uganda, found that road traffic incidents accounted for 62% of TBI cases, most of which were pedestrians and motorcyclists (Kuo et al., 2017). The global health disparities in incidence of TBI are largely as a result of limited access to surgical care in many LMICs which poses as a barrier in emergency medical situations. One study found that delays to TBI care are typically as a result of underreporting or routing victims to mortuaries, accounting for 50% of mortality within the first two hours of the incident (Faul et. al, 2010). This time sensitive nature

of TBI is important to consider when examining the delays to care and its consequences on patient outcomes.

2. Objectives

The purpose of this study was to determine the factors that impact TBI patient caretakers' health literacy at Mulago National Referral Hospital (MNRH) neurosurgical ward, Uganda, and how these factors influence the three delays to care: seeking, reaching and receiving.

2.1 Specific Objectives:

- To determine the various health literacy factors that impact TBI patient caretaker's experiences when seeking, reaching and receiving care.
- To assess the ways in which identified health literacy factors act as barriers and cause delays in care for TBI patients
- To design a framework for caretaker health literacy factors within the three delays to care model

2.2 Future Objectives:

- To provide information for culturally appropriate and context-specific health education interventions tailored to caretakers' health literacy needs
- To lay the foundation for the development of effective strategies and incentives to empower caretakers as they navigate the healthcare system

3. Methods

Data collected was based on the Consolidated criteria (COREQ) guideline which includes a 32-item checklist for reporting the important aspects of a qualitative research study (Tong et al., 2007).

3.1 Study Design

The goal of this study is to understand the perceptions of delays in care for TBI patients from their caretakers at MNRH neurosurgery ward. Semi-structured in-depth interviews were conducted with 27 patient caretakers over a 10-week period. After data collection, the caretaker in-depth interviews were transcribed and analyzed for the study.

3.2 Study Setting

In 2011, there were only four neurosurgeons serving the entire Ugandan population of 38 million people (World Fact Book 2016). The Duke Global Neurosurgery and Neurology, founded by Dr. Michael Haglund, MD, PhD, sought to address this issue by establishing a collaborative program in Uganda's largest hospital: Mulago National Referral Hospital (MNRH) in Kampala. 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 and surgical expertise. (Tran et al., 2015). At the time of this study, the MNRH neurosurgery ward had 4 neurosurgeons, 6 neurosurgical residents, 5 neuro-ward nurses and catered to an average of 30-50 patients daily with a variety of brain-related injuries or illnesses.

3.3 Participants

The study included 27 research participants all of whom were patient caretakers. In order to participate in the study, the participant must have met the following requirements: (1) a

caretaker for a Traumatic Brain Injury (TBI) patient assigned to the neurosurgical ward at MNRH (2) proficient in a language understood by the interviewer and the study participant, (3) able to coherently answer all interview questions. Children and members of any vulnerable population were excluded from the study. Convenience sampling was used to obtain the study data and participants were approached in the ward when they were not preoccupied with caretaking tasks like feeding and administering medications.

3.4 Procedures

The ethical review boards at Duke University and the Mulago Hospital Research and Ethics Committee approved all study procedures. Before each interview, each potential participant was approached by the interviewer and informed about the details of the study and gave consent to participate in the study. Following verbal consent, using the consent script, the interviewer then conducted an in-depth interview and asked the participant about their experiences and observations regarding delays in care for TBI patients. The interviews were audio recorded using a small handheld device in the neurological ward at MNRH. Each participant had a one-on-one interview which lasted anywhere from 30 minutes to 1 hour. Participants were offered snacks after the interview as compensation for their time. There were no costs or immediate risks involved to the caretakers that participated.

3.5 Patient Caretaker In-depth Interviews

The topics of the semi-structured in-depth interview were related to the three delays in care: seeking, reaching, and receiving care. Participants were interviewed in the MNRH neurosurgical ward by the study's research assistant. Additionally, some of the questions were tailored towards ways to diminish the effect of delays and barriers on patients. In-depth

interviews were divided into three sections. The first section had information on the purpose of the study and the overarching structure of the interview. The second section provided the definitions of delays and barriers in the context of the interview. The third section posed questions about the three delays in care: seeking, reaching and receiving. Each of the delay sections were subdivided into a description of the delay, the time period in question, and concludes with the proposed solutions for managing delays in care.

3.6 Analysis

Each interview was transcribed verbatim by two research assistants and each inaudible or crosstalk events were noted in the transcription. The two transcripts were compared for differences by one research assistant and if a difference was found, it was discussed until the nature of the difference was resolved. After each interview transcript was completed, all identifying information was deleted. The transcriptions were entered directly into the study laptop, stored in an encrypted drive, and later uploaded into an encrypted cloud-based server.

The data were analyzed inductively using content analysis on NVIVO Version 12 software. Prior to data analysis, the researcher read through the transcripts and identified broad themes related to caretaker health literacy and the relationship to the three delays. Three main codes were created for perceptions and topics that were recurrent in various interviews. Within each code, three sub-codes were created for perceptions and topics related to the main code.

Manual coding was done on Microsoft Excel to categorize the caretaker health literacy codes and sub-codes under the three delays of care. Each delay section in the transcript was analyzed for specific sub-codes that were recurring in the interviews and then connected to their main code with a brief explanation of the overarching theme of the perceptions mentioned noted.

A tally system was used to denote how many participants mentioned a specific sub-code within each delay. This process was continued until the researcher reached a saturation point where no new themes were evident. Results for each category/theme are presented and participant quotes are reported as examples.

3.7 Ethical Considerations

3.7.1 Informed Consent

Verbal informed consent was obtained from all respondents in the study in English. The interviewer did not document consent because this information would be the only identifying information in the study. Instead, verbal consent was required and was approved by both Duke University Research and Ethics Committee and the Mulago Hospital Research and Ethics Committee. The audio interview began immediately after consent was obtained from the participant.

3.7.2 Confidentiality Assurance

Specific information provided by respondents was only accessible to the designated respondent and per study protocol. Interviews were held as privately as possible in the neurosurgery ward and no demographic data were collected for the purposes of the study. All data were stored on an encrypted drive, computers were password protected and stored in a secure location.

3.7.3 Study Risks

This study design posed no greater than minimal risks to participants. However, there were two ethical concerns: (1) Respondents may have perceived that the study interviewer was obtaining information for hospital administration and (2) Responses that portray the hospital in a

negative way may be reflected upon the participants. The interviewer ensured that no identifying information is used for the study and that all recordings needed to transcribe data were deleted to protect the identities of every participant. The interview transcripts were stored on an encrypted drive and the interviewer ensured all participants had a clear understanding of the study aims and procedures. The interviewee's questions or concerns were answered or addressed by the interviewer and primary investigator of the study. The participants had the liberty to leave the study or refuse to participate in the study at any time, and their refusal or exit did not count against them. They were also informed on the dissemination of the results of the study, and the potential for the results to be submitted for publication in a peer-reviewed journal and used in a thesis project. There are no conflicts of interest in this study.

4. Results

4.1 Overview

Thematic analysis of the 27 in-depth interviews with caretakers of TBI patients identified three main themes, each with three sub-themes (see Figure 1), that affect caretaker health literacy: *Intrinsic Factors*, *Extrinsic Factors* and *Health System Factors* within the three-delay framework of seeking, reaching, and receiving care. *Intrinsic Factors* explain the health literacy elements that are inherent to the caretakers and impact their approach to their caregiving role and ability to process health information to help the care recipient. *Navigation Skills*, *Understanding Health Information* and *Emotional Challenges* were the three sub-themes coded within the *Intrinsic Factors* theme. *Extrinsic Factors* theme described the health literacy factors that caretakers have no control over but instead influence their capability to find, understand and use health information to care for TBI patients. Government Support, Community Support and

Financial Burdens were the three sub-themes coded within the *Extrinsic Factor* theme. The *Health System Factors* theme described the factors related to hospitals and clinics in the study setting that impact caretakers' health decision making and delays to care for TBI patients. *Physician Support, Lack of Medical Resources and Access to Health Information* are the three sub-themes within this theme.

As shown in Figure 2, *Financial Burden, Government Support, Lack of Medical Resources* and *Physician Support* are common caretaker health literacy factors in all delay categories. *Community Support, Navigation Skills, Access to Information, Emotional Challenges, Understanding Health Information, and Lack of Medical resources* were recurring themes within the *Seeking Care* delay category. *Lack of Medical Resources* and *Physician Support* were the main health literacy factors within the *Reaching Care* delay category while *Emotional Challenges* alongside the four common sub-factors were recurring in the *Receiving Care* delay category. Table 1 shows the number of caretakers who described each health literacy sub-factor in their interview responses to delays in seeking, reaching and receiving care.

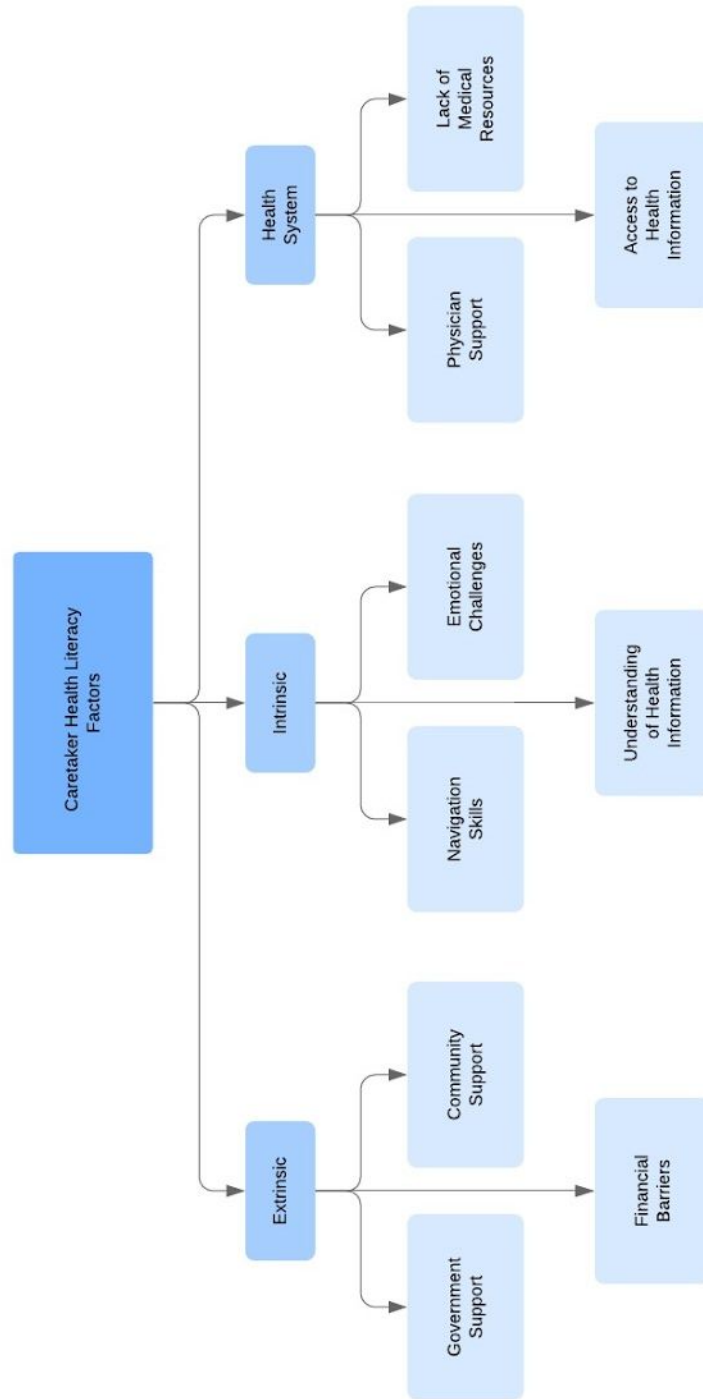


Figure 1: Caretaker Health Literacy Main and Sub-themes

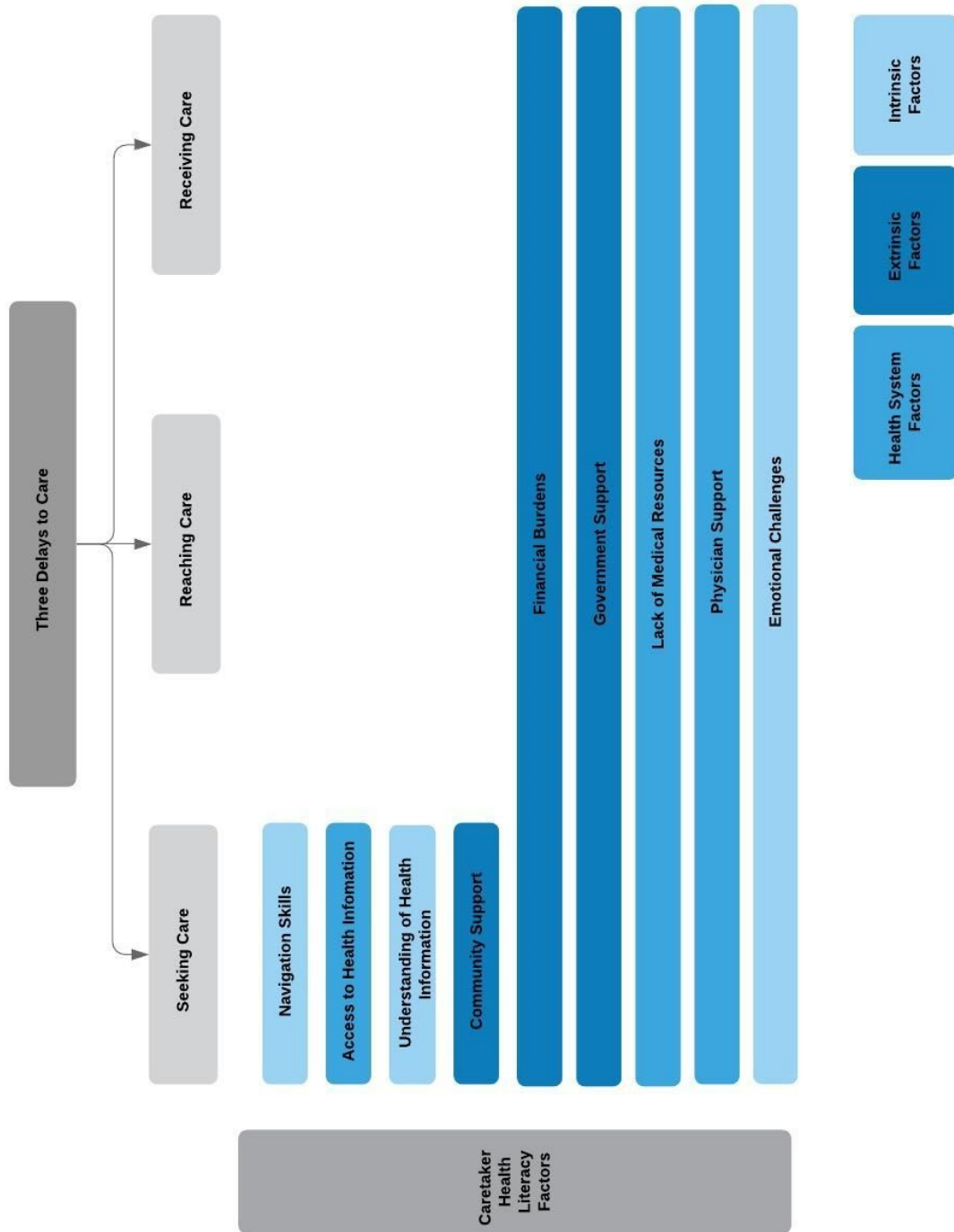


Figure 2: Conceptual Framework of the Three Delays to Care and Caretaker Health Literacy Factors.

Delays/Sub-Themes	Number of Caretaker Responses (out of 27)	Key Points	Main Theme
Seeking Care			
Financial Burdens	9	<ul style="list-style-type: none"> Buying fuel to transport patient in private cars or ambulances Cost of public transportation Initial cost of care in clinics and hospitals 	Extrinsic
Community Support	7	<ul style="list-style-type: none"> Relying on community members to seek care on behalf of caretakers Assistance with fundraising for transport 	Extrinsic
Government Support	5	<ul style="list-style-type: none"> Providing medical services like ambulances, and medical tests at lower costs Bettering roads and the public transportation system 	Extrinsic
Navigation Skills	5	<ul style="list-style-type: none"> Looking for to the hospitals or clinics after the injury Many referrals from clinic to clinic 	Intrinsic
Access to Information	7	<ul style="list-style-type: none"> Lack of knowledge on the injury or patient's condition Uncertainty on where to get help Lack of medical personnel to assist and provide information 	Health System
Emotional Challenges	1	<ul style="list-style-type: none"> Feeling overwhelmed, scared, tired, confused 	Intrinsic
Understanding of Health Information	3	<ul style="list-style-type: none"> Patient and caretaker did not know the severity of their illness 	Intrinsic
Physician Support	4	<ul style="list-style-type: none"> Physicians did not advise caretakers properly on steps to take Poor interactions with physicians i.e. the need to stop "trial and error" method of diagnosis 	Health System
Lack of Medical Resources	6	<ul style="list-style-type: none"> Inability to help patients due to lack of medical supplies and personnel 	Health System
Reaching Care			
Emotional Challenges	1	<ul style="list-style-type: none"> Feeling anxious due to patient's condition 	Intrinsic
Government Support	7	<ul style="list-style-type: none"> Need for more hospitals and bigger wards Subsidized cost of care for poor families 	Extrinsic
Financial Burden	10	<ul style="list-style-type: none"> Cost of CT scans, lab tests and medications 	Extrinsic
Lack of medical Resources	16	<ul style="list-style-type: none"> Lack of CT scan or patient beds Lack of adequate transportation to hospitals and ambulance Power outages in operating rooms 	Health System

Physician Support	6	<ul style="list-style-type: none"> • Poor communication amongst physicians and with caretakers • Physicians attending to patients needs urgently • The need to save a life first before demanding money 	Health System
Receiving Care			
Financial Burdens	18	<ul style="list-style-type: none"> • Buying medications and paying hospital bills • Lack of medication, surgical equipment and scanning machines in hospitals 	Extrinsic
Government Support	6	<ul style="list-style-type: none"> • Need for affordable healthcare • Use taxes paid by citizens to provide adequate healthcare 	Extrinsic
Lack of Medical Resources	12	<ul style="list-style-type: none"> • Lack of scanning machines and inconvenient visit to pharmacies to buy drugs • Physicians don't have medical resources to work with 	Health System
Emotional Challenges	3	<ul style="list-style-type: none"> • Stress from raising money and navigating the healthcare system 	Intrinsic
Physician Support	3	<ul style="list-style-type: none"> • Putting the patient first before medical bills • Prescribing expensive drugs and supplies 	Health System

Table 1: Caretaker Health Literacy Factors and Key Points within the Three Delay Framework

4.2 Theme One - Intrinsic Factors

4.2.1 Navigation Skills

Caretaker health literacy is influenced by a myriad of factors inherent to their ability to discern health information and navigate the healthcare system in order to ensure their TBI patient receives adequate care. *Navigation Skills*, a sub-theme within *Intrinsic Factors*, encompasses the skills caretakers use to pursue medical care for their patients. *Navigation Skills* is the most recurring factor in this theme within the seeking care delay category. These caretaker skills important in seeking care from the moment the patient injury occurs and will often determine the

patient's health outcome. In the case of road traffic accident, victims are typically unconscious and the responsibility of seeking care therefore falls on caretakers, who are often family and community members. Many caretakers seek out and rely on the public transportation system to get their patients to medical care as reflected in the quotes:

“Immediately [after] the accident, he lost conscious completely, we rushed him to the Health Center and we used a motorcycle...From Apala Hospital to Kampala we used a bus and a motorcycle to reach here”
(Seeking Care)

“On getting information of the accident, we rushed him on a motorcycle to nearby a clinic, but they just offered first aid and advised us to take him to a hospital...” (Seeking Care)

Some caretakers mentioned that the need to raise money in a short amount of time impacted their ability to easily navigate the healthcare system and reach care for the TBI patients.

“Due to lack of money, we could pull money amongst ourselves to buy the prescribed medicine” (Receiving Care)

“The accident victim had no money on himself, neither [did] we relatives. We had to look for money for hospital bills and transport, this factor initially delayed him receiving health care at earliest.” (Receiving Care)

Caretakers also explained having to move from one clinic or hospital to another due to referrals, severity of the TBI, or lack of medical resources as a perceived reason for delays in reaching adequate care as shown in the quotes:

“We took him to Kasana Health Centre, Doctors gave him medicine, but it never helped to reverse his condition. He fell again and developed some paralysis in the leg, I took him back to Kasana Health Centre, but the problem persisted, and we decided to take him to Bombo Military hospital with hope that they would manage the problem and when no improvement was observed, we decided to take him to Kiruddu Hospital-Mulago branch.” (Reaching Care)

“We sought health care in our village clinics, but were unable to detect the problem, until the situation worsened. We decided to take her to a good private clinic” (Seeking Care)

“We moved him from hospital to hospital, we could not get a health professional to diagnosis his problem early enough” (Receiving Care)

Few caretakers did not know where to receive help or where to find the victim after the accident and this resulted in the delay of healthcare delivery for the patient, as reflected in the quotes:

“We failed to know, where he could get the required health care at first, the friends who picked him from the accident scene sought he could get some help from the clinic”(Seeking Care)

“I failed to hear well the name of the place, where the incident occurred and failed to locate the victim for assistance very fast” (Seeking Care)

Caretakers navigational skills impact their ability to assess their environment and healthcare system in a time sensitive manner in order to ensure their TBI patients reach care. Their ability to take actions and make care decisions on behalf of the patient is affected by multiple factors within and beyond their control.

4.2.2 Understanding of Health Information

The ability for caretakers to understand health and disease information impacts the level of care they can provide TBI patients. Caretakers’ processing health information and using that information to seek out care for the patient was a prominent theme in the interview responses.

Some caretakers had a better understanding of the patients’ health status and cause of illness and could then use that understanding to make decisions about the course of action for patient care, as reflected in the following quotes:

“At Kiruddu Hospital- Mulago branch, [the patient] was referred to Mulago here for an operation, that he had an intestinal obstruction, on reaching here, consultants found out that it was not the problem, instead they told us do a CT scan of the head”
(Seeking Care)

“The blood clot in my mother’s head was noticed, after they did a CT scan on her head at mount Elgon hospital, as the main cause of her condition and we were advised, it needed an urgent operation.” (Seeking Care)

“He fell again and developed some paralysis in the leg, I took him back to Kasana Health Centre, but the problem persisted, and we decided to take him to Bombo Military hospital with hope that they would manage the problem and when no improvement was observed, we decided to take him to Kiruddu Hospital-Mulago branch.” (Seeking Care)

4.2.3 Emotional Challenges

Caretakers faced several emotional challenges that made it difficult for them to carry out their role and process information to help care recipients. Many of them expressed feeling exhausted, confused, anxious and occasionally unwell from the rigorous experience of caring for TBI patients.

“I never went to Nakasero hospital to [the patient], my son and daughter went with him. I was too exhausted” (Reaching Care)

“When a patient remains there, the bills continue accumulating, every week we were paying two million and every time we have borrow, borrow and borrow from everyone to meet the expectations, it is very stressful and people get tired of us.”
(Receiving Care)

“After learning about the patient’s accident] I immediately experienced loss of sense [and] confusion...until I composed myself” (Seeking Care)

4.3 Theme Two - Extrinsic Factors

4.3.1 Government Support

Many caretakers reiterated the need for strong support from the government in order to assist them in their roles. Most caretakers also expressed the importance of having access to better transportation and equipped hospitals as the government's responsibility in order to help them better navigate the healthcare system, reduce delay times and improve patient outcomes, especially during the process of reaching and receiving care. Some caretakers expressed dissatisfaction with transportation in the country and called on the government to make the process of seeking care easier, as reflected in the quotes:

“The Government should provide transport facilities in the hospitals to help in transport.” (Reaching Care)

“The Government should work on the traffic jam issue in Kampala and neighboring districts, so as to ease movement of patients in critical need of fast health care” (Reaching Care)

Caretakers also mentioned that government support is essential in improving the quality of care hospitals provide and making their caregiving roles easier by providing resources within the hospital to minimize the time it takes to reach and receive care as shown in the following statements:

“The Government should at least put machines required and professional Doctors in hospitals to ease suffering of patients” (Receiving Care)

“The Government should put all required medicine in this hospital, this will help many patients to get immediate care. Most patients get these accidents, when they do not have money for care, fail to get care...Patients can be charged

later, after saving their lives and sell their assets to pay for the hospital bills.” (Receiving Care)

Two caretakers recognized road traffic accidents and robberies as the main reasons for TBI and viewed government action as a feasible way to mitigate this issue in their communities and reduce the cost of care, as reflected in the quotes:

“In our villages, roads are too narrow, while riding on the sideways of the road, one is likely to be knocked by a vehicle, I urge the Government to make bigger roads to reduce such accidents” (Reaching Care)

“The Government should provide security to its people and investigate these cases with the aim of arresting these perpetrators to be prosecuted in courts of laws without fear or favor.” (Seeking Care)

Caretakers also deemed it the government’s responsibility to ensure better access to hospitals in the country to allow patients easier access to care and prevent the time and transportation delays in reaching care, as shown in the quotes:

“The Government should also increase on the number of hospitals which handle cases of the head injury to reduce congestion in Mulago Hospital and ease service delivery.” (Receiving Care)

“The government should have functional machines in place here, instead of Doctors telling us to take patients to Nakasero and also stock medicine in the hospital” (Receiving Care)

“I would advocate for appropriate health care and machines in our regional referral hospitals and the Government should adopt it, because being here caring for the patient is costly and everything need money.” (Receiving Care)

4.3.2 Community Support

Caretakers expressed the need for strong community support in order to assist them in seeking and reaching care for their patients. Many deemed it important to have members of their immediate community aware of TBI symptoms and prepared to assist victims of RTIs in reaching care due to its severity of as shown in the quotes below:

“I may say sensitization of the community about accidents and other things on how urgently to seek health care for head injury cases” (Seeking Care)

“The public response to emergencies when such incident happens is still low, our communities still have I do not care tendencies, unless the victim is known to them”(Seeking Care)

“The community should also be sensitized on how to prevent and care for head injury accidents, because they are costly to treat due few Doctors and machines” (Receiving Care)

Some expressed gratitude for kind community members who sought care for their patients when caretakers were unable to and contributed financial and emotional support in times of need. Overall, caretakers saw the presence and actions of community members as important in ensuring their patients had positive health outcomes after a TBI:

“Family members and friends had to pull money to buy fuel for the ambulance, and other expected costs, as we would be directed by the health care professionals.” (Reaching Care)

“We had no money, we started contributing for this cause, but our good friends came for his rescue and we managed to raise money for a salon car hire, but it took us some time to pull together the required sum and caused the delay.” (Seeking Care)

“There was no major delay, because after the incident kind people rescued them fast from the scene of the incident” (Seeking Care)

4.3.3 Financial Burdens

The cost of seeking and receiving care was a prominent theme throughout the caretaker interviews. Most caretakers experienced significant financial burdens when seeking care particularly with transportation costs such as using an ambulance or private and public transportation that led to the delay in reaching care, as expressed in the quotes below:

“There was no transport like an ambulance to bring my brother here, and getting money for public transport was another barrier which delayed us, until we reached here after three days.”

(Seeking Care)

“We had issues of money and to do a scan, it costs a lot of money and even we did not have transport to take the patient to Nakasero. When we got money, we took him late”

(Reaching Care)

“The [patient] had no money on himself, neither were we relatives. We had to look for money for hospital bills and transport, this factor initially delayed him receiving health care at earliest.” (Receiving Care)

Some caretakers also experienced significant financial burdens when reaching and receiving care such as the high cost of referrals, medications and obtaining CT scans and had to fundraise or borrow money in order to meet the health care costs of their loved ones as shown in the quotes below:

“I had to order the sell my goats in the farm to raise money to buy medicine after the operation, for my patient” (Receiving Care)

“Buying drugs also pose a challenge to getting health care so quickly” (Receiving Care)

“We were informed that we need to do a CT scan of patient’s head...we could not do it fast, because we had to pay for this service and we did not have the money at hand by then”

(Receiving Care)

“We could be told to buy expensive medicine which is not in hospital and at times money is not readily available, it would

require us to look for the money and this would delay treatment.”
(Receiving Care)

4.4 Theme Three - Health System Factors

4.4.1 Physician Support

Most caretakers identified physicians and other medical personnel as key players in helping them navigate healthcare for their loved ones. They mentioned the need for strong physician support in order to help them with understanding and processing complex health information in order to care for the TBI patients as shown below:

“If Doctors from upcountry hospitals can advise traumatic brain injury patients and their family members to seek appropriate health care from professionals early enough, it would reduce such delays like this one.” (Seeking Care)

“If, I come from a remote village upcountry, [physicians] should be able to help me and understand my situation” (Receiving Care)

Some caretakers experienced poor physician support and expressed their dissatisfaction in their interactions with medical personnel throughout their time in the hospitals. Some had received incorrect information from the physicians and others had mentioned that physicians misdiagnosed patients and made errors during treatment, leading to confusion, delays in receiving care and allowing caretakers to incur more expenses, as reflected below:

“It has taken us more than two months for Doctors in our area to diagnose his problem, we have really wasted a lot of money not treating the very problem.” (Receiving Care)

“We moved him from hospital to hospital, we could not get a health professional to diagnosis his problem early enough and we get him appropriate health care from specialists who would manage his problem.” (Receiving Care)

Some caretakers had positive experiences with the medical personnel and appreciated their efforts in helping their patients despite the resource poor setting and conditions of the ward, as expressed in the following quotes:

“I appreciate the work done by health professionals here in Mulago to save life, amidst scarcity of essential medical requirements.” (Receiving Care)

“Doctors and all medical team have worked hard and helped us so much to save my husband’s life!” (Receiving Care)

According to some caretakers, the absence of physicians at the time of need led to delays in receiving care for TBI patients as shown in the following quotes:

“We reached at causality [ward] late in the night and a few medical officials were available to give her first aid, until the next morning when Doctors came for duty.” (Receiving Care)

“Most of time, night health care officials on duty sleep too much, at times we have to come here and knock when the patient is in need of attention and we cannot manage it on our own.” (Receiving Care)

“The health center and Hospital where we took him first had no professional Doctor...to examine his head problem and this delayed his diagnosis and eventually we had to be referred to Mulago here” (Receiving Care)

Some caretakers were not satisfied with the way medical personnel handled patient care and deemed that some of them neglected their patients. Some noted that physicians were not cognizant of the financial burdens they faced and did not communicate health information properly when needed, as shown in the quotes below:

“There was a lot [of] relaxation among the health care personnel to clear his way for an operation. I do not know what was happening, but the process was slow according to my analysis.” (Receiving Care)

“This might delay her healing process, because when Doctors direct you to buy medicine and you cannot afford, they simply bypass your patient.” (Receiving Care)

“[doctors] simply give you an ambulance without fuel and we had to organise to fuel it to bring the patient here.” (Reaching Care)

“There was a power outage...two doctors at the causality department hesitated to work on our patient and said they do not work in darkness. After pleas and many requests, they agreed to work on him” (Receiving Care)

4.4.2 Lack of Medical Resources

Many caretakers emphasized that there is a lack of adequate medical and healthcare resources that make healthcare delivery and navigation difficult. They reported that the absences of functional medical equipment (such as CT and MRI scanners) and laboratories for testing leads to the delay in receiving care for the patients, as shown below:

“We know this is a Government hospital, why do you we have to go to Nakasero hospital for a CT Scan? This situation delays the patient from receiving health care.” (Receiving Care)

“The Doctors, said they were not with the machines to check his head and referred us” (Receiving Care)

One caretaker noted that while there are physicians who are able to treat patients, their capabilities are limited by the lack of medical resources needed to properly attend to them.

Another explained that the congested ward and lack of beds led to delay in receiving care, as shown in the two quotes:

“Doctors here have no problem and they are capable of what they are doing, but they do not have what to use, no medicine, no requirements, they tell you we do not have

gloves, they do not have medicine but the Government has money!” (Receiving Care)

“The first set back which we faced was lack of a bed for a patient, but we managed to see one Doctor, who prescribed and wrote medicine to buy.” (Receiving Care)

Some caretakers noted that the lack of a fully stocked pharmacy in Mulago National Referral Hospital has led to delays in receiving care since they have to travel to private pharmacies to buy important medications for their patients. This is often unexpected for many caretakers and they are forced to raise money and buy medications on short notice, consequently causing delay in receiving care as exemplified in the quotes below:

“The hospital does not have most medicines, the reason we are told buy them for the patient outside. When they write for us medicine to buy, it needs money and the medicine is expensive, this delay care.” (Receiving Care)

“Most of the time essential medicines are always out of stock, we have to buy every medicine and other requirements” (Receiving Care)

“Except that we could be told to buy expensive medicine which is not in hospital and at times money is not readily available, it would require us to look for the money and this would delay treatment” (Receiving Care)

Some caretakers also mentioned that the ambulances provided by the hospital were either not readily available or were not fully equipped to handle patient transport and this consequently led to inevitable delays in reaching and receiving care, as shown in the following quotes:

“The ambulance was not available [when] we were instructed to take the patient...to do the scan” (Reaching Care)

“The ambulance to take him had no oxygen, the nurse had to move here and there” (Receiving Care)

Caretakers noted that there were hospitals and clinics throughout the country that were ill-equipped to properly manage TBI cases, and these hospitals were typically the first place they went to for patient care, as reflected in the following quotes:

“The first Clinic, where we took him could not handle his case, this delayed us to get him fast diagnosis” (Reaching Care)

“The health center and Hospital where we took him first had no professional Doctor and CT scan machine to examine his head problem and this delayed his diagnosis and eventually we had to be referred to Mulago here” (Receiving Care)

4.4.3 Access to Health Information

Caretakers emphasized the importance of having access to adequate health information about TBI and their patients’ health status in order to help them care for their patients. Lack of health information led to several delays in seeking and reaching care for some caretakers who were unaware of the severity of their patient’s injury or where to seek help, as exemplified by the following quotes:

“We did not know the right hospital and health care professionals to handle his case and this delayed diagnosis.” (Seeking Care)

“Lack of information about this incident, created hours of delay to seek health care” (Seeking Care)

One caretaker expressed disappointment that they were misinformed about the type of care their patient would receive at a government hospital like MNRH because patients were required to seek medical attention at other hospitals first before being attended to at MNRH. Another caretaker was not aware of their patient’s condition until several hours after the incident, as shown below:

“When we are there in our villages, we were told that there are government hospitals but when we reach here, we are told to go Nakasero to pay for the scan!” (Receiving Care)

“We are told he got an accident at around midnight and we were informed of the accident at 4am.” (Seeking Care)

Some caretakers mentioned that they were never given information from medical personnel on how to navigate care and this consequently led to the delay in receiving care for their patients, as shown in the following quotes:

“The problem we got, Doctors even in Government hospitals, never advised us on what to do and where to get professionals to manage his head condition. If Doctors can always refer patients whose conditions they cannot manage, it would help patients to get treatment and cure timely.” (Receiving Care)

“It has taken some months. I told you, at first, we took him to Kasana health centre and Bombo Hospital, but nothing was done and they never advised us for any referral to bring him here” (Receiving Care)

Caretakers deemed that the access to health information was fairly limited and mentioned that it was important for the members of the community to be given appropriate information about TBI, how to care for TBI patients and where to receive care immediately, as exemplified by the following quotes:

“The most important method is to sensitize the public about traumatic brain injuries, how to prevent them and in an event of such incident the public should be informed on where to take the patient.” (Seeking Care)

“The community should also be sensitized on how to prevent and care for head injury accidents, because they are costly to treat due few Doctors and machines” (Seeking Care)

5. Discussion

This purpose of this study was to determine the factors that impact TBI patient caretakers' health literacy at Mulago National Referral Hospital, Uganda, and examine how these

factors influence the delays to seeking, reaching and receiving care. The study's findings show that there are nine factors that impact patient caretakers' ability to seek, understand, evaluate and utilize health information to assist their patients in obtaining immediate and adequate health care. Each of these nine factors: *Government support, Community Support, Financial Burdens, Emotional Challenges, Understanding of Health Information, Navigational Skills, Physician Support, Medical Resources and Access to Health Information*, fall within one of three broader categories: *Extrinsic, Intrinsic and Health Systems* factors. A better understanding of these factors and the circumstances that influence them will allow for future global health interventions to focus on supporting caretakers' health education and literacy due to their direct impact on patient care to prevent delays to care.

5.1 Caregiver Health Literacy and Seeking Care

Due to the nature of traumatic brain injuries (TBI), patients are typically unable to seek care for themselves and therefore rely on loved ones to do so on their behalf. This is exceptionally true in LMICs like Uganda, where relatives and friends occupy roles of primary caregivers for patients and first responders due to severe physician and nurse shortages and lack of a prehospital system. One study found that TBI patients are less likely to seek care if they are older, suffered a mild TBI grade or were injured in the home (Senik and Bazarian, 2009). Consequently, the burden of responsibility to seek care quickly for victims falls on the caretaker. As shown in the results, a caretaker's ability to carry out this role is affected mostly by their access to health information, financial burdens and community support.

In order to process and partake in the decision-making process of seeking care, caretakers must first have access to accurate information about the health issue, where to find help and who can provide care. This study found that their access to information is heavily dependent on the ***Health System Factors*** (*Physician Support* and *Medical Resources*) and not their level of health literacy. Caretakers rely on physicians and other medical personnel to provide health information on how to manage the patient's condition and where to obtain tests and scans and medications. Caretakers in this study have expressed that their need to have access to health information for TBI patients has been largely unmet due to negligence by or absence of medical personnel. This argument is consistent with other studies that have found caretakers information needs are neglected due to poor communication by hospital staff which consequently leads to delays in seeking care for patients (Longacre, 2013). Some studies have stressed the use of the health care team to spearhead the availability of health information delivery systems for caretakers to ensure they are able to access care seeking and care management information (Washington et al, 2011).

Since caretakers may not always be available at the time of the accident, they rely on members of the community to seek patient care on their behalf. The need for community support is crucial because TBI patient caretakers are often not able to navigate care seeking on their own or with the help of their patients. In many instances, caretakers depended on other relatives or friends to bring the care recipients to the hospital and raise money for ambulance transportation, medications and costs of CT scans. This social support system is important for the caretaker's emotional wellbeing and can serve as a stress reliever during the rigorous care seeking process. Studies have found that health literacy of caretakers is impacted by their social network as they will draw upon the health literacy skills of others to seek, understand and use health information

(Edwards et al. 2013). Lack of support from the community is highlighted in this study as an important extrinsic factor that contributes to delay in seeking care especially when caretakers are unable to do so themselves.

Study findings present *Financial Burdens* as the most significant factor that affects caretaker health literacy when seeking care. The cost of seeking care is found to be a deterring factor due to the significant financial barriers it presents. These burdens are typically cost of transportation and the initial cost medical evaluation, which can prevent caretakers from seeking treatment for their patients in the first place. Zafar (2015) argues that there is a need for improved cost-related health literacy so that patients and their caretakers are made aware of the potential costs of care in order to make timely decisions on the most cost effective approach to care seeking. Hospital administrators and physicians have a role in ensuring that low-income caretakers are financially supported throughout the care-seeking process by providing resources and treatment that are affordable to prevent delays.

A caretaker's *Navigation Skills* also plays an important role during care seeking. The ability to look for and make decisions on where to receive care and the best means to get there requires adequate navigation skills. Many caretakers reported difficulty in finding health care facilities due to transportation barriers and lack of knowledge, causing delays in seeking care. Caretakers' ability to maneuver their way through large and complicated health systems will directly impact TBI patient outcomes especially in time sensitive situations. This study's findings have shown that navigation skills are impacted by the presence or lack of medical resources as caretakers have encountered difficulty in seeking care due to limited basic healthcare amenities such as emergency medical services, ambulances, laboratory tests and

scans. Therefore, there is a need to improve access to these medical resources to help improve caretakers' self-efficacy and diminish delays in care seeking.

While caretakers' understanding of health information and emotional challenges played a less significant role in seeking care in this study, there is still need for support from community members and physicians to assist caretakers to cope and manage the stress from their caregiving role (Yeun, 2015). There is also a need for physician support while seeking care by improving communication with caretakers and providing them with resources needed to make care seeking tasks more feasible (Yeun, 2015).

5.2 Caregiver Health Literacy and Reaching Care

Studies have shown that delays to reaching care are typically exacerbated by travel and transportation barriers which lead to poor patient outcomes and increased mortality (Syed, 2013). This study's findings posit that *Financial Burdens* and *Lack of Medical Resources* are the two main caretaker health literacy factors that directly influence caretaker's ability to reach care for TBI patients. Caretakers have expressed that the lack of medical resources within an already complex health system makes reaching care difficult, after they have sought care. The main medical resource emphasized in this delay is the lack of an adequate ambulance system in place which prevents patients from reaching care and forces caretakers to use on other means transportation of which may be unreliable and increase risk of poor health outcomes. Patients with transportation barriers shoulder a greater burden of disease which may, in part, reflect the relationship between poverty and transportation availability (Syed, 2013). This relationship is seen in the way public and private transportation present their own costs and caretakers are

required to pay out of pocket. The amount of time needed to raise money to afford transportation to the hospital is the main reason for delays in reaching care. Work should be done to find avenues to mitigate transportation barriers and support caretakers in reaching care for their patients.

Physician and government support are practical support systems that can assist caretakers in reaching care. The demands of the health care system in this setting requires caretakers to encounter difficulty in reaching care on time due to multiple referrals or inability of hospital staff to care for patients. This delay is further exacerbated by transportation barriers (e.g. bad roads) or the cost of transportation (e.g. fueling an ambulance or paying for public transportation). Physicians that lobby with the government for improved EMS can help address this delay by actively engaging with caretakers throughout the care reaching process. One study estimated that about 45% of deaths and 35% of disability-adjusted life years can be addressed by developing robust emergency care systems in LMICs (Kobusingye et al, 2006). Consequently, government support can involve strengthening health systems by providing emergency medical resources and cheaper means of reaching care and implementing national programs and policies to improve health literacy (Nutbeam et. al, 2018).

It is important to highlight that the only intrinsic caretaker health literacy factor in this delay is and emotional challenges. This suggests that delays to reaching care are caused by health literacy factors beyond the caretakers control and emphasizes the need for strong government and physician support system in place to assist caretakers reach care on time.

5.3 Caregiver Health Literacy and Receiving Care

After reaching care, TBI patients require urgent medical attention depending on the severity of injuries. As shown in this study's findings, the delay in receiving care is primarily attributed to the caretaker's *Financial Burdens* and *Lack of Medical Resources*. Financial Burdens in this delay manifest as cost of medications pre and post-surgery, cost of CT scans, hospital bills and cost of surgical materials such as gloves and gauze. The cost of CT scans in Uganda typically range from \$70-\$132, which can be the average monthly income of households in Uganda (Kuo et al, 2017). This shows the likelihood of catastrophic expenditure just from imaging and scans alone. These findings are also consistent with that of other studies that show how the costs of receiving care in LMICs often involve buying some expensive surgical materials and supplies which increases the financial burden of receiving care.

A 2010 study by Kushner and colleagues found that district hospitals across many African countries had under-equipped operating rooms and lacked essential medical and surgical supplies. This lack of infrastructure translates to increased financial burden for caretakers and requires them to spend time raising money to cover costs, leading to delays in receiving care. One study in Mulago Hospital, Uganda found that 5% of TBI patients failed to receive surgery due to infrastructural limitations, 33.6% of patients waited more than four 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 several financial barriers (Kuo et al, 2017). Many of the barriers and financial challenges caretakers face can be addressed with adequate government intervention. Due to lack of scanning and laboratory equipment at Mulago Hospital, caretakers are forced to take their patients to the private Nakasero Hospital, about 3 km away, to obtain

head CT scans needed for surgical decision making. Arranging transportation to and from Nakasero hospital increases delays and prevents patients from receiving care urgently. There is therefore a strong need for federal action to provide financial support to caretakers and provide medical resources in public hospitals, especially during this stage of care, to ensure access to quality care for vulnerable populations (Tang et. al, 2004).

Lack of physician support was also noted as a barrier to reaching care. This is exemplified by the need for caretakers to pay hospital bills, provide certain medical supplies or undergo tests and scans at other hospitals before physicians could attend to their patients, contributing to delays in receiving care. In order to mitigate the delays in receiving care, the caretaker needs a healthcare provider who is cognizant of their financial challenges and engages in various strategies to assist him/her to understand, compare and contrast, and make decisions about health information (Yuen et al, 2015).

The stress from navigating the very complex healthcare system can take a toll on caretakers' emotional wellbeing and affect their capacity to process health information. Consequently, caretakers will continue to rely on community and physician support to help address issues that may arise when receiving care. One study posited social work liaison programme, long-term follow-up and peer support as promising approaches to enhancing coping for families of TBI patients (Verhaeghe, 2005).

5.4 Implications for Further Research, Policy and Practice

Findings in this study have examined how various intrinsic, extrinsic and health system factors pertinent to caretakers health literacy influence the delays to care. Findings from this

study can be used as baseline information to measure the direct impact these health literacy factors have on patient outcomes. It will also be important to measure patient outcomes with respect to the three delays. Future studies can examine how interventions focused on improving government, community and physician support for caretakers can improve TBI patient outcomes. With the strong emphasis on financial burden across all three delays, further research can focus on finding ways to mitigate delays through interventions that reduce cost of care when seeking, reaching and receiving care. Steps should be taken towards improving caretaker's access to health information and ensuring they are equipped to provide care for TBI patients throughout the care continuum. Future studies can work to create conceptual framework models that highlight other factors that influence caretaker health literacy in order to better understand how these factors affect patient care. There is also potential for future research to examine the factors that influence both critical and interactive health literacy which focus on more advanced health literacy skills that are strongly influenced by social determinants of health.

Health literacy is a concept that can be used by policy makers to support a full spectrum of policy positions that will increase public engagement in health decision-making (Nutbeam et al, 2018). This can have a negative effect by shifting the burden of improving health from the state to the individual. Therefore, policy makers must pay attention to the health education needs of patient caretakers brought up in this study such as improved access to health information, financial and psychosocial assistance. A potential route for impact would be federal assistance in improving transportation services throughout the country to overcome transportation barriers that delay reaching care. Caretakers remain at the forefront of healthcare delivery and are important stakeholders in patient care, especially in LMICs, consequently, allocating funding resources to

interventions that support them as they navigate complex health systems will potentially improve patient outcomes.

5.5 Study Strengths and Limitations

Being the first of its kind, this study's findings allowed for development of hypothesis that can be the basis of a larger and more representative sample. Since most caretakers present the ward were interviewed, the sample captured the broad experiences and perspectives of TBI patient caretakers in Mulago Hospital. More importantly, this is the first qualitative research study focused on evaluating the influence of caretaker health literacy factors on delays to care for TBI patients in an LMIC setting. One limitation of this study was that the nature of the interview questions focused mainly on the negative experiences of caretakers in the care continuum. Hence, some participants could have felt their responses reflected poorly on the government, physicians and hospital staff, particularly in the receiving care delay where the caretakers described issues within the hospital and health system that prevent patients from receiving care. However, no information given could be connected to specific care providers.

Another limitation is the lack of perspectives from patients and physicians who are also key players in healthcare delivery. Understanding their perceptions of care, health literacy and delays to care will help to create a holistic viewpoint for factors affecting delays to care in Uganda. There is also a potential to have these perspectives extend to the other two regional referral hospitals conducting neurosurgeries for TBI, Mbarara and Gulu in western and northern Uganda respectively. These two locations could present other caretaker health literacy factors not captured by participants in at MNRH. This limitation could be mitigated through the continuation of this ongoing study with new data from patients and their families.

6. Conclusion

Caretaker health literacy is influenced by several intrinsic and extrinsic elements that are affected by socioeconomic, community and individual factors. This study's findings show that most of the actionable work needed to reduce delays in care for TBI patients falls on extrinsic and health system factors (financial burdens, physician and government support) that influence caretaker health literacy. Governments should invest in improving transportation systems and access to medical services particularly for low income caretakers for whom monetary challenges are a deterrence to seeking care. Another area of improvement would be to focus resources on making the process of seeking, reaching and receiving care affordable and investing in public health education. Additionally, providing strong support systems to encourage caretakers will involve addressing the intrinsic health literacy factors (emotional challenges, navigational skills, and understanding of health information). Healthcare workers can assist caretakers in seeking and understanding health information and actively engaging with them throughout the care continuum to avoid delays. A key understanding of how health literacy of caretakers impacts delays to TBI patient care is crucial for the development of contextually and culturally relevant interventions targeted at improving their ability to navigate the healthcare system. It will also assist the state and policy makers in tailoring health education and communication strategies to caretakers health literacy needs.

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Appendix A

IDI Guide: Patient Surrogate

Section A:

Description of interview

Today, I will be asking you questions about delays and barriers that [*relationship of patient to surrogate*] experienced during the time after the incident that ultimately caused their 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 [*relationship of patient to surrogate*]?

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

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

Where did the incident occur?

What was [*relationship of patient to surrogate*] 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 [*relationship of patient to surrogate*] 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 [*relationship of patient to surrogate*] 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 [*relationship of patient to surrogate*] 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 the decision was made to seek medical intervention, what delays and/or barriers did [*relationship of patient to surrogate*] experience while reaching care?

Reaching care refers to the time interval after [*relationship of patient to surrogate*] made the decision that he/she needed to pursue medical intervention and then ends at the point of first contact with a healthcare 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 healthcare professional was made, what delay(s) and/or barrier(s) did [*relationship of patient to surrogate*] experience while receiving care?

Receiving care refers to the time interval of first contact with a healthcare 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 [*relationship of patient to surrogate*] 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.