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The state of the referral system and how this influences maternal healthcare in the Kabarole district, Uganda

A playground for inequality and corruption

Msc thesis

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SUMMARY

The referral system was introduced in line with the decentralization of the healthcare system in Uganda and should distribute the burden of disease among the different levels. Healthcare was supposed to become more accessible for Ugandans. However, the referral system can be labelled as dysfunctional in many respects. A lack of trust from the care-seekers' perspective, non-functionality of the health facilities, limited transportation possibilities at the time of referral and an incomplete registry which makes the accountability almost non-existent. The result of all this is a high amount of self-referrals which create a barrier for improvement. As long as the self-referrals are not reduced, it is hard to change anything within the functionality of the referral system.

Different hierarchies seem to influence the functionality of the referral system as well. A distinction can be made between hierarchies in the healthcare system and social hierarchies. The former includes hierarchies between private and public facilities and hierarchies between public facilities itself. Both promote self-referrals because they imply that the lower level facilities are not as good as the higher levels. The latter includes hierarchies between men and women which limits the possibilities of women to receive the necessary care; hierarchies between women themselves, which reinforces bribing practices and promotes inequality within the healthcare system; and hierarchies between health workers and patients, which promotes inequality and decreases the trust of mothers in the healthcare system. All the hierarchies reinforce the dysfunctionality of the referral system, mainly because the mother loses her trust and the lower level facilities are being downgraded.

Multiple issues are observed as causes for the dysfunctional referral system. This dysfunctionality requires methods of coping from the health worker as well as the patient. For the health worker the non-functionality of many health facilities and the absence of doctors reduces the possibilities for referral and leaves her with a large responsibility. The mothers tend to adopt an accepting attitude with regard to the dysfunctionality of the referral system. They do not see possibilities for improvement and try to make the current situation most bearable. Only through self-referrals can they express their influence.

Corrupt practices are also a consequence of the dysfunctional referral system. The number of self-referrals due to the dysfunctionality causes congestions at the hospital. This creates opportunities for the health workers to take advantage of the situation. They have the

luxury position of working in a hospital which provides all the necessary care. Because of the congestion, they cannot provide the necessary care to everyone in time. This means that those who are willing to pay can receive the care first. At the same time, the corrupt practices also reinforce the dysfunctionality of the referral system.

The functionality of the referral system changes the level of quality care in the same direction; if the functionality is improved, the quality of care will improve as well. The functionality is largely restricted by several bottlenecks which result in self-referrals. Inequalities in the form of hierarchies play a big role in the level of healthcare mothers receive. Mothers appear to have a rather powerless position. They are confronted with dependency towards their husband first of all, and secondly with a dependency towards the health worker. Only money seems to be able to cause a change in this dependent position.

Health workers share positive experiences about law enforcement and good leadership. These two powerful variables can drive the necessary spoke into the wheel of the dysfunctional referral system and improve the level of quality care delivered to the mother.

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Webale muno!

Anneloes Malgo

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TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

LIST OF PICTURES

LIST OF ABBREVIATIONS

ADHO = Assistant District Health Officer

ANC = Antenatal Care

CLD = Causal Loop Diagram

DHO = District Health Officer

HC = Health Centre

HMIS = Health Management Information System

HSD = Health Sub District

IPD = In-patient Department

MCC = Mother and Child Care

MDG = Millennium Development Goals

MMR = Maternal Mortality Ratio (nr. of maternal deaths/100.000 live births)

MoH = Ministry of Health

NGO = Non-Government Organization

NRH = National Referral Hospital

OPD = Out-patient Department

PNC = Postnatal Care

RRH = Regional Referral Hospital

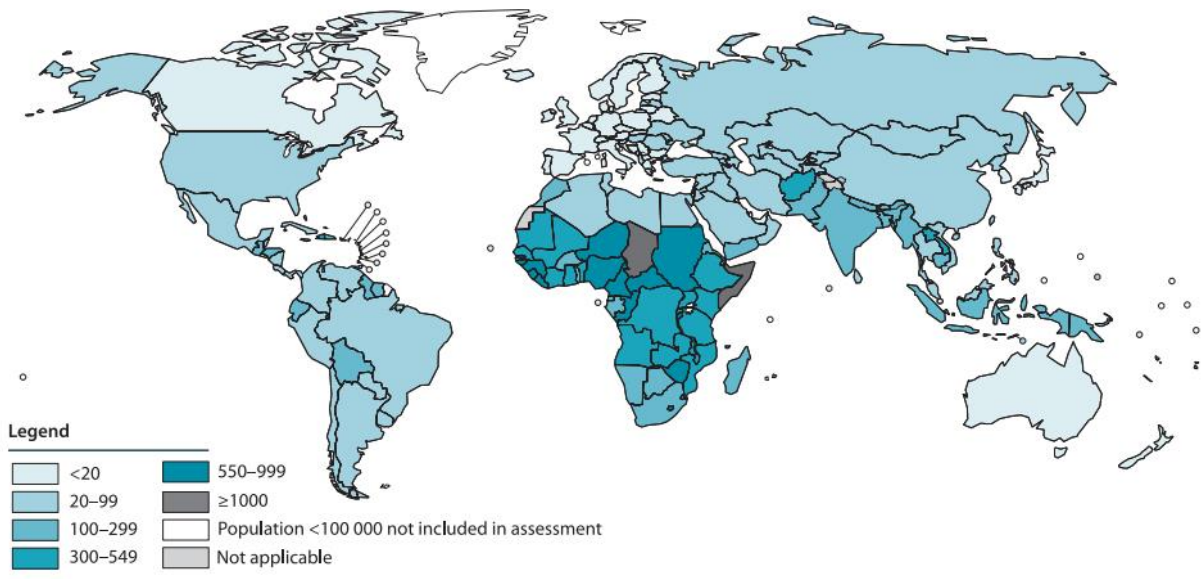
TBA = Traditional Birth Attendant

1 INTRODUCTION

This year marks the end of the Millennium Development Goal (MDG) period. The United Nations set up 8 development goals to be reached in the period from 1990 till 2015. Two of these goals, MDG 4 and 5, are related to maternal and child mortality. MDG 4 aims to reduce under-5 mortality with 75%, and MDG 5 aims to reduce the maternal mortality ratio (MMR) by 75% (UN, 2011). The WHO defines the maternal mortality ratio as the number of maternal deaths during a given time period per 100 000 live births during the same time period (2012). Both goals will not be reached in 2015, and despite noteworthy progress that has been made worldwide in the past 15 years, there is still a long way to go.

The MDGs focus on the world's developing regions which account for 284.000 of the total 287.000 maternal deaths worldwide. Of all maternal deaths in developing regions, 162.000 occur in sub-Saharan Africa (WHO, 2012). Figure 1 indicates the prevalence of maternal deaths worldwide; the more intense the colour, the more maternal deaths per 100 000 live births.

FIGURE 1: MAP WITH COUNTRIES BY CATEGORY ACCORDING TO THEIR MMR, 2010



SOURCE: WHO, 2012:23

Also child mortality is a complex issue in developing regions. The MDG 4 focuses on under-five mortality, but the most vulnerable period is the neonatal period - the first four weeks of

life. The yearly amount of neonatal deaths is stated to be around 3 million, of which 99% occurs in low- and middle-income countries and of which at least one third are estimated to find death within the first day of life (Rwashana et al., 2014). Many intervention programs to combat child mortality focus on for example repeated vaccinations, diarrhoea, malaria and other important issues (UN, 2011; Rwashana et al., 2014). Despite their necessity these interventions all focus on the death risk after the first month of life, while it is often especially the first day that the determines the life or death of the neonate.

A significant amount of research has been done on both the high neonatal as well as maternal mortality rates, and they often result in the same line of arguing. The women who receive adequate care often receive it (if at all) at a too late stage, rather than the clinical care not being sufficient at the moment of treatment. Many of the deaths are thus caused by emergency obstetric complications and could be treatable if the non-clinical influences would function properly (e.g. Mbonye et al., 2007; Musooko et al., 2014; Pacagnella et al., 2012).

1.1 Research question and objectives

There is a great need for research concerning the organizational capacity of the quality care delivery in developing countries. Delivering quality care demands two important capacities: organizational and technical. The technical capacity contains all biomedical aspects of quality care. The knowledge and skills. The organizational capacity thus contains all non-biomedical aspects of quality care. The management, the administrative power, the human resources, equipment supply, possibilities for referral and much more is included in this aspect. Questions have been raised about the effectiveness of certain biomedical interventions, types of treatment and knowledge transfers while ignoring the other side of the coin. Western loans and grants are distributed among the leaders of communities, but what happens with this money? New treatments are introduced, but can patients accept these treatments within the boundaries of their religion? These kind of questions need to be raised to make a long-term and lasting change in the healthcare system of developing countries.

An important subject of analysis when looking at the organizational capacity of maternal healthcare in Uganda is the referral system. The referral system is a crucial part of the health system and its functioning influences the delivery of quality care. The objective of this research is to understand the dysfunctionality of the referral system in Uganda and find

out how this influences the delivery of quality care. The following question will be central to the research:

What is the influence of the functionality of the referral system on the delivery of quality care to local women in the Kabarole district (Uganda)?

The following sub questions were dealt with in chapter 5, 6 and 7:

1. How is the referral system intended to function and what goes wrong?
2. How do inequalities on different levels in Uganda have an influence on the referral system?
3. What are the consequences of the dysfunctional referral system?
4. What is the position of 'the referral system' in an analysis based on the systems thinking approach for the quality of maternal healthcare in Fort Portal?

The purpose of the research is to find explanations for the dysfunctionality of quality care delivery in relation to the malfunctioning referral system that is in place. Houweling et al. state that the survival of any child in the world in the first month is mostly affected by *'wealth, education, caste and access to health care'* (2014:436). According to them the challenge in upgrading mother and child care (MCC) is based on social change, and not on technical interventions. The current research focusses on these non-technical influences through grasping an understanding of the constraints of the referral system which poses a limit to the quality care delivery for pregnant women in Fort Portal.

1.2 Maternal healthcare related context in Uganda

With a Total Fertility Rate (TFR) of 6.7 birth/woman the population in Uganda is growing. IndexMundi (2012) estimates that only Qatar, Zimbabwe and Niger have a higher population growth rate than Uganda, who thus takes the fourth place in the list of countries ranked in order of their population growth rate. The present poorly functioning health system does not have the resilience to cope with the ever expanding population (MoH, 2010). The maternal and child health conditions in Uganda account for 20,4% of the total burden of disease. This is the highest contribution to the burden of disease.

Uganda experienced a significant reduction of the MMR in the period ranging from 1990 till 2010. It decreased by 47%: from 600 towards 310 deaths per 100 000 live births (WHO, 2012). However, the total number of maternal and neonatal deaths a year is still unnecessarily high. The lack of access to effective, quality care throughout entire Uganda is a major cause for this problem. A positive relationship between poverty and access to healthcare can be distinguished (Peters et al., 2008) which unfortunately targets the largest share of Uganda's population. Thus the poor and vulnerable in this low income country in sub-Saharan Africa suffer from a disproportionate burden of disease, due to restricted access to quality care.

Health services in Uganda are provided through public and private operating facilities. The provision of public health services are free since march 2001 (Nabyonga-Orem et al., 2008) and are delivered through the following hierarchical referral pathway:

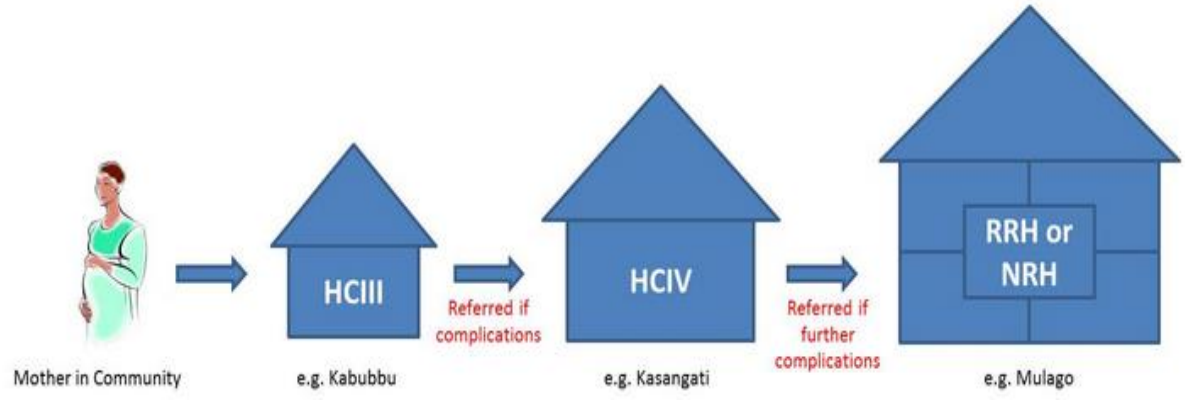
1. HC (Health Centre) I
2. HC II
3. HC III
4. HC IV
5. General Hospital
6. Regional Referral Hospital
7. National Referral Hospital

Every health unit within the referral system (from HC II till the NRH) should theoretically be able to deal with basic emergency obstetric complications. However, it appears from the 2011 annual health sector review that in the area of Kampala only 24% of the HCs were properly functioning. Some of the HCs did not provide any maternal care, while some provide only basic services with no functional theatre (LMP, 2015). The referral system in Uganda is not functioning as it is intended to. The different levels of the system are supposed to reinforce and complement each other. A woman should visit a certain health centre (HC), for example a HC III, that is accessible to her. Once she experiences complications she can be referred to the next level, which would be a HC IV or possibly a General Hospital in this case. If she experiences extreme complications she can be referred to an RRH (Regional Referral Hospital) or an NRH (National Referral Hospital).

The referral system embodies a hierarchy of quality care and research. The higher the level, the better the care. At least, that is how the referral system is experienced but it is not how it was intended, and that is the core of the problem. A high level is supposed to be able to deal with more complicated clinical cases, but the quality of offered care, the organizational capacity, should be the same at all levels.

Figure 2 depicts the regular procedure of a pregnant woman who seeks care. If she experiences complications, she is referred to the next level. If this referral pathway would function, it would enable women to access care in a nearby area instead of having to travel a long distance to reach a more upgraded health facility. Also, if functioning properly it would allow health workers to practice their profession as supposed to: without time, money and resource constraints. The state of many HCs is not as wished, which results in health workers who have to deal with complications for which they do not have the resources. Besides that, there is a tremendous shortage of human resources for health (Chen et al., 2004; Nabudere et al., 2011).

FIGURE 2: REFERRAL PATHWAY AS INTENDED

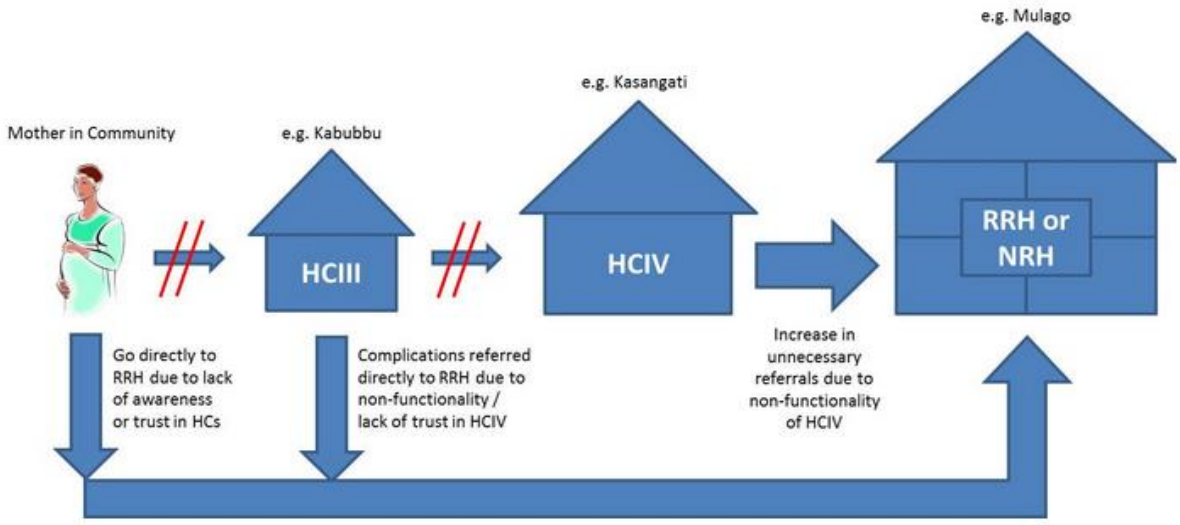


SOURCE: LMP, 2015

Figure 3 depicts the failing referral system. Many HCs are not functioning properly and therefore the mother has no choice but to by-pass them. In this case the mother does not have a choice; she simply cannot receive any care at the facility. Sometimes the mother does have a choice to go to a lower level facility, but she might not want to take the risk of not being able to reach the HC or arrive there to find that no one is available or capable of dealing with her issues. She takes the matter into her own hands and 'self-refers' straight

towards the hospital. Munjanja (2012) describes these self-referrals as a phenomenon taking place among *'women with means'*. Either way, the referral pathway is disturbed.

FIGURE 3: DISTURBED REFERRAL PATHWAY



SOURCE: LMP, 2015

The core of the problem is that women do not have access to the care they want and need which results in high neonatal and maternal mortality rates. It is a reinforcing loop: women do not trust the quality of the HCs and the referral system that should function if complications occur. Therefore they go straight to the RRH or NRH. The majority of hospital-based deliveries are not referred by a health professional, but are self-referrals (Pacagnella et al., 2012). Due to all the forced referrals and self-referrals it is difficult for the HCs to upgrade its functioning. It slowly downgrades and the problem worsens.

The cause for this problem in the referral system is a complex one and thus difficult to change due to several reasons. First of all a health system has a strong social and political character. Secondly, the health system consists of clear tangible (infrastructure, equipment supply) and intangible elements (health sector reforms, governance). Both these elements influence the state of being of the health system, but are not always easy to point at (Mavalankar and Raman, 2012). Thirdly, health systems are *'constantly coping and adapting to actions or changes in other parts of the system'* (Rwashana et al., 2014). All together, the health system is an interconnected mechanism that should be studied from a holistic perspective to grasp a full understanding of its functioning. Intervening in the system produces ripple effects and therefore a gap is often experienced between written down

policies and the actual implementation of those plans. The *'disparity between the theoretical hierarchical 'referral pyramid' and actual practice'* should be reduced (Pacagnella et al., 2012) to provide mothers with quality care. We should however not perceive the pathway as a single object of study.

1.3 Relevance of the research

Understanding the relationship between the state of the referral system and the final delivery of quality care requires a full understanding of what determines the functionality of the referral system. This research studies this relationship from a holistic perspective. In doing this it aims to find those variables which have a negative influence on the functionality of the referral system. This has both theoretical as policy-related relevance. If the negative variables are indicated and their position in the field of influences on the functionality of the referral system is understood, resolute and founded changes can occur. In perspective of the theoretical knowledge; chapter 2 describes how this research contributes to filling the existing knowledge gap,

1.4 Thesis outline

This thesis investigates the relationship between the functionality of the referral system and the level of quality care. After this introductory chapter, chapter 2 will provide the relevant theoretical knowledge and the knowledge gap is highlighted. Chapter 3 presents the research outline including a conceptual framework, an extensive methodology and a description of the main limitations. Following this comes chapter 4, where the Systems Thinking approach and the Causal Loop Diagrams (CLDs) are explained to be used for the analysis. Chapter 5, 6 and 7 are data-describing chapters. Chapter 5 describes what goes wrong in the referral system and how it is supposed to function; chapter 6 describes the observed hierarchies that influence the functioning of the referral system; chapter 7 describes how mothers and health workers cope with the current dysfunctional referral system and which role corruption and law enforcement play in this. All these chapters end with a reflection on what the NGO Baylor Uganda is doing with regard to the discussed topic. Chapter 8 analyses the data with the systems thinking approach by creating a Causal Loop Diagram (CLD). Chapter 9 discusses the findings in relation to the theoretical knowledge and to policy implications. All of this leads to the conclusion in chapter 10.

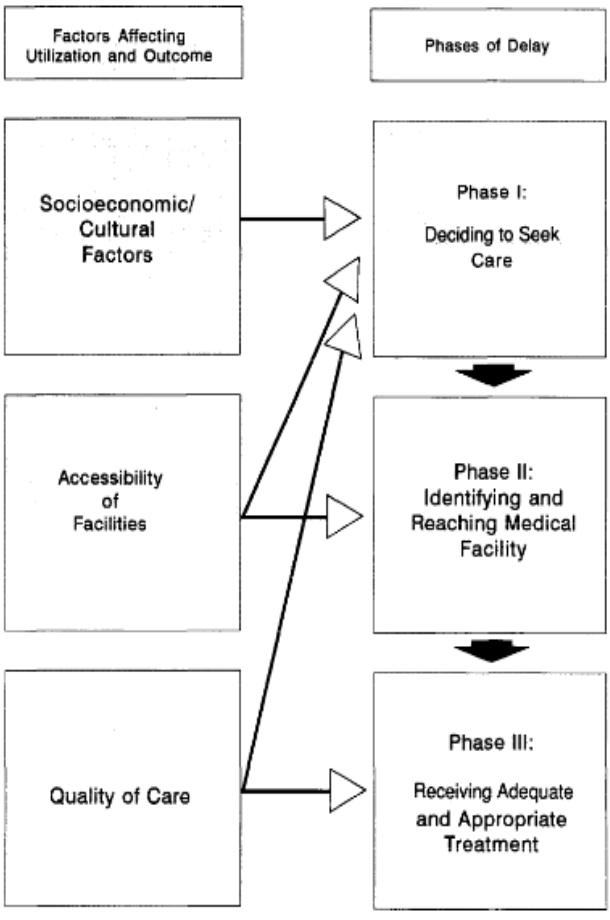
2 THEORETICAL UNDERSTANDING OF THE PROBLEM

Extensive research has already been done concerning maternal health and its bottlenecks in developing countries. This chapter discusses the currently available and relevant knowledge on the organizational capacity aspect of maternal and child health (in Uganda). The existing knowledge gap about understanding the relationship between the referral system and the delivery of quality care is identified.

2.1 The Three Delays framework

The Three Delays framework was developed in 1994 by Thaddeus and Maine. It is probably the most consulted model in respect of maternal and child health care. The framework is still useful today due to the unfortunate fact that emergency obstetric complications are still one of the largest causes for maternal and neonatal deaths. The framework explains maternal mortality in the context of emergency obstetric complications. This being a major cause for maternal deaths, the authors try to understand what happens in the timespan before the eventual complication or death occurs. If a patient receives care on time, the outcome is mostly satisfactory. Therefore Thaddeus and Maine (1994) conclude that a delay in being treated is the biggest reason for maternal deaths. They identify three phases in the decision-making process which can all three lead to a delay in receiving the necessary care.

FIGURE 4: THE THREE DELAYS FRAMEWORK



SOURCE: THADDEUS AND MAINE (1994:1093)

Phase 1 Delay: Decision to seek care

Phase 2 Delay: Arriving at health facility

Phase 3 Delay: Provision of adequate care

As figure 4 shows, the delays are affected by external influences. Phase 1 is influenced by socioeconomic/cultural factors of the care seeker, by the physical accessibility and affordability of health service and by the quality level of provided care. Once the decision is made to seek care, the actual arriving at the health facility is influenced by the accessibility of the facility. When a woman arrives at the facility, the cumulative effect of the phase 1 and 2 delays contributes to the number of women that reach the facility in a serious condition (Pacagnella, 2012). The level of quality care provided at the health facility determines if the patient receives adequate and appropriate treatment in time.

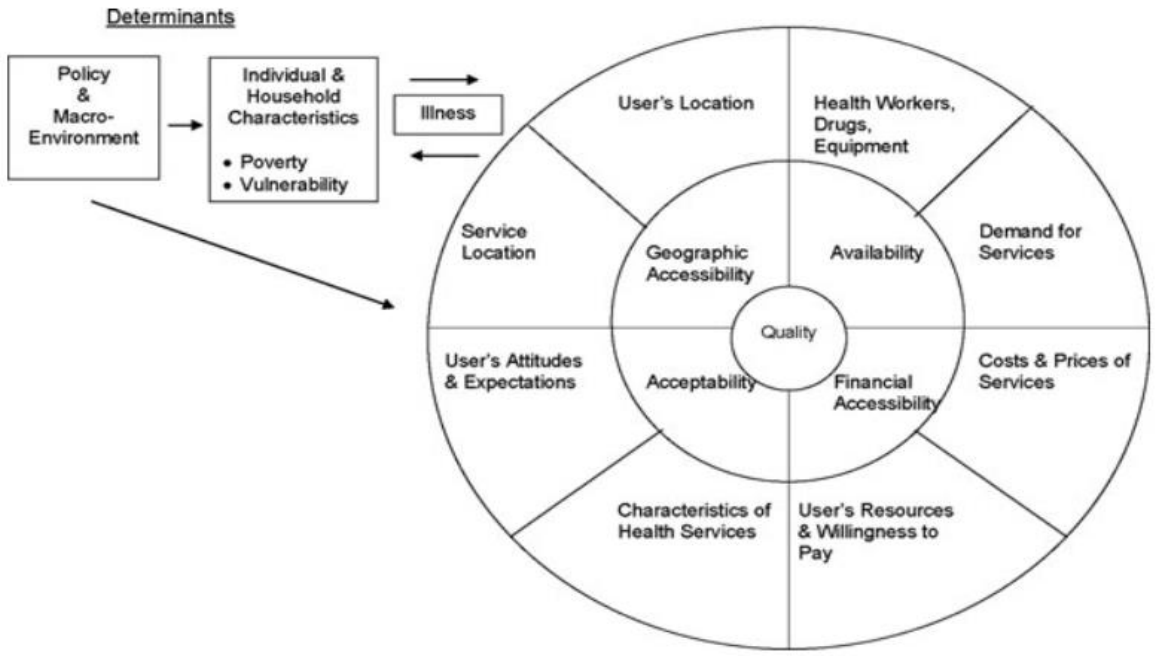
2.2 The Access model

Peters et al. (2008) designed a conceptual model to assess the access to quality care along four dimensions (figure 2):

1. Geographic Accessibility (physical distance and possibilities to bridge that distance)
2. Availability (necessary care is present – (human) resources, location, time)
3. Acceptability (relation between social and cultural values of users and of providers)
4. Financial Accessibility (prices of services and the possibility/willingness of users to pay)

All four dimensions are individually influenced by a factor from the demand side and a factor from the supply side. For example Geographic Accessibility is influenced on the demand side by the location of the user, and on the supply side by the location of the service. The Access model includes some distal determinants in the left corner (see figure 2). The policy and macro environmental level and the individual and household level both influence the access to health services and the eventual delivery of overall quality care (Peters et al., 2008). Furthermore it is explained that the poverty level of an individual is an important determinant in establishing that person's health needs, which they describe as 'illness'. So the level of illness interacts with the level of poverty.

FIGURE 5 THE ACCESS MODEL



SOURCE: PETERS ET AL. (2008:162)

The Access Model is developed in a similar line of thought as the Three Delays Model (Thaddeus and Maine, 1994) so they have some common ground. They both discuss if quality care is within reach for the care seeker and how this influences their decision-making and the eventual care delivery. The Access Model is however applicable to a wider variety of health contexts and does not only focus on maternal health. Also, the Access model tries to explain the relationship between poverty and access to health care, while the Three Delays Model tries to relate the high mortality rates to delays in receiving care.

2.3 Systems thinking approach

Rwashana et al. (2014) studied the complexity of stagnating neonatal mortality rates in Uganda. They argue that an integrated, holistic, systems thinking approach towards this issue creates opportunities to understand the underlying causes. Mapping the interlinkages in causal loop diagrams (CLDs) helps to find causal relationships and get to the core of the problem, instead of curing the symptoms which only results in reoccurrence of the problem. The complexity of the condition itself (maternal and child mortality) is placed in the system in which the condition is interacting and evolving (the health system). Rwashana et al. (2014) are the first ones to look at maternal and neonatal issues in developing countries by applying a holistic approach. The CLDs they created visualize the supply and demand side in maternal and neonatal healthcare in Uganda and both contain a lot of information. All

influencing factors are included; from maternal literacy to attending ANC and from funding for maternal healthcare to the motivation of the workforce. They linked all the different factors and described their relations to try and grasp an understanding of the underlying dynamics of the high neonatal mortality rates in Uganda. They make a first step towards creating a platform where the strategies to combat the visualized problematics can be addressed.

The holistic systems thinking approach takes a step back and tries to capture the whole picture. The health system has to deal with multiple different influences. Rwashana et al. mention *'the interactions between technical, policy, behavioural, and cultural issues'* (2014:12). The Three Delays framework and the Access model both focus on a part of the whole system: the delays as a cause for high mortality rates and the influences on access to healthcare respectively. The systems thinking approach applied by Rwashana et al. (2014) analyses all influencing aspects and tries to find the core of the reoccurring bottlenecks.

It is remarkable that in these gigantic CLDs the issue of referrals is only mentioned once. The influence on the referrals between health units is said to be 'Ambulances/Transport'. Furthermore a positive relation is denoted between 'Timely and adequate referrals between Health Units' and 'Maternal and Neonatal Healthcare Service Delivery' (Rwashana et al., 2014). Thus it is stated that improvement in the referral pathway will lead to an improvement of maternal and neonatal healthcare. In this research we zoom in on this causal relation between the referral pathway and the quality of provided healthcare. We aim to amplify this indicated relation by creating a new CLD. Chapter 4 elaborates upon the general systems thinking approach and chapter 6 presents our application of the approach with regard to the influence of the referral system on the level of quality care.

2.4 Knowledge gap

A knowledge gap with regard to the organizational capacity is distinguished. Concerning the position of the referral system in Uganda not much research has been done. The issue of 'a referral' is mentioned here and there, but it has not received notable attention. Beginning to fully understand the importance of organizational capacity and the role which the referral systems plays in this demands a focus shift in the current research paradigm regarding maternal and child healthcare issues in developing countries. The focus should be more equally divided between technical and organizational capacity.

Both Thaddeus and Maine's (1994) as well as Peters et al.'s (2008) framework contribute substantively to understanding the current problematic maternal and child health situation in Fort Portal (Uganda). They are relevant for this thesis, but the influence of the referral system on maternal and child healthcare cannot be analysed only by taking the delays and the relationship with poverty into account. They grasp the problem in a straightforward way and in doing this they tend to stay above the surface in understanding it. The models are both extensively used for analysis and cited in other researches. Even the Assistant District Health Officer (ADHO) and the programme manager of Baylor who were interviewed in this research mentioned the Three Delays. They were close to being rattled as the most important causes for the high mortality rates in the region.

The extensive use of a theory can mean that it touches upon an important reality, but it can be dangerous to fully depend on one perspective. It is important to stay critical and to keep asking questions. Rwashana et al. (2014) take a fresh step by applying the systems thinking approach to the neonatal mortality rates in Uganda. They aim to include all influences and understand their interconnections and consequences. As is said, the referral system (and the organization capacity in general) has not often been investigated. This research zooms in on the relation that is found in the CLD from Rwashana et al. (2014) between quality care and the state of the referral system.

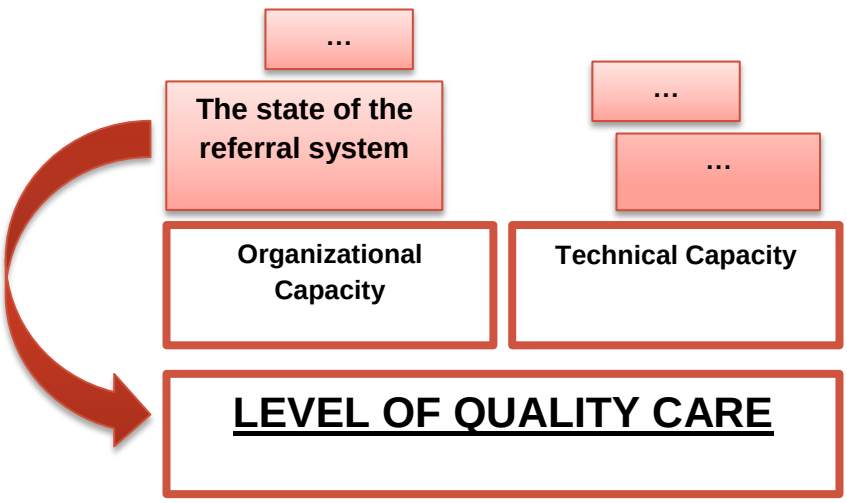
3 RESEARCH OUTLINE

After an extensive introduction into the Ugandan health system and a solid presentation of the most important and relevant theoretical knowledge, this chapter discusses the research outline. The research objective, as stated in the introduction, is to understand the influence of the referral system on the delivery of quality care to mothers in the area of Fort Portal (Uganda). First, the conceptual framework will be presented to visualize the research objective. Secondly a few important concepts will be operationalized. Thirdly the methodology will be presented including the research strategy, data collection description and an elaboration on the research area and research population. Fourthly the methods of data analysis are justified and the chapter concludes with a reflection on the main limitations.

3.1 Conceptual framework

The above discussed research objectives resulted in the following conceptual framework (figure 6).

FIGURE 6 CONCEPTUAL FRAMEWORK



The level of quality care is the centre point of analysis because it is the final product delivered to the care seeker. The level of quality care is determined by the organizational capacity and the technical capacity. They are visualized as two building blocks; together forming the level of quality care. The little blocks placed on both organizational and technical capacity represent the different aspects that the different capacities contain. For technical capacity this can for example be the present knowledge or the type of medication used. For

the organizational capacity this can be the amount of midwives in a HC or the communication between a health worker and a mother. This research aims to find out how the delivery of quality care is influenced by the referral system in place, this is mentioned in the conceptual framework as a building block for the organizational capacity as well. The conceptualisation shows how the state of the referral system has an influence on the level of quality care.

3.2 Operationalization of concepts

To prevent any confusion, this section shortly elaborates upon some main concepts.

- Different characteristics can be attributed to the concept *'quality care'*. This research interprets quality care as the result of adding *'organizational capacity'* and *'technical capacity'.* This is for example done by Nabyonga-Orem et al. (2008). They say that quality care consists of an observed/ technical element (defined standards of care), and of a perceived/ consumer assessed element (perceptions of users of health services).
- This research often mentions the term *'health workers'*. This is simply a short term to address both midwives and nurses. It does not include doctors or clinical officers.
- The problem central to this research (influence of the dysfunctional referral system on the quality care) is placed in a '*holistic'* perspective by applying the systems thinking approach. Holistic does not mean limitless and it is therefore important to add some boundaries. The focus is on those variables which influence the functionality of the referral system and how this relates to the quality of care.

3.3 Methodology

This section discusses several aspects of the methodology. First of all the research strategy will be outlined; secondly the data collection methods will be explained; thirdly and fourthly the research area and research population are elaborate upon.

3.3.1 Research strategy

The preparation phase of the research took place in the Netherlands in December 2014 and January 2015. During this time extensive literature and policy research was done and the

research proposal was written. Table 1 provides an overview of the research questions that were formed and the methods which were used to gather data.

TABLE 1: METHODS USED PER SUB QUESTION

What is the influence of the malfunctioning referral system on the delivery of quality care to local women in Fort Portal (Uganda)?	
Sub questions	**Methods**
1. How is the referral system intended to function and what goes wrong?	- Literature and policy research (preparation phase). Interviews with people on a policy level and interviews with health workers. - Analysis of the maternity register - Participant observation
2. How do inequalities on different levels in Uganda have an influence on the referral system?	- Interviews with mothers and health workers about their experiences with dependency relations and inequalities. - Participant observation
3. What are the experiences of mothers and health workers who have to cope with the referral system?	- Interviews with mothers and health workers. - Participant observation
4. To what extent can 'the referral system' be considered a cause in a systems thinking approach towards maternal healthcare in Fort Portal? And what are the consequences?	- Literature and data analysis

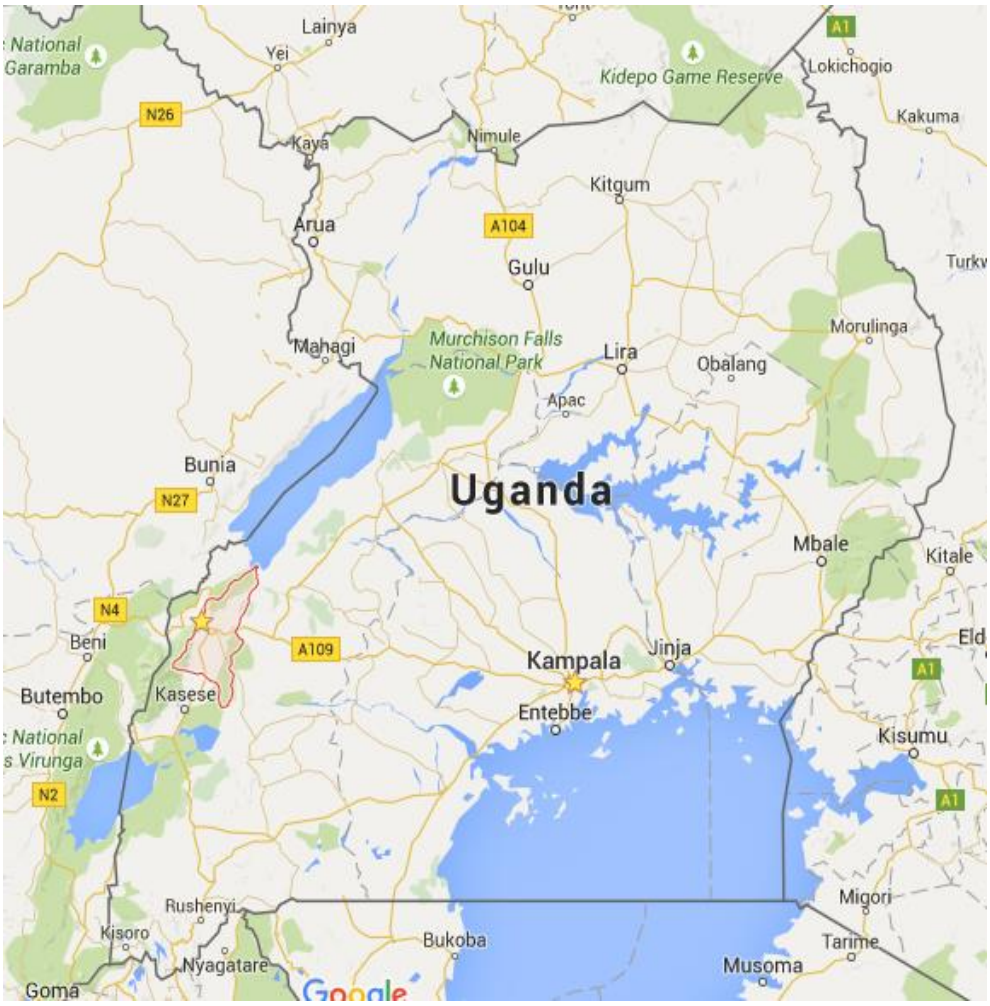
The actual data collection started mid-February 2015 in Fort Portal, Uganda. The research broadly consisted out of three phases.

1) Exploratory: participant observation and data collection from the maternity register
2) In-depth interviews with mothers
3) In-depth interviews with staff

3.3.3 Research area

The area in which the research was executed is the Kabarole district in Western Uganda (see figure 7). In consultation with LMP, the host organization, this area was considered to be interesting for this research. LMP recently started intervening in this area and some of its volunteers were placed there as well.

FIGURE 7: MAP OF UGANDA // KABAROLE DISTRICT HIGHLIGHTED



The Kabarole district in Western Uganda is a mountain region (next to the Rwenzori Mountains) and the population is diverse. There are people who live high up in the mountains and people who live in the city. This makes it interesting with regard to the maternal healthcare provision and especially to the referral system. Fort Portal is the capital of Kabarole and this was the base area from which the research was executed.

Figure 8 shows a more detailed map of the Kabarole district. On the left the Rwenzori Mountains are clearly visible. The three stars in the mid-section of Kabarole represent the

health facility where the participants were selected. The most left star is Bukuuku HC IV, the middle star is Kagote HC III and the most right star is Buhinga RRH.

FIGURE 8: MAP OF KABAROLE DISTRICT
STARS SHOW THE LOCATION OF THE RESEARCH UNITS: BUHINGA RRH, BUKUUKU HC IV AND KAGOTE HC III

3.3.4 Research population

The sampling methods with regard to the research population and the characteristics of the participants are described in this subsection.

3.3.4.1 Sampling

The research population consists of all the mothers in the Kabarole district. Random sampling is difficult, especially in (mountain) areas where complete registers are often non-existent or unavailable. Also time, money and logistical constraints played a role in this. Because of this the research participants were chosen by opportunity sampling which is a satisfying method for this qualitative research. As said before, it was tried to reduce the similarity in backgrounds of the participants by selecting them from different health facilities.

Three health facilities were included in this research. The first one is Buhinga Regional Referral Hospital (RRH), which is one of the 13 RRHs in Uganda and serves the districts Bundibugyo, Kabarole, Kamwenge, Kasese, Ntoroko and Kyenjojo. The second one is Bukuuku HC IV, which is a relatively functional health facility at the foot of the mountains. They serve many patients who live in the mountains. The third health facility is Kagote HC III, a small but functional health facility in Fort Portal town. The facility has recently been upgraded and is now delivering mothers in their maternity ward.

In both Kagote and Bukuuku the mothers who came for ANC visits were approached. In Buhinga this was more complicated. Eventually permission was granted to interview a limited amount of mothers in the postnatal ward. Entering the ward the mothers who were awake and not too worn-out from the operation were approached to participate.

Opportunity sampling was also used during the third phase: interviewing health workers. Multiple health workers from the included health facilities were approached. Those who were willing to make time for an interview were included in the research. Overall the most important target of the in-depth interviews was to gather thick and useful data. This resulted in some interviews of more than 90 minutes and some of barely 25 minutes. In general all interviews with mothers lasted between 25-60 minutes and all interviews with health workers lasted between 60-90 minutes. If a research participant was uncomfortable or unwilling to share useful information or simply did not have any experiences or interesting insights then there was no need to proceed.

3.3.4.2 Characteristics of research participant

This section shortly provides an impression based on characteristics of the mothers who participated in the research.

FIGURE 9: BAR CHART AGE PARTICIPANTS

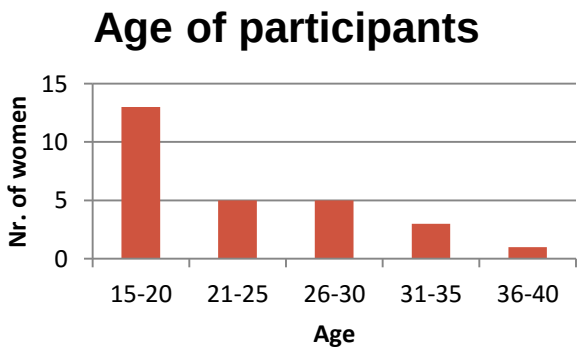
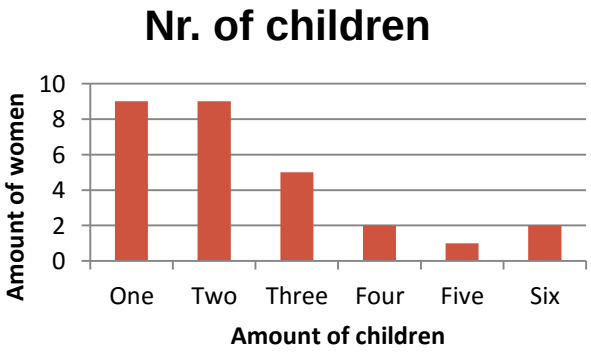


FIGURE 10: BAR CHART NR. OF CHILDREN



A total number of 28 mothers agreed to participate in the research. Their age ranges from 17 to 39, of which most women fell in the lower age category of 15-20 (see figure 9). Considering that 13 out of 28 participants were aged between 15 and 20 it is not remarkable that the largest share of them only had 1 or 2 children (see figure 10).

All the mothers who participated indicate to be religious. Figure 11 visualizes the different religions which are present among the participants. It is also interesting to take the highest level of schooling into account. As figure 13 shows, 16 out of the 28 mothers indicated primary school to be their highest level of education. This information relates to figure 12, which shows the different occupations of the mothers. The largest share (36%) says to be working in agriculture. This mainly contains women who work on the land of their husband.

FIGURE 11: RELIGION OF THE MOTHERS

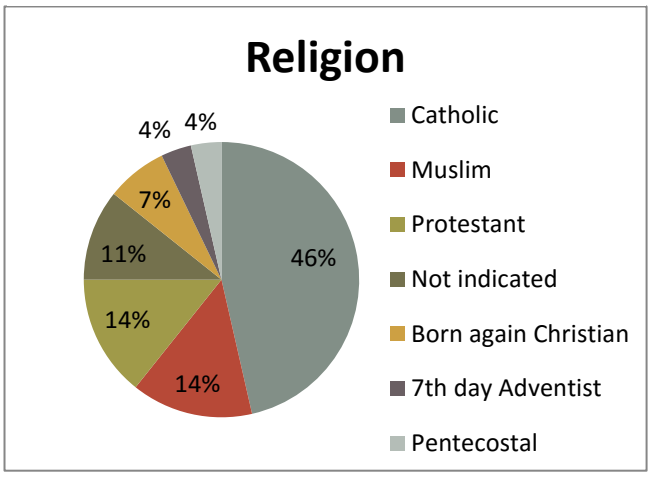


FIGURE 12: OCCUPATION OF THE MOTHERS

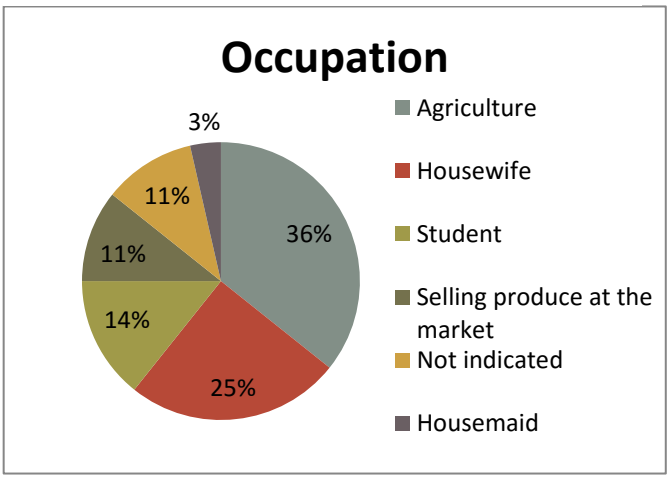
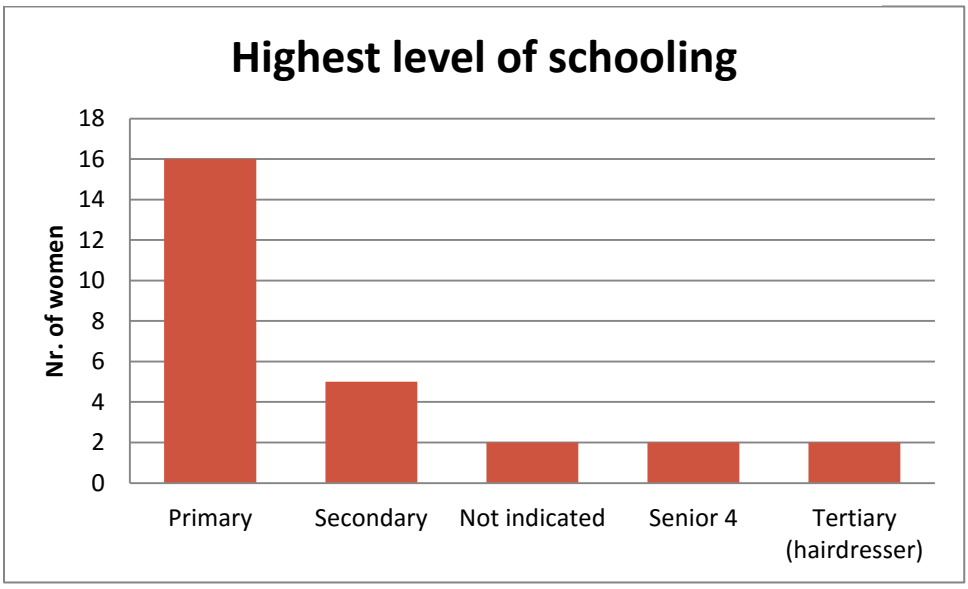


FIGURE 13: LEVEL OF SCHOOLING OF THE MOTHERS



3.3.5 Data collection

The first phase took place in Buhinga RRH. After asking permission from the hospital director the maternity ward from this hospital was accessible to study the maternity register. This exploratory phase consisted of seven days in maternity ward, mainly analyzing the registry books from all the patients that were received in the year 2014. The registry books provided useful information with regard to the referrals and created an impression of the factual numbers. Also participant observation was a large part of this phase. By spending a large amount of time in the hospital many issues with regard to the referral system and quality care could be closely observed.

The second phase of the research were the in-depth interviews with mothers. In the end 'the mother' was chosen as the unit of analysis because she is the receiver and seeker of maternal health care. We tried to include mothers from different backgrounds to vary the data and make the final conclusions more reliable. Because of this three different level health facilities were included: Buhinga RRH, Bukuku HC IV and Kagote HC III. In total 19 mothers were interviewed in Kagote HC III, 4 mothers were interviewed in Bukuku HC IV and 5 mothers and 1 couple were interviewed in Buhinga RRH. See appendix 1 to 3 for the interview guides.

The interviews aimed at gathering productive data to answer sub question 2 and 3 especially (see table 1). Therefore in these in-depth interviews it was tried to get as much information about the mothers' experiences with referrals as possible. It was discussed how they felt and if anything interesting popped up than this was immediately responded to and follow-up questions were asked. The interview guides were broadly organized around the '*range of nine priority areas - organisational, technical, and social-relational - which seem to be important for optimising the capacity of maternity referral systems in developing countries'*, outlined by Murray and Pearson (2006). The in-depth interviews in Bukuuku and Buhinga almost followed the same interview guides because their usefulness served the same objective (sub question 2 and 3). The interviews in Buhinga took a slightly different direction. All the women I spoke with were in the in-patient department in postnatal care (PNC) and just had a caesarean section. All of them entered Buhinga by means of a referral which asked for more follow-up on that. Also the issue of bribing health workers came forth in the interviews as an urgent topic and a large share of the time was dedicated to this as well.

The third and last main phase of the research consisted of interviews with health workers. After the interviews with the mothers and writing an interim report for which some preliminary data analysis was done, it made sense to include the health workers perspective as well. They are on the supply side of the referral system, but are also subject to the health system as a whole with all its rules and regulations. The prevailing inequalities and the bribing practices were already an outcome of the preliminary data analysis, but more information was necessary. To understand their influence on the functioning of the referral system required information from other participants than only the mothers. Four midwives were interviewed who are employed at Kagote HC III, two midwives and one neonatal nurse were interviewed from Bukuku HC IV, and one clinical officer was interviewed at Kagote HC III who is employed in Kyenjojo (the next district).

The registry analysis and the interviews with the mothers and health workers formed the main body of this research. Besides that three more interviews were held with people on a policy level. One interview was done with the assistant district health officer (ADHO) of the Kabarole district. She represents the Ministry of Health and operates under the district health officer (DHO) in overseeing the well-being of the health facilities in Kabarole. The second interview was done with a programme manager of Baylor Uganda, a large NGO operating in the Kabarole district as well. They intervene in the maternal and child healthcare with major consequences. The third interview was held with Christopher Ategeka, who is the CEO of 'Rides for Lives', an American organization which tries to influence the healthcare provision in Uganda. These three interviews provide information from above. They reveal how policy makers perceive the problematics around the referral system and how they try to change this.

3.4 Data analysis

After all the data was gathered in the field it was analyzed back home in the Netherlands. All the in-depth interviews were recorded on tape and were then transcribed to ensure inclusion of all information. The qualitative data analysis program Nvivo 10 was used to analyze the qualitative data (incl. the participant observation notes) which led to a coding tree. This coding tree formed the basis to structure the final thesis. It revealed the thick data about hierarchies and the stories about coping with the current state of the referral system. Also bribing turned out to be an important 'branch' in the coding tree.

The data from the maternity register was all sorted in Microsoft Excel. Some tables and graphs were made with this program to visualize the data gathered from a larger selection of the research population than only the research participants from the in-depth interviews. It was the intention to create maps using ArcMaps with this data. This turned out to be too complicated, due to the fact that the registered referrals-in in the maternity register were all from different administrative levels. Some health workers indicated the village and some the parish or the sub county. Only someone originally from the region can bring this all back to the same administrative level to enter it in the program.

3.5 Main limitations of the research

This final section of the chapter about the research outline discusses the main research limitations, to add some nuance and to justify the findings.

The first and foremost largest limitation is the fact that the research only targets 3 health facilities in one region of the Kabarole district. The analysis of the maternity register includes women from all over the district, but they are not included in the qualitative data gathering. Due to time, money, resource and logistic restrictions it was not possible to travel to different regions in the Kabarole district to find participants there as well. Due to the aforementioned constraints and to the fact that complete population registries are not available it was also not possible to select participants by random sampling methods. Despite these limitations, this does not imply that the found results are without value for the rest of Uganda or for comparable areas in other developing countries.

Another influencing limitation to the gathering of data was the congestion in Buhinga RRH. In the beginning it was tried to do questionnaires among the women who came for ANC in the OPD of Buhinga. After one day this was cancelled. There were too many women and there was no place where we could explain something about the research or make the women fill in the forms. It was decided that this would not provide useful data. At the end of the research period permission was granted to select research participants from the postnatal ward in the IPD. Here the limitation of congestion was also experienced. There were no possibilities to move to a private room, which resulted in interviewing the mothers behind the counter or by sitting on their beds. This might have influenced the topics we could discuss and the freedom mothers felt to share their experiences.

The final main limitation was the fact that the maternity registers are incomplete. The quality of the level of keeping up with the admissions completely depend on the person on duty. There seem to be no policies for this. Sometimes only a name was jotted down, while other admissions included all the necessary information. The admissions are recorded in big books, which means that sometimes it is unreadable or pages are missing. The data that was collected from 2014 includes only 9 months. The book which contained August, September and October was unfindable.

4 THE SYSTEMS THINKING APPROACH AND CAUSAL LOOP DIAGRAMS

Thorsen and Sundby conclude on the basis of multiple case studies in Malawi that *'if reducing maternal deaths were as simple as crunching numbers and implementing biomedical interventions to prevent them, all low-income countries, like Malawi, would reach MDG5'* (2012:1). They highlight the importance of the organizational capacity. Investing money, time and resources in biomedical interventions only is not going to save lives. This is the reason why we want to grasp a full understanding of the functionality of the referral system and its influences on the quality care delivery. It is useful to analyse the gathered data by applying a holistic systems thinking approach.

Roberts (1983) was one of the first to introduce the systems thinking approach. She used the Causal Loop Diagrams (CLDs) for computer simulation. Since then it has been used to analyse a wide variety of subjects, including for example the stagnating neonatal mortality by Rwashana et al. (2014). Basically *'what we want to do is to map part of the reality in such a way that it gives us a basic understanding of a complex issue'* (Haraldsson, 2000:13). By creating CLDs we can dive under the surface and discover the causal and interlinked relations and understand the relationship between the functionality of the referral system and the delivery of quality care. Often a certain problem is adressed based on its consequences. Without understanding and tackling the cause of the problem this is not long-term effective, because the consequences will keep reoccurring.

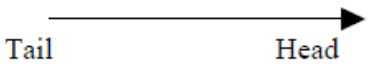
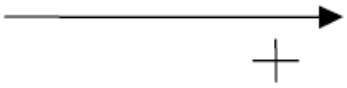
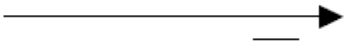
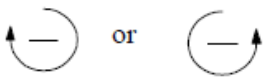
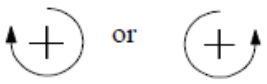
A central concept to the systems thinking approach are the aforementioned CLDs. They are the means to structure and conceptualize certain problems.

> *'Causal loop diagrams provide a language for articulating our understanding of the dynamic, interconnected nature of our world. We can think of them as sentences which are constructed by linking together key variables and indicating the causal relationships between them. By stringing together several loops, we can create a coherent story about a particular problem or issue'* (Kim, 1992:5).

All connections and feedbacks related to a certain issue are depicted in a CLD. Every CLD consists of two components; variables and influences. Variables are separate 'units' and the

influences are the links between these variables. A certain unit can influence another unit in the same direction, or in the opposite direction. Table 2 shows the symbols which are used to create CLDs and their meaning.

TABLE 2: EXPLAINING CLDs

Symbol	Meaning
Arrow  Tail Head	The arrow is used to show causation. The item at the tail of the arrow causes a change it the item at the head of the arrow.
	The + sign near the arrowhead indicates that the item at the tail of the arrow and the item at the head of the arrow change in the *same* direction. If the tail *increases*, the head *increases*; if the tail *decreases*, the head *decreases*.
	The – sign near the arrowhead indicates that the item at the tail of the arrow changes in the *opposite* direction. If the tail increases, the head decreases; if the tail decreases, the head increases.
	This symbol (also B), found in the middle of a closed loop, indicates that the loop continues going in the same direction, often causing either systematic *growth* or *decline*, behaviour that unstable moves away from equilibrium point. This is called a *positive feedback loop*.
	This symbol (also R), found in the middle of a closed loop, indicates that the loop changes direction, causing the system to *fluctuate* or to *move toward equilibrium*. This is called *a negative feedback loop*.

Source: Harldsson, 2000:20

Actions that take place can reinforce or balance the connected variable, which is called 'feedback' in systems thinking. Feedback means *'any reciprocal flow of influence'* (Haraldsson, 2000:9) and it is assumed that nothing is ever influenced in one direction only. The particular issue which is at stake in this research is the influence of the non-functional referral system on the delivery of quality care. Therefore a holistic approach will be applied to this issue by including all the variables, links and feedback loops and create a CLD in chapter 8. The systems thinking approach is applied because a lot of qualitative data was gathered throughout the span of the research. After analysing it with Nvivo and creating a coding tree it was found that there were many influencing and important variables who played a role. Creating a CLD maps all these variables and provides a clear overview of the influences of each variable separately.

5 DYSFUNCTIONALITY OF THE REFERRAL SYSTEM

The Western approach of the free market was widening its swath and international stakeholders expected Uganda (among others in the developing world) to adapt nationwide public sector reforms. Decentralization of the health system and the implementation of HMIS (health management information system) was one of the consequences. Due to their sudden top-down implementation the desired consequences (that took place in the developed world) did not come into being, and the health units seemed to be constrained instead of enabled. This chapter describes the current dysfunctionality of the referral system. First the intended functionality and the original vision behind it will be explained. Secondly the four main bottlenecks to the functionality are addressed. After this the issue of self-referrals is elaborated and at the end of the chapter attention is given to the work of the NGO Baylor Uganda.

5.1 Decentralization and its intended function

Decentralization of the healthcare system in Uganda was taking place to improve the delivery of services and it has been a major intervention. In 1993 the Ugandan government started the implementation of a health management information system (HMIS) which marked the beginning of the decentralization of the health system as part of the overall public sector reforms (Gladwin, 2003). The aim of the decentralization process was to promote democracy and enhance local participation in development (Hutchinson et al., 1999). The country was divided into Health Sub Districts (HSDs); the implementation levels within the district. They carry out planning and implementation, facilitate in-service training, coordinate service delivery and undertake supervision of lower level health units within their areas of responsibility. These HSDs are headed by an HSD referral facility, which is a hospital or upgraded Health Centre IV (Nabyonga-Orem, 2008; Hutchinson et al., 1999). As part of the decentralization to the health sub districts (HSDs) a transfer of power took place from higher to lower levels. However, this power transfer was not accompanied by the necessary financial means and thus the HSDs, until this day, still depend heavily on the central government.

The decentralization intended to assure a health system in which care would become more accessible for Ugandans. Better informed decisions could be made by health district

managers by using the HMIS and being closer to the issues at hand. The idea behind it is that all information can be collected in the same systematic way and all in the same system. All health units (public and private) collect, process and report routine data. Every health district can then reflect the national health policy through implementing interventions adjusted to the local needs. The problem experienced during the time of decentralization and HMIS was the absence of a realization that this was '*an introduction not only of statistical techniques, but also a new management approach with wider organizational consequences*' (Gladwin, 2003:220). The problem described by Gladwin proves how the organizational capacity is underestimated. Without a properly functioning healthcare system a nation cannot offer quality care to all its people. Not even if they have the newest technologies available and an infinite stock of medicines.

5.1.2 Different service delivery per health facility

As explained before, the health service delivery in Uganda operates through different levels. Table 3 describes the kind of service delivery that every type of health facility should offer according to the Ministry of Health. The VHTs (Village Health Teams) primarily focus on health education within the communities and assisting and advising village members.

TABLE 3 SERVICE DELIVERY BY LEVEL OF HEALTH FACILITY

Level of Health Unit	Target population	Services provided
Health Centre I (Village Health Teams)	1,000	Community based preventive and Promotive Health Services. Village Health committee or similar status.
Health Centre II	5,000	Preventive, Promotive and Outpatient Curative Health Services, outreach care, and emergency deliveries.
Health Centre III	20,000	Preventive, Promotive, Outpatient Curative, Maternity, inpatient Health Services and Laboratory services.
Health Centre IV	100,000	Preventive, Promotive Outpatient Curative, Maternity, inpatient Health Services, Emergency surgery and Blood transfusion and Laboratory services.
General Hospital	500,000	In addition to services offered at HC IV, other general services will be provided. It will also provide in service training, consultation and research to community based health care programmes.
Regional Hospital	2,000,000	In addition to services offered at the general hospital, specialist services will be offered, such as psychiatry, Ear, Nose and Throat (ENT), Ophthalmology, dentistry, intensive care, radiology, pathology, higher level surgical and medical services.
National Hospital	10,000,000	These provide comprehensive specialist services. In addition, they are involved in teaching and research.

SOURCE: MOH, HEALTH FACILITIES INVENTORY, 2012:1

The HC II's are focussing on preventive and curative outpatient care only. This means that they are supposed to have a small clinic, resources and staff present and the availability to provide emergency deliveries. From the HC III upwards all health facilities are supposed to

offer in-patient care; the possibility of admitting a patient overnight should be there. As can be read in table 3, the quantity of services increases when you 'move up' in the level of health unit. The quality is not supposed to 'move up' along with the level of health facility, because it is supposed to be good all along the line. Unfortunately this is not the experience of most women who participated in the research.

The division into health districts and health sub districts (HSDs) is accompanied with an equal division of health centres. Every HSD, for example, is supposed to have a HC IV and an ambulance. This is all mandated by the Ministry of Health (Interview Clin. Off. Kyenjojo, 2015; Interview ADHO, 2015). Every health centre is supposed to deal with basic emergency obstetric complications. A mother can go to the closest HC and receive the care she needs. In case of a complication the concerning HC can call the ambulance of the HSD and refer the mother to a higher level facility. The aim of the referral system is to distribute the burden of disease. Following the assumption that people go to the HCs that are linked to their village or parish, this will ensure that the burden of disease can be equally distributed among the health facilities. Only those people with severe issues will be referred to the referral hospitals which (theoretically) means that there will be enough time and resources available for those cases. The intention of the referral is to bring the health facilities closer to the mother.

This however, is not the case. HC III's are for example supposed to facilitate deliveries, but many of the HC III's do not have an in-patient department (IPD), and are thus not able to facilitate deliveries. Kagote HC III is a good example of a success story. Since the summer of 2014 the HC facilitates deliveries in their IPD. Before this they did not perform any deliveries at all so every mother who was in labour had to pass Kagote HC III and go straight to Buhinga.

5.2 Bottlenecks

The referral system in place is not functioning as it is intended to function. This section presents the observed bottlenecks experienced within the referral system. The referral system is a logical consequence of the decentralization process of the health system. All health facilities are arranged in a specific sequence to reach the biggest range of patients and distribute the workload. However, in practice this is not experienced by everyone as it was theoretically conceived.

5.2.1 Lack of trust

It was discussed with 16 mothers (or mothers to be) from different health facilities how they felt with regard to the possibility of being referred. Two mothers who visited Kagote HC III for antenatal care (ANC) indicated that they would go straight to Buhinga at the time of delivery to prevent a referral. A total number of 9 out of 16 mothers said that they were concerned about being referred and that they wished it could be prevented. The other 7 mothers told us that they were not feeling concerned because they know that if you are referred that it is necessary. The participants whom we spoke to at Bukuuku HC IV expressed their trust in the health facility. One mother said: *'I am not worried, because everything here at Bukuuku is in order'* (Interview mother Bukuuku 1, 2015). Bukuuku HC IV has been subject to many positive changes over the past years and the mothers expressed their trust in the health facility. Due to this trust the possibilities of referral have been minimized, but they still do not like the idea of having to be referred. One mother explained it as follows:

> *'I feel scared because when you see here that they can't manage you, and they are also very qualified people, then I feel scared about even where I would be referred to. It could not be a success'* (Interview mother Bukuuku 3, 2015).

From the 28 mothers who participated in in-depth interviews, 12 had a personal experience with being referred during a pregnancy or delivery in the past. From the remaining 16, who didn't have their own experience, 8 mothers could tell us stories about a close relative or friend who had been referred. Besides that, all 28 mothers said they knew *someone* who had been referred during her pregnancy or delivery. The possibility of creating a delay because of the movement between facilities and the likely extra costs that come along with this are the biggest reasons for mothers to feel insecure and concerned about the possible referral. They might need money for transport between the facilities, money for food, money for extra medication if it is not available at the new facility. The general anxiety which mothers feel when we speak about 'a referral' causes a negative association with the referral. This might lead to an unnecessarily high amount of women who decide to bypass the facilities which they do not trust. Kagote HC III is a good example of a health facility which is functional, but which some mothers might still pass at the time of delivery. Also a mother who was in Kagote HC III for ANC explained her wish of going directly to Buhinga when her delivery would start:

´I would go to Buhinga direct for delivery, instead of first moving to other health facilities where they will tell you: go here, go there. I would rather go direct to Buhinga. But again, if I am sure that at those health facilities that all the requirements are there then she would not go to Buhinga' (Interview Kagote 14, 2015).

5.2.2 No health workers, medication or other equipment

Some of the concerns expressed by mothers are not based on a negative association only. It is a fact that there are health facilities where a significant part of the basic necessities are missing. This can also cause referrals that would not have been necessary if the equipment was present. A nurse from Bukuku HC IV shares a story:

'When a mother has delivered, PPH [red: Post-Partum Haemorrhage, severe bleeding] *may occur, you pass an IV line and you do everything you can do, but then you don't have a scan here. It should be, but it is missing.* (…) *So you have to refer to just be sure that nothing goes very wrong. You send her to town, there everything she needs is present'* (Interview Nurse Bukuuku 1, 2015).

The issue of medication not being present was discussed with 14 out of 28 mothers. Eight of these 14 mothers have the experience of medication not being available when they needed it. This means that they have to go to the pharmacy themselves and buy the prescribed medication. This is often medication which is supposed to be available for free.

There is also the issue of health workers not being present at the health facilities where they are supposed to be working. A significant portion of the mothers and staff that participated in the research could share some experiences about this.

'You find here that sometimes a mother comes and you ask her: why are you coming all the way from Kicwamba? She tells you she has reported there at the HC but there was no midwife, and she even has bleeding after birth' (Interview Nurse Bukuuku 1, 2015).

If health workers are not on duty as they are supposed to, then this influences the decision-making process of mothers. They might decide to skip certain HCs. It simultaneously influences the referral process. A mother who delivered in Buhinga was referred there straight from a HC III, Kyanyambari.

'The reason is, at Kyegegwa they operate but the doctor is not there fulltime, he is not there 24/7. So you can go there and you find that he is not there. So only when he is there you can get an operation' (Interview Buhinga mother 6, 2015).

Officially a mother with complications should be referred from Kyanyambari HC III to Kyegegwa HC IV, which is the closest and next in line. This HC IV is supposed to have twenty-four hour theatre services and should thus receive referrals and be able to perform operations. In reality this HC IV is often bypassed because the medical officers who are supposed to perform the caesarean sections are not present. This specific case indicates that malfunctioning HCs do not only influence the mother's decision making, but it also influences the flow in the referral system. The health workers from Kyanyambari HC III do not even bother to send the mother to Kyegegwa HC IV first, because they know it is likely to cause a delay or even worse.

5.2.3 Transport in referrals

The transport between different health facilities at the time of referral is a major issue. A total of three ambulances is available for the district of Kabarole. Two ambulances are provided by the NGO Baylor College of Medicine Children's Foundation – Uganda (from now on this will be referred to as Baylor Uganda), and one ambulance is provided by the Ministry of Health (Interview midwife Bukuuku 2 and 3, 2015). If a health worker makes the decision to refer a mother, she can call for the ambulance to pick up the mother and bring her to a higher level facility. Due to the low number of ambulances, this can take a long time. Sometimes the ambulances might be just on its way to another place, or it might be stationed somewhere far away from the concerning HC.

Six mothers were interviewed in Buhinga after they had been referred and had a caesarean section. From these six mothers only two were transported to Buhinga by an ambulance. The remaining four women all came by boda boda, matatu taxi or walking. Two mothers were on a boda boda for 20 minutes, another mother was on the boda boda for two hours and the last mother travelled for 4 hours to reach Buhinga. She took a boda boda to the main road, then took a matatu taxi (public transport) to reach Fort Portal and then she walked from the matatu stage to Buhinga.

'Did they try to call an ambulance for you?

They just wrote me a referral note and told me to go. No transport arrangement was made' (Interview mother Buhinga 6, 2015).

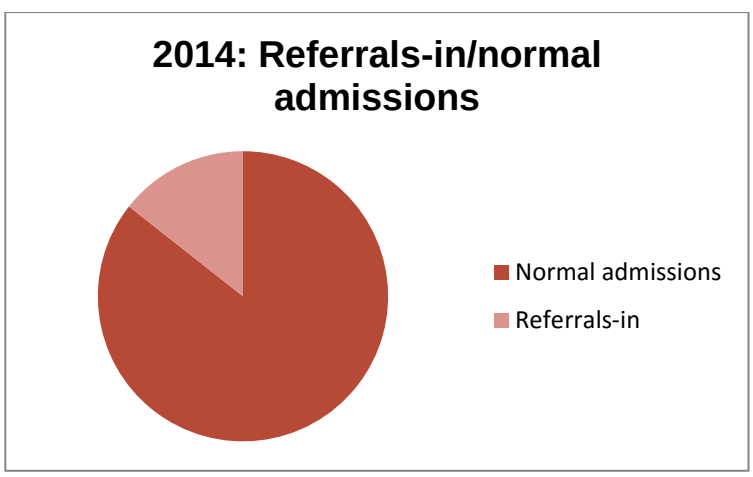
Being transported by an ambulance is definitely not the expectation of most Ugandan mothers. They assume they have to take care of their own transport, which is also a reason why they wish to prevent a referral. It can cost a lot of money, it can cause a serious delay and worst of all: it can cause death.

'She was referred when the baby was still alive. But due to the distance, the means of transport, by the time she had reached Buhinga the baby had died' (Interview mother Kagote 13, 2015).

5.2.4 Registry and accountability

As part of the research the registry books of the Maternity Ward (IPD) at Buhinga were studied and analyzed with a focus on the referrals that came in during the year 2014. The goal was to find all the registries from 2014, but unfortunately part of these books were missing. For this reason the months August, September and October 2014 are missing and the analysis has thus been made with the nine remaining months from 2014. It should be noted that the registry books are big, blank books which are filled in by hand by the midwives, nurses or students on duty. When a patient enters the ward she is registered by a person on duty and then she is assigned a bed or a place to wait. If it concerns a referral, *'Ref'* is written down somewhere next to the patients name. Depending on the person on duty, the place where the patient is referred from and the reason why is added as well. The register is unclear, incomplete and parts are missing. Nobody seemed to be concerned about this. The midwives and nurses did not think it was being used for anything important after all.

FIGURE 14: PIE CHART REFERRALS-IN 2014



In the nine months of 2014 that are part of this analysis, a total number of 5230 admissions were registered. Of these 5230 admissions, 752 were noted as being a 'referral in'. So on average 14,4% of the total admissions are mothers who were referred from other health facilities. For a Referral Hospital this seems to be a quite low percentage, considering the fact that a Referral Hospital is offering specialist services and higher level surgical and medical services (MoH, Health Fac. Inventory, 2012:1). Services are more upgraded and specialized to handle more complicated cases which are referred from out of the whole region. Buhinga RRH is responsible for the districts of Kabarole, Bundibugyo, Kamwenge, Kasese, Ntoroko and Kyenjojo. All the HC IV's in this region can refer the cases which they cannot deal with to Buhinga RRH. Due to the status of the maternity register books it is a realistic possibility that there are more referral cases than the above mentioned number, but these might simply not be registered.

If cases (whether referrals or not) are not properly registered, this impedes the possibilities to trace specific incidents. If it concerns a case of neonatal or maternal death and the impression is created that mistakes were made at some point within the procedure, than there is no possibility of keeping someone accountable.

> *'And even you will find that there are some units who have not documented anywhere that they have referred that mother. They don't document anywhere. So it becomes a challenge. But the referrals are there. The problem is that it now becomes very hard to trace them'* (Interview clin. off. Kyenjojo, 2015).

No-one can be held accountable, neither can anyone take responsibility for any act, because the documentation is very poor or non-existent. For example a number of 86 referrals (out of the 752) in 2014 were registered with no reason for referral at al. Even more remarkable is that 325 out of 752 were registered as 'in labour', or only 'labour'. This suggests that the communication between health facilities is also poor. What is Buhinga RRH supposed to do with a mother who arrives with a referral note which only says: *labour*, or has no reason for referral at all? It can be said that this does not improve the quality of care in any way, and if something goes wrong there is no-one to be held accountable.

5.3 Self-referral

All above discussed bottlenecks have a negative influence on the functionality of the referral system. An overarching consequence of these problems is that they cause self-referrals. Munjanja et al. defined a self-referral as a situation of '*by-passing, in which women with means avoid the lower level facilities and go direct to the district hospital as self-referrals'* (2012:144). Lack of trust in the lower level facilities causes mothers to by-pass these particular facilities and go straight to Buhinga RRH. They have not been referred by a health worker, but decide for themselves to take matters into their own hands and prevent a referral in case of a complication. And *'those ones are very very many'* (Interview Bukuku staff 2, 2015). A mother who delivered in Buhinga explained how she felt.

> 'Why do you decide to go straight to Buhinga?
> *'When I go to Kataraka, a HC IV, and maybe I spend many hours without delivering and then they have to push me towards a higher level anyway. It can be okay, but for me I feel it is disturbing, so I thinks it is better to come straight away'* (Interview Buhinga 2, 2015).

It is important to notice the distinction that Munjanja et al. make when they say that it concerns women *with means*, and not just any type of women. They ascribe referrals to women with means because it requires financial means to be able to go to the highest level health facility straight away. First of all, because instead of going to the nearest HC, which would keep transport costs as low as possible, they decide to move further away. Secondly, Buhinga RRH is a congested and crowded hospital. Waiting times are usually much longer, which involves money for food at the hospital. The differences between the women with and without means will be elaborated upon in the next chapter. Thirdly there can be costs involved in the form of a bribe when a woman decides to go to a high level facility. This will be elaborated upon in chapter 7.

Many mothers expressed that a referral was bad news. In Kagote the impression was raised of a functional health center where women felt welcome and safe. Even though a large share of the participants were positive about the services offered and how they wish they could deliver in Kagote, many of them indicated that they would probably go to either Buhinga, Virika Hospital or Kabarole Hospital (the last two are both private hospitals). The

mothers fear that something will go wrong and that the necessary competence or material is not available at Kagote. One of the mothers from Kagote HC III said:

> *'I would like to deliver from Buhinga because here they don't have equipment to operate the mothers in case of any problem, and by the time they could have an ambulance to bring you to Buhinga, you never know at that time you could have died. So I choose to deliver from Buhinga instead of here'* (Interview Kagote 15, 2015).

In the in-depth interviews it was discussed with the mothers if they saw room for improvement for the functioning of the referral system. From the 22 mothers whom this was discussed with, only 13 could mention specific problems which they wish could be improved. Six of these 13 women said they wished that all the lower level health facilities would have all the equipment in place and could perform operations in a theatre. The availability of a theatre would sooth the mothers worries about the chances of being referred at the time of the delivery.

> *'For example here in Kagote, it is a good health facility, good health workers, but there lacks one thing. They don't operate mothers. If they could maybe have services to operate mothers if they have complications, then it could be better'* (Interview Kagote 15. 2015).

But it is short-term thinking and not a realistic solution to provide theatres including the necessary equipment and personnel everywhere. It is however a nudge in the right direction of fulfilling the functionality of the referral system. Upgrading the lower level health facilities to their intended function *and* regaining the mothers trust in these facilities is crucial. A midwife from Kagote HC III explained the importance of this. She said: *'Every pregnant mother should be taken to a center 3 or 4 for ANC and deliveries. Then we can provide the care they need and reduce the big lines'* (Interview midwife Kagote 4, 2015). Mothers taking the extra time and money to go straight to Buhinga results in delays. Avoiding this will reduce the congestion and improve the quality of care.

5.4 Baylor Uganda and the functionality of the referral system

Baylor Uganda is an NGO which operates in the Rwenzori Region and other places in Uganda. They focus on reducing maternal and child deaths through supporting the existing structures in place from the Ugandan government. They intervene where necessary.

> *'As Baylor, we don't go down on the ground and do the work. It is more of supporting (…). But all this as a buffer, and not to suppress the Ministry of Health. There is already a system that supplies, but it is deficient. So we try to fill in those gaps'* (Interview Project Manager Baylor Uganda, 2015).

Baylor Uganda targets the challenges of the referral system for maternal health through different programs. They provided the district of Kabarole with two ambulances to enhance the functionality of the referral system. Baylor Uganda finds the gaps between what is necessary and what the government is supplying and tries to fill those. A need for ambulances is an important gap which they filled. There used to be various problems with the ambulances and their drivers which influenced the possibilities for referrals. Mothers had to pay the driver, or had to pay for fuel and the quantity of ambulances was also not enough. Still today there is one ambulance supported by the government. All the health workers included in this research said that they always called the Baylor ambulance first. Only if necessary would they call the government ambulance.

> '*Baylor simplified our work, but back in the days you would see that this mother is not going to deliver from the HC. You try to refer this mother: Please you have to go to a hospital because you cannot deliver from here because of such and such a problem. The mother looks at you and tells you: I don't have money for transport. So she goes home, looking for the money, sells what is at home and then comes back. She is getting worse, we stress as midwives, and the mother also gets stress. But when Baylor came, immediately when we have detected something bad, you can call and they send an ambulance (…). It has released our work very much'* (Interview midwife Kagote 1, 2015).

The ambulances are one way in which Baylor Uganda influences the functionality of the referral system. They can also intervene in human resources where they find a need. At the moment a neonatal nurse, employed by Baylor Uganda, is working at Bukuuku HC IV.

Another way in which they intervene is by constructing a brand new neonatal unit at Bukuuku HC IV. According to them it all depends on the need which they find in the Rwenzori Region and on the funding they get from international donors. They match those and invest in the most necessary cases.

6 THE INFLUENCE OF HIERARCHIES

There are several types of hierarchies which influence the functionality of the referral system in maternal healthcare in Uganda. A hierarchy implies that there exists an inequality within a relationship. Hierarchies can be found within differing contexts; social, economic, technical or political. The hierarchies that come forth through the research are elaborated upon in this chapter. First of all the hierarchy between public and private health facilities is explained, followed by a description of the hierarchies between the public facilities. After this the hierarchy between men and women is elaborated and also the different hierarchies between women themselves are explained. The last hierarchy is the one between health workers and patients. The chapter finishes with an elaboration on the work of Baylor Uganda that is focussed on reducing the hierarchies.

6.1 Hierarchy between public and private facilities

Health services in Uganda are offered through both public and private facilities. Private facilities are offered through the same decentralized system as the public facilities, except that they don't have Regional or National Referral Hospitals. Research shows evidence of a quality and efficiency difference between private and public health facilities in developing countries in favor of the private health facilities (Hutchinson, 1999). The public health facilities in Uganda are free. User fees have been abolished since 2001 to decrease the financial barriers to healthcare (Nabyonga-Orem et al., 2008). The private health facilities did not abolish the user fees, patients have to pay to receive care in any private health facility. A midwife from Bukuuku HC IV who used to work in a private health facility said:

> *'In private hospitals the patients pay, in Bukuuku it is free. The mothers are very different. In private clinics the mother who goes there can be rich. That is different from Bukuuku, here we can deal with mothers who have nothing'* (Interview midwife Bukuuku 3, 2015).

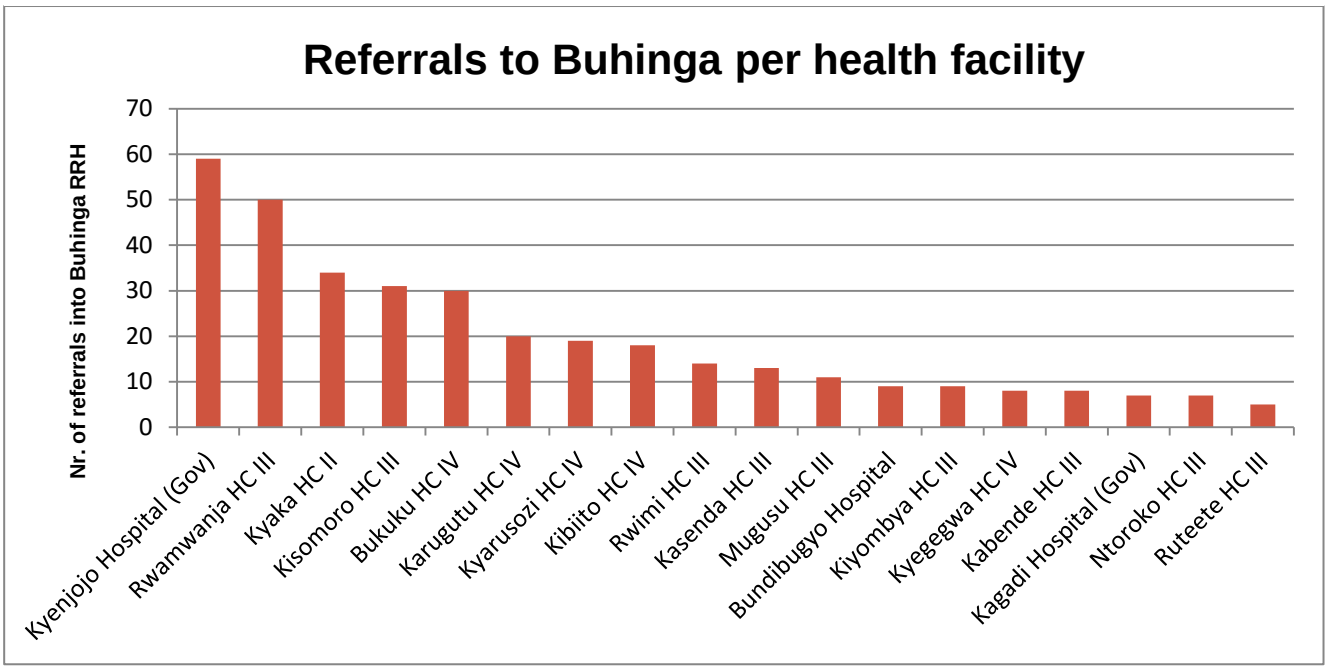
Another midwife from Bukuuku confirmed this statement. Buhinga is a Regional Referral Hospital, so it exceeds the general private hospitals. But she states that if a mother with sufficient financial means goes to Buhinga, it is only because she needs the specialized services:

´Those ones who are able to provide for themselves have already left Bukuuku and Buhinga and all. They go to the private hospitals like Virika and Kabarole. She can go to Buhinga because she maybe needs a specialist and she has no choice, then she only goes there for that and not because it is free service. And she probably will be going to Buhinga private wing' (Interview midwife Bukuuku 1, 2015).

The quality of care in public health facilities appears to be lower than in the private facilities. Nabyonga-Orem et al. (2008) elaborated upon the lack of human resources and medication in public facilities. Due to the absence of user fees there is less money available, which results in fewer skilled health workers and a lack of resources. The health workers who participated in the research all complained about the salary and about the working hours and high responsibility. All of this affects and limits the possibilities for quality care delivery to the mother. In general the private facilities are experienced as better, but also more expensive and thus less accessible for the common Ugandan.

In 2014 there was a total number of 752 registered referrals to Buhinga. Figure 14 shows the number of referrals to Buhinga per health facility. Only the health facilities who referred five or more cases to Buhinga in 2014 were included in the graph.

FIGURE 15: REFERRALS TO BUHINGA PER HEALTH FACILITY 2014



Not one of the 18 health facilities who referred at least five cases in 2014 is a private facility. A total number of 66 different health facilities were distinguished in the year 2014 for having referred at least one case to Buhinga. Only seven of these 66 are private facilities. This

shows that the private facilities operate on a more independent scale, because they depend less on the opportunity of referral to Buhinga than many of the public facilities.

6.2 Public hierarchy

The different levels in the referral system are accompanied with the idea among patients that a higher level health facility equals a higher level of quality care, as is mentioned in chapter 5. This is the case for both private and public health facilities, but the private facilities have the advantage of being perceived better than public facilities in general. The ranking of health facilities is not always as straight forward. Sometimes a HC III is for example functioning properly and is carrying out deliveries, while a HC IV does not have a functional theatre and its employees are chronically absent. Mothers know which health facilities are good and which are not. It is 'local' knowledge. They often even know which health workers are present on which days and that determines where they will go for their visit (Interview midwife Bukuuku 2, 2015).

It is argued by most mothers that if you have the means it is better to go straight to Buhinga and by-pass the lower health facilities to prevent a referral. Thus the quality of the HCs can be debated and does not always depend on the indicated level, but it is commonly accepted that Buhinga exceeds the lower level facilities in terms of technical capacity. The knowledge and medication are available and they can operate you if necessary. Money seems to be the decider. The first hierarchy within the service delivery declares that if someone can afford it she will prefer a private facility over a public facility. This second hierarchy declares that if you are bound to the public system, it is better to pick the highest level possible to prevent referrals.

6.3 Hierarchies between men and women

Besides the hierarchies that are present within the health system, there is also the hierarchy between men and women which leaves its marks on the functionality of the referral system. Male involvement over the whole course of a woman's pregnancy is low. From the 28 mothers who agreed to participate in the in-depth interview, only one was accompanied by her husband at the time of the interview. The involvement of the father of the baby was discussed with 22 mothers. The pie charts in figure 15 and 16 show the male involvement as indicated by the mothers.

FIGURE 16: MALE INVOLVEMENT ANC

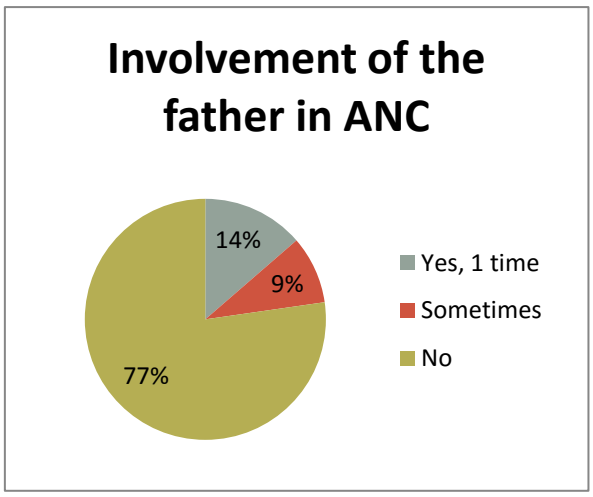
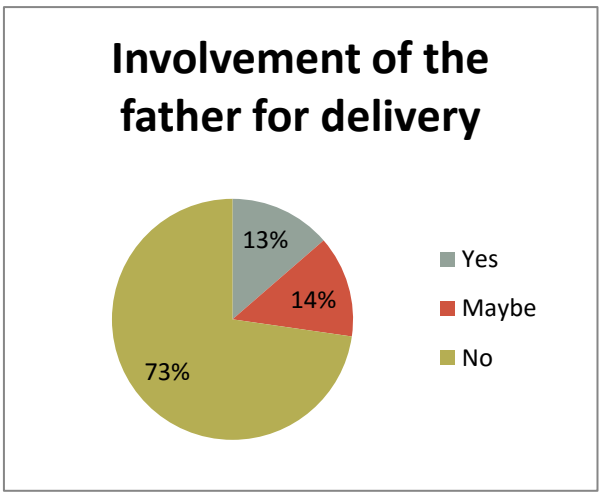


FIGURE 17: MALE INVOLVEMENT DELIVERY



As can be seen, it would be an exception if a man would accompany his wife to all ANC visits and be present during delivery. It is understood to be not masculine for a man to visit a health facility. Male health seeking behavior in general is low, which could be one of the reasons why men do not accompany their wives. Another reason is the fact that if a man comes along with the woman, they are both tested for HIV. A few of the health workers explained that a large share of the men do not want to be tested, because they fear the outcome. Extramarital relationships are said to be rather common for men, which results in them not knowing their HIV status. A midwife from Bukuuku explained this. She added that men fear the label of being HIV+, because their wife might leave them. But *'this is very often not the case. The women stick with the men, they are loyal. But if it is the other way around, then the man chases the woman away: You are going to kill me!, he says.* (Interview midwife Bukuuku 2, 2015).

Sometimes a mother decides to spent the last weeks before her delivery at her parents or at her parents-in-law. It is common for the female family members to accompany a mother-to-be during her delivery. This also restrains the possibilities for the father of the baby to be involved. Another limitation for male involvement is the fact that some men work in another district. This means that he lives and works somewhere else and comes home during the weekend or in holidays. The overall low male involvement leads to a high level of ignorance among men concerning the pregnancies and deliveries of their wives. It can be said on a hunch that a division between men and women is implied, namely that women are there to have children. A midwife from Bukuuku (Interview 2, 2015) expressed this by saying that *'some women are just there for their husbands'*.

This inequality is aggravated by the fact that men are the decision-makers in a family.

> '*Most women depend on the man. Even if she is working, the man is the money controller because he is the head of the family. So that also tends to bring women down'* (Interview midwife Kagote 3, 2015).

The low level of understanding between men and women concerning pregnancy and delivery can lead to unpleasant financial situations. A woman depends on her husband for giving her what she needs, but if the man's involvement in her pregnancy is limited then he might not know what she needs. He might not value the importance of ANC, because he has never accompanied his wife nor will he encourage her to go for all the visits. The man does not witness the necessities of ANC, but all he sees is that it requires money for transport. Some women shared their experiences of their husbands not allowing them to go, or not providing them with money for transport or for necessary materials for the delivery. This causes delays. Lack of awareness among men about when the delivery starts or when the wife has to start moving towards the facility for delivery also causes delays.

> *'You may find a mother who has come late for delivery or for ANC. When we ask them why, they tell us that they don't have money themselves, they have to ask for money from their husbands. They come to the facility with nothing. They think that because it is a government institution that everything will be free of charge (…). Sometimes we tell them: this and this is missing. Then they can say: I asked for transport for my husband and I asked for some money to buy some things. Then the husband says: you try to steal from me, the hospital is free so you don't need money. Then they come with nothing, no clothing for the baby, no clean sheets (…). This is really a challenge'* (Interview midwife Bukuuku 2, 2015).

It should be noted that the hierarchies of this proportion which are discussed above are common for the women that were included in the research. These are all women who seek health in public facilities which are free of charge. They were selected by opportunity at the facilities, but without a doubt there is a bias in the population sample due to the limited number of facilities and the limited variety in type of facility (only public).

6.4 Hierarchies between women

The hierarchies within the healthcare system and the hierarchies between women and men have been discussed. The following paragraphs elaborate on the hierarchies between women. This includes the wealth hierarchy and the hierarchy between urban and rural.

6.4.1 Wealth hierarchy

The first observed hierarchy between women in and around Fort Portal is the hierarchy on the wealth spectrum. This hierarchy has a relation with the hierarchies within the health system (see paragraph 6.1). Women with sufficient financial means at their disposal have the opportunity to receive maternal health care from a private facility. *'What makes the difference is their pocket. Without money you go to a public hospital, with money you go to private of course'* (Interview midwife Kagote 4, 2015). This hierarchy can broadly be divided into three categories:

TABLE 4: WEALTH HIERARCHY

Nr.	Category	Facility
1	Women with sufficient access to financial means	Private
2	Women with average access to financial means	Buhinga (self-referral)
3	Women with low access to financial means	Lower level health facilities (From HC IV down to HC II)

The division into categories is a visualization of reality, but it should be clear that it is not as straightforward as the table implies. Some women who have average access to financial means will not self-refer to Buhinga, but will just go to the closest HC III or HC IV. Table 4 is an impression of what has been observed throughout the research.

Being poor is generally seen as an enhanced risk for maternal and neonatal deaths. Not having the money for transport or for subsistence in the hospital is described by a midwife from Kagote HC III as a reason for maternal mortality. The midwives who participated in the research from Kagote and Bukuuku observed a general hierarchy between rich and poor among the women who visited their facilities. Mothers who come for delivery are supposed to bring a package with the necessary materials such as clean sheets and clothes for the baby. The content of the package is seen as a mirror of the access to financial means of the mother.

'But some don´t have anything and then it can be a challenge because sometimes the supplies are also not here from the government. Some mothers don't have a pad, they don't have a knickers, she just comes to give birth.' (Interview midwife Bukuuku 1, 2015).

´For the second time I asked if she could give me the clothing for the babies [red: she was delivering twins]. *I got them and they were very old and torn, and even dirty. I looked at the mother and asked: Is this what we are going to put on the new babies? She said: these are the only ones I have, the husband is not with me, I don't stay with him. So she is just at home and she has no income´* (Interview midwife Bukuuku 2, 2015).

Services and medication at a public health facility are free. Normally there are however some costs involved in visiting a health facility. This can be due to transport or because a mother is supposed to bring (and thus buy) certain materials for the delivery. Despite these costs it is also possible that a mother has to pay something extra at the health facility. Sometimes patients are charged extra costs for medication, for calling the doctor, for being given a bed or for other reasons. The involved costs for ANC and delivering in public health facilities were discussed with 25 mothers. They were asked if they had any experience with having to pay for something at the public health facility which was supposed to be free. This does not include medicines which were out of stock at the HC and which the mother therefore had to pay for at a pharmacy. It only involves those cases where the mother had to make a payment, for any reason, at the health facility itself.

FIGURE 18: COSTS AT PUBLIC FACILITY

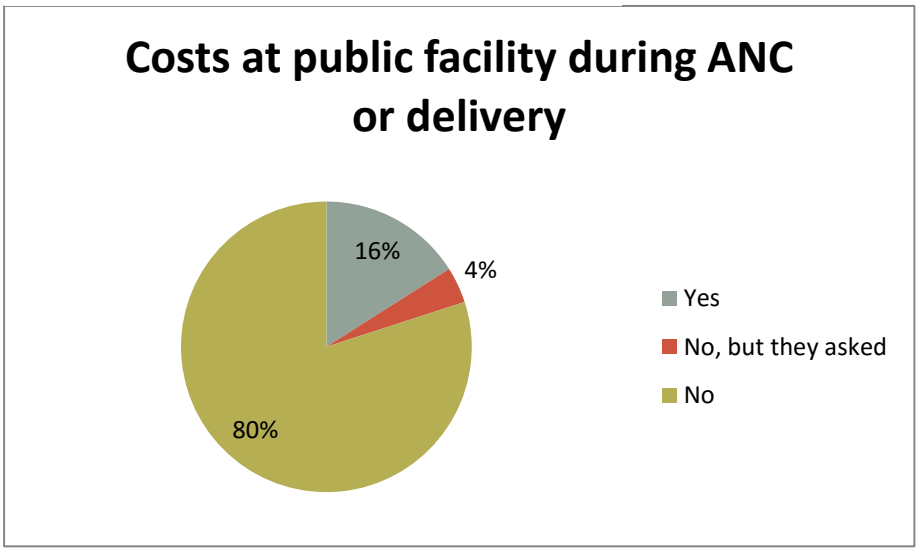


Figure 18 shows that 16% of the 25 women have paid money during ANC or delivery at a public health facility. It is interesting to note that these four women are all participants who were interviewed at Buhinga. Also the one woman (4%) who has never paid extra money, but was asked for it, was a participant from Buhinga. One of these mothers told us:

> *´If you want quick services you have to pay the under table money, the under table fee. But for me the case is that I do not have that money. So I have a feeling that I am not being cared for as the other people because those women that were operated on the same day as me, most of them have been discharged. But because I didn't pay that 20.000 I think that those nurses are not caring´* (Interview Buhinga 3, 2015).

Buhinga is a hospital where all types of women go; women who wish to go there and travel from far, and other women who arrive there on referral because they have no choice. The above example shows how the women that did not go there voluntarily have difficulties receiving the care they need. They do not fit in. Mothers with slightly more access to financial means will feel more comfortable at Buhinga, they are willing to pay extra for more security.

There is a distinct difference in the level of financial means accessible to a mother. Some mothers who were referred told that the attendant had to go home to sell something before she could receive services in Buhinga. This causes delays and unnecessary long stays at the hospital. Also the fact that most lower level facilities are considered to be free of any charge (see figure 18) while Buhinga requires money, will keep the occurrence of richer mothers by-passing the lower levels in place.

6.4.2 Urban and rural

Even though a substantial share of data points out that the division made between rich and poor can be extended into the division between urban and rural, it would be too simple to just assume this. For that reason this paragraph highlights the reasons for a visible hierarchy between women from urban areas and women from rural areas.

Mothers from urban areas are generally perceived in a different way than mothers from rural areas. The participants with whom this subject was discussed emphasized a difference in the level of education between these mothers. The mothers from the rural, and thus more remote, areas are perceived as having less knowledge about the reasons to come to a health facility for ANC and delivery. This results in mothers delivering from TBA's houses

(traditional birth attendant) which carries a higher risk of complications due to limited knowledge, and mothers who delay in reaching the HC because they first went to the TBA.

> *'Often the unit is a little bit far, which means they need some transport. There the TBA is near, so she hopes to first go there. Especially when the birth happens at night'* (Interview clin. off. Kyenjojo, 2015).

Mother from urban areas are said to have more purpose than merely delivering babies. They know the risks of having many children, for example through the radio, and they take into account that there is limited space, food and money for education to raise children. The HC's are close to them, so they go for ANC and receive education about family planning. This is in contrast to the mothers from rural areas. They often have to travel further to reach a HC which results in less ANC visits and thus less family planning. The space and food shortage is not an issue in rural areas and people tend to care less about education. Also, having children is a way of spreading risks for the future (Interview midwife Kagote 3, 2015).

> *'In urban areas people are now learned, so they come to health units for services. Those from remote areas they don't think of reaching the health unit. Sometimes it is just too far away, they are often not literate and they don't have enough knowledge about the services offered and their importance'* (Interview midwife Kagote 4, 2015).

The offer (quantity) of health facilities is described in the HSSP III (Health Sector Strategic Plan III) as sufficient: *'72% of the households in Uganda live within 5 km from a health facility'* (MoH, 2010:5). The number of health facilities is not the problem, but the distribution is. The presence of health facilities in really remote areas is limited.

> *'Yes, the quantity of health facilities would be enough, but the distribution is the problem. Look at Fort Portal. This small municipality has three hospitals and many health centres. When you look at the dispersion of the facilities you find that there are some places far away and they don't have anything'* (Interview Baylor Uganda, 2015).

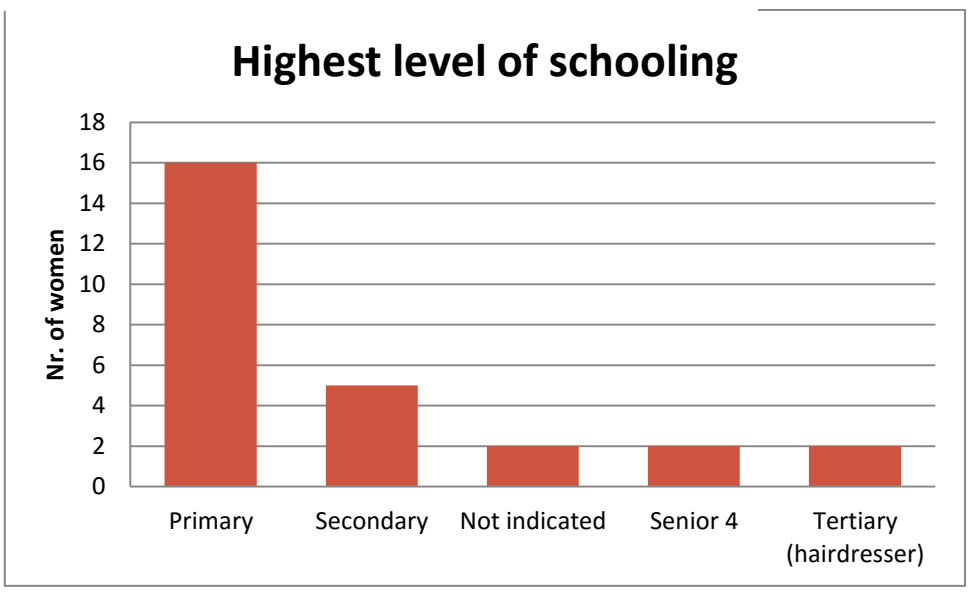
The hierarchy between mothers who live in urban areas and mothers who live in rural areas influence the functionality of the referral system as well. It disadvantages the mothers from remote areas and prevents them from receiving enough necessary care. Also, mothers who do come to the facilities in rural areas often come too late. Altogether there is a higher risk for complications due to the delays and the fact that mothers often did not come for ANC.

6.5 Hierarchies between HW and patients

The fifth and final observed hierarchy is the hierarchy between health workers and patients. Patients depend on the judgement and work done by health workers at any place in the world. However, this dependency relation between health workers and patients is observed to be different in Uganda from the dependency we might be familiar with.

Figure 19 depicts the highest level of schooling of the mothers who participated in the research. It also includes those mothers who are still a student, for example a mother in tertiary who is studying to become a hairdresser. The figure shows that 16 of the 28 mothers only finished primary school. The level of education hints to their social status and background.

FIGURE 19: LEVEL OF SCHOOLING OF THE MOTHERS



In comparison, the highest level of schooling of a health worker is at least tertiary level. This creates a gap between the mothers and the health workers: they are not on the same level. All 7 participating health workers have 4 children or less with reasonable age differences. They are all in a serious relationship or married. Also, all their children were delivered at a private facility (and a few at Buhinga), and the husbands accompanied them during delivery and in most cases also for ANC. This creates a distinctive social hierarchy between the mother and the health worker.

A midwife spoke about the responsibility they carry as health workers. Due to the low salaries and difficult working conditions, it tends to be tempting for some to show up late or leave early. But she says that *'if you leave, there is no one else there to help the mother, so*

then it is the mother who will suffer' (Interview midwife Kagote 4, 2015). The mothers in Fort Portal area depend heavily on the attitude and willingness of health workers. This puts the health worker in a powerful position which comes with great responsibility.

> '*In most cases those mothers are not sure what they are supposed to do or to ask. So it is really up to you, the midwife, to inform her on what she is supposed to do'* (Interview midwife Kagote 3, 2015).

The above described hierarchies influence the functionality of the referral system. The different levels in the health system are the foundation for the referral system. Distorted value labels are attached to the different levels, which results in the existing hierarchies. Private is better than public, and the hospital is better than the lower level facilities. These hierarchies cause self-referrals in which women by-pass the lower levels and create congestion at Buhinga. The hierarchy between man and woman creates a dependence relationship between husband and wife. Low male involvement leads to misunderstanding of necessary means to go through pregnancy and delivery safely. This results in delays to and at the health facility, and delays within the referral system. Clear differences between the mothers can be observed on the wealth spectrum and between rural and urban settings. These hierarchies maintain unequal treatment within the health system at certain facilities. The hierarchy between health workers and mothers is an inequality which can result in misunderstanding in the relation. The health workers carry a great responsibility for the mother which they have to take seriously. The mothers completely depend on their attitude.

6.6 Baylor Uganda and the hierarchies

Baylor Uganda is aware of the position of maternal care-seeking women. They introduced a program called 'Boda for Mothers', which makes the HCs more accessible for them. A

PICTURE 1: BODA FOR MOTHERS VOUCHER

mother-to-be can buy a voucher which provides six one-way trips to the closest health facility. They can go for four ANC visits, one visit for delivery and one visit for postnatal care (PNC). The vouchers are originally intended for the poorest mothers. They are sold at a price of 1000 UGX (+/- €0,30), an affordable price for poorer women.

The first aim of Baylor Uganda is to improve the maternal and child health in the area, which is done through this program by increasing the possibility for every mother to access good ANC and delivery from a health facility. By focusing on the poorer women, they intervene in the hierarchy between rich and poor and try to bring them to an equal level. The second hierarchy in which they intervene is the hierarchy between men and women. It creates independency of the mother when she can go to the health facility whether the husband will pay for her transport or not. Also, the voucher only grants one-way transport to the HC, but they do not bring the mothers back. This is for several reasons. Firstly, the budget is limited so this helps to reduce the cost. However, the more important reason is to involve the husband or other family members in the pregnancy of the mother. To leave them with a tad of responsibility as well. It is the hope that this encourages husbands to accompany their wife and make sure they get home safe, instead of creating a dependency between the mother and Baylor Uganda.

> *'What we encourage is that when the pregnant woman has a husband, or she has a family, then they should be able to contribute to this as well. We are trying to make the burden less when it comes to transport, but we don't want to create dependency'* (Interview Baylor, 2015).

7 COPING WITH THE REFERRAL SYSTEM

Chapter 5 and 6 discussed the bottlenecks in the referral system and the influences of several hierarchies on its functioning respectively. This third and final data describing chapter will discuss how the research participants cope with the malfunctioning referral system. The experiences of both patients and health workers will be revealed. Furthermore the structural consequences of the malfunctioning referral system are discussed in this chapter.

7.1 Experiences of midwives

The health workers are submissive towards the health system. On the one hand the equipment, the facilities and the possibilities for referral enable them to perform their job and serve the patients. On the other hand it is the same system which limits and complicates their job; for example if the collaboration with higher level facilities is deficient or if the HC they work in is not equipped as it should. This paragraph elaborates on the experiences of the participating health workers with the malfunctioning referral system and how they cope with the options at their disposal.

7.1.1 Non-functionality of health facilities

The functionality of the referral system partly depends on the status of the different health facilities. Due to the fact that a large share of the health facilities are not offering (all) the services they are supposed to offer, many difficulties are created for the health workers to cope with. The issue of self-referrals is explained in chapter 5. Self-referrals can be mothers who skip all the lower levels and go straight to Buhinga, but it can also concern mothers who skip the HC II's and III's surrounding their village and go straight to Bukuuku HC IV for example. It boils down to a situation in which a limited number of functional and trusted health facilities serve mothers in a much wider range than they are supposed to due to the non-functionality of other health facilities.

A midwife from Bukuuku was asked why she thought that there were so many mothers who came to Bukuuku from all different places. She responded: *'Because it is surrounded by HC III's who don't do their job'* (Interview midwife Bukuuku 1, 2015). A midwife from Kagote is also confronted with the same situation. She complains about Kataraka HC IV, which is the HC IV of the same HSD that Kagote HC III is in, so she is

supposed to refer a mother to Kataraka HC IV. She is however constrained by its dysfunctionality and has no choice but to refer mothers straight to Buhinga.

> *'Our level is HC III, from HC III you go to a HC IV and from HC IV to a big hospital. Kataraka is supposed to send the mothers to Buhinga, not us. That is the protocol. To prevent congestion. (…) But if I find a mother who needs a caesarean section then what will Kataraka do? Because they don't have a theatre also'* (Interview midwife Kagote 4, 2015).

The non-functionality of health facilities forces health workers to deal with congestion at those facilities which are considered to be functional and with a limited number of possible health facilities to refer mothers to. Besides the direct link the non-functionality of facilities has with the receiving and sending of mothers, it also influences the daily practices of the health workers.

7.1.2 Large responsibility

The midwife carries a great responsibility towards the mother in general, which has been mentioned as the hierarchy between health workers and patients in chapter 6. Due to the malfunctioning referral system this responsibility becomes even greater. The midwife has to build a relationship with the mother based on trust. Both the midwifes from Bukuuku as well as from Kagote pinpointed the importance of the relationship between them and the mothers. Kagote and Bukuuku are both HCs which are practically functioning at the level they are supposed to, and the midwives partly assign this to the way they receive and conduct mothers.

> *'Mothers come with their problems. They want to be counselled, they want to be talked to, they want to be helped with their problems. And I think that is why they are coming here'* (Interview midwife Kagote 3, 2015).

Evidence gathered from the mothers who visited Kagote and Bukuuku shows the value that mothers attribute to health workers treating them well.

> *'The ones in Buhinga are not very welcoming, but the people here welcome us and give comfort'* (Interview Kagote 1, 2015).

'Here they check our pregnancies very well. They don't talk to us in a rude way. But in Buhinga they do talk in a rude way to the patients. The health workers shout at the patients.

Is that also why you like Kagote?

Yes, that is why I come here' (Interview Kagote 13, 2015).

Also a mother from Bukuuku HC IV told that she receives all the services she needs every time she comes to the facility. She appreciates the health workers and likes coming back to the facility (Interview Bukuuku 2, 2015). Due to the problems in the referral system the responsibility of the midwife seems to become larger. Mothers who fear referrals and want to by-pass the lower levels need to be reassured of the quality care in the lower level facilities. The lack of trust that is generally present among the mothers has to be taken away, and that requires time and effort from the midwives.

The absence of doctors also appears to be one of the major issues for which health workers need to find a way of coping with. If a doctor is not present the midwife is left with the responsibility of making the judgment whether to refer the mother or whether to try and call a doctor. A HC IV is supposed to have twenty-four hour availability of a doctor. If there are however no staff houses for the doctor to sleep at night or not enough doctors to divide all the shifts with, which is the case in Bukuuku, then this is difficult to realize.

Whether night or day, if the doctor is not present then the midwife is ought to call him. She is supposed to do this with her own phone and the airtime she spends on this is not refundable. This means that the referral of a mother can depend on the airtime budget of the midwife. The midwife calls the doctor if she cannot handle the occurring complication. A midwife from Bukuuku explained that she calls the doctor at night:

'If he's not able to come at night he tells you: I am not able to come, refer the mother (…). So you make a call to the ambulance, it may be stationed somewhere else in town. Then he should come directly, picks the mother and brings her to Fort Portal.

So when you are working at night and you have such a complication, would you rather first call the doctor or just call the ambulance straight away?

Like at night we are sure doctors won't come so we call the driver actually right away' (Interview midwife Bukuku 1, 2015).

The midwife is the main caregiver for the mother. She has to make important decisions concerning the mother's and baby's life. The current amount of pressure is one of the consequences of the dysfunctional referral system, and health workers have to cope with it.

7.2 Experiences of mothers

Also the mothers have to cope with the dysfunctional referral system. This section describes in which ways they do this.

7.2.1 Accepting role of women

In the hierarchies described in chapter 6 it is the mother who holds the lower position. A position in which she depends on other people for her well-being. During the in-depth interviews 22 mothers were asked what they considered to be points of improvements in the healthcare system. Nine of them did not see anything that could be improved. Even after asking multiple times, they did not see anything that could be better. The other 13 came up with suggestions for change. They did however almost all need encouragement to share their concerns. The care that is provided seems to be perceived as a given entity on which they have no influence whatsoever. Evidence suggests that the prevailing hierarchies and the general position of a pregnant care-seeking woman has a major influence on the acquiescent attitude.

An accepting attitude is observed among the mothers who participated in the research. If they are confronted with problems they manage to find a way around it, instead of trying to address the (re)occurring problem. A mother who visited Kagote HC III for ANC told the story of how she came to Kagote for delivery late in the evening and then found that nobody was there. She says: *'When I found nobody here, I said: let me gently move to Buhinga, they could also help me'* (Interview Kagote 6, 2015). She expressed no anger or frustration. She explains that there were no other options than to find a boda boda and go somewhere where they can assist her. Another mother arrived at a small HC III near her village at 10 pm for delivery. On arrival all the health workers had left the place. When asked how she felt the mother replied:

> *'I felt bad, but I see that health workers don't stay on a health facility because then there were no staff houses at that health center. I had no alternative but to move to Kibiito'* (Interview Bukuku 2, 2015).

The poignant reality is that it is true; this mother had no alternative but to move to Kibiito. The participants expressed no urge to strive for improvements or to find solutions to the problems they are confronted with. One of the mothers from Kagote said that the health facilities around town are plenty in quantity. She said: '*If you fail at Buhinga you can try it at Kagote. If you fail at Kagote you can try it in another health facility'* (Interview Kagote 17, 2015). It appears that mothers accept the situation as it is and look for ways to make it most bearable.

7.2.2 Self-referrals

Arguably, self-referrals are an important way in which patients cope with the referral system. Self-referral comes as close as possible to taking the matter into your own hands. The decision to move is based on the availability of services. It is important to note that many of the participants in both Kagote and Bukuuku were highly satisfied with the services they received. The space and quick services were valued in both health facilities. This, often in combination with the distance they had to travel to reach the HCs, were the main reasons why mothers came there for ANC. Apparently the HCs are functioning sufficiently enough according to the mothers. In Kagote especially there is however the case of a missing theatre. This means that mothers have a reason to feel insecure about a possible referral, which creates the temptation of a self-referral. Most women indicated that they would like to deliver from Kagote because the services are good, but if they have the possibility they would rather go to Buhinga. Just to be safe.

This shows that women (and sometimes their husbands) try to have some influence in the fields where they find it appropriate. Women are accepting of the overall situation and are not trying to make changes to the system, they find ways to cope with it. They do however try to have influence on their personal situation. This comes forward in self-referrals, but another largely influencing way in which patients can take an active role in the quality of care they receive is bribing.

7.3 Corruption

Corruption in the Uganda healthcare system is a major issue for the delivery of quality care. Evidence shows that Buhinga is a breeding place for bribes, but Kagote and Bukuuku apparently are not. Five out of the six mothers who were interviewed in Buhinga told us they were asked for extra money for a certain service or medicine. Four of them actually paid it.

'It requires money to be here [red. Buhinga]*. First of all coming here and going back it requires money for transport and when you are here they also ask for extra money'* (Interview Buhinga 4, 2015).

The 22 participants from Kagote and Bukuuku did not have any experience with paying extra money in the facility, but nine of them told us they knew from former experience or from other people's experience that this happens in Buhinga. *'We knew it from other people that you can't just come here and get free services'* (Interview Buhinga 4, 2015). Both the mothers and health workers from Kagote and Bukuuku were straightforward if this issue was discussed: it happens in Buhinga, but it does not happen in Kagote and Bukuuku. *'That thing doesn't happen in Kagote'* (Interview Kagote 5, 2015).

The money that is paid is never 'just' something extra, there is always a reason why the patient is supposed to pay a certain amount to the health worker. One mother pays for her catheter, another one for the operation and yet another one to look for the right doctor. And this is only a part of the list.

'They asked 20.000 UGX [red. €6,-] *and I bargained and told them I had only 10. But then the nurses said: no, then we cannot work on you, it is 20.000 UGX for looking for a doctor, another 20.000 for an operation'* (Interview Buhinga 5, 2015).

Considering that all healthcare in public facilities is supposed to be free this leads to unpleasant situations. Many people seem to know about the practices taking place at Buhinga hospital, but some do not know about it or they cannot take part in it, at least not voluntarily.

'They said they cannot operate unless they have money. I had to go back home and borrow the money for the operation (…). In total I paid 13500 UGX [red. €4,-] *extra for the drugs, on top of the 30.000 UGX* [red. €10,-] *that I paid for the operation.*

This is problematic, because it creates and reinforces the wealth hierarchy described in chapter 6. Due to the self-referrals Buhinga is congested and there are neither enough health workers nor equipment to assist all patients properly. Bribing is a way in which patients can influence the level of quality care they receive. If a health worker has to choose who to work

on, he/she will likely favour the patients who can give them something beneficial as well. Two mothers from Kagote said:

> *'I heard it from many people. But that money is just to bribe the nurses that they will take care of you more than when you would not have paid them'* (Interview Kagote 4, 2015).

> *'They talk in a rude way to the people who don't give them money. But if you give them some money then they treat you very well'* (Interview Kagote 13, 2015).

This results in the poorest not receiving the same quality care as the more well-off patients. The hierarchy between health workers and patients is also reinforced by this. It creates room for health workers to take a powerful position in which they get to decide who receives which care.

Considering this, it is interesting to cite the vision from the interview with Christopher Ategeka (director of the NGO 'Rides for Lives') about the corrupt practices. He explains how Ugandan people tend to have a short-term mind-set. They have an accepting attitude towards the situation they are in. He said: *'If you give them some seeds they will fry them and eat them for dinner instead of planting them and waiting for the longer term profits'* (Interview Christopher Ategeka, 2015). This partly has to do with poverty, but he thinks it is also a cultural thing. He relates this to the bribing practices. People accept the situation as it is and they do not think about the bigger picture. If they are in a certain situation which requires healthcare then they are looking for relief in that specific moment. If a nurse can relieve them and asks for extra money, for whichever reason, then the patient is willing to cooperate and be part of this system if he can afford it. So the core problem is that it is generally accepted that this is 'the system'. It is seen as 'paying the system' and not as 'paying a nurse who asks for a bribe'.

Despite the fact that the information from the interviews is rather unambiguous, it is important to add some nuance. Only 6 patients were interviewed in Buhinga, so we can definitely not draw conclusions about bribing practices from this for the whole maternity ward, let alone for the whole hospital or for other large hospitals. The participants from Kagote and Bukuuku were also convincing about the fact that bribing practices occur in Buhinga and not in Kagote and Bukuuku. It should however be noted that Bukuuku and Kagote are both

relatively functional health facilities which can be a reason for different work ethics as well. They do not represent all lower level health facilities.

Bribing practices are a consequence of the failing referral system. Health workers and patients look for ways of how to cope with this dysfunctionality and bribing gives both parties something of their desire: good healthcare and some extra salary respectively. An attitude change among health workers is necessary to reduce the bribing practices. This analysis is however too short-sighted. An attitude change will not be possible without a change in law enforcement practices.

7.4 Lack of law enforcement and leadership

One of the prevailing problems influencing the health system and the referral system in particular is the misbehaviour of health workers at the health facilities. This can concern their absence, their rude attitude towards patients or asking for extra money while health services should be offered for free. It was discussed with the health workers who participated in the research if they observed any change in this over time and what they thought could be the reason for this change. From their stories and opinions we can conclude that real law enforcement and persecution is often not taking place, especially not in the past. If a midwife did not show up when she was on duty, then who could persecute her? A slow but effective change is observed by multiple health workers. If health workers are disciplined and perhaps punished then the overall attitudes of health workers can change.

> *'Now we can report to our in-charges. They say now: if you don't want to work then we can get other people who can work. If we give you a job, but you want to eat money for free than you can leave. Now sometimes they come with a team from the district and they talk with that midwife if normal disciplining didn't work. And it helps a lot'* (Interview midwife Bukuuku 3, 2015).

A story was told by one of the midwives about a former colleague who was used to working short days or not showing up at all at Bukuuku. After multiple complaints and disciplining efforts she was transferred to a HC more far away and next to a road.

> *´This one got a transfer to a HC which is on the road so that people keep on passing and can check on you. They can keep monitoring you. This one is now okay, she has learned from that bad experience´* (Interview midwife Bukuuku 3, 2015).

Another important aspect of these developing changes is good leadership. A strong leader should monitor the health facility and most important: feel responsible for the wellbeing of the health facility and its health workers. Especially in the current state where facilities have to make the best of what is present in terms of health workers and medication, it is important that someone sets a good example and supervises everything.

> *'I think the supervisors should support better supervision on the ground. Those health workers are not doing their job as it is supposed to be done. They should be following up those missing midwives at the stations'* (Interview midwife Bukuuku 1).

A supervisor is supposed to follow up on the performances of the health workers and has the position to either punish them or report them to a higher level. It is important that better leadership leads to law enforcement and persecution to slowly start removing the faults in the system. Only if misbehaviour is immediately suppressed and everyone follows the same rules, then actual improvements can take place in the quality of care for maternal health in Uganda. The quality care at every health facility level will improve because of this, and this will improve the functionality of the referral system.

An important note to make is that law enforcement should also start taking place in favour of the health workers. The MoH is not keeping its promises with regard to the number of health workers who should be employed at a health facility, their working hours and the salary they receive. This is not an excuse for the current misbehaviour of health workers, but once their working conditions are improved, the behaviour might improve as well.

7.5 Baylor Uganda and the consequence of the dysfunctionality

Baylor Uganda recognizes the ways in which patients and health workers have to cope with the (consequences of) non-functional referral system. They try to intervene in this to reduce the negative effects as much as possible. Examples of this are the ambulances and the 'Boda for Mothers' vouchers. Another thing they do to relieve the health workers and mothers is that they provide human resources if they observe a gap in this. One of the health workers who participated in the research for example is a neonatal nurse who is employed by Baylor. They are also building a new neonatal unit at Bukuku HC IV, because they see a big need for this at this place. They intervene where they find necessities and they do this to support the Ministry of Health in the job they have to do.

Baylor Uganda recognizes the corrupt practices which take place. The program manager said the following about this:

> *'Yes, this is a big problem especially in Buhinga, and it is really affecting service delivery. Really really big. But if we could get the HC IV's working to their capacity, and then the community regains confidence also in the facilities and they know that they don't have to come to Buhinga. That reduces the crowdedness in Buhinga which is already a solution for some of the bribing'* (Interview Baylor Uganda, 2015).

An active attitude to intervene in the leadership and law enforcement issues has not been observed. In the practices where they intervene they do however demand certain work ethics and have set up a strict system. For example the boda boda drivers and the midwives both have to collect a certain slip if a mother comes to the health facility. They can only receive their compensation if they hand in this proof of the work they have done. Also the neonatal nurse, who is employed by Baylor Uganda, told us that she has to keep track of the amount of hours she works. This work ethic is in contrast with the common Ugandan ways and the corrupt practices and it promotes equal treatment for all. Through the interventions of Baylor Uganda the corrupt practices are indirectly targeted. One of the midwives stated the following:

> *´I think that a lot of things in those bribing practices are already changing with Baylor. For example for the ambulances. First you maybe had to pay for the fuel or something. But now with Baylor the drivers are all screened and that is not a problem anymore'* (Interview midwife Bukuku 1, 2015).

8 DEPICTING THE PROCESSES IN A CLD

This chapter presents a CLD which embodies all the findings from this research and their causal interrelations. Rwashana et al. (2014) who created CLDs for the stagnating neonatal mortality in Uganda, plea for the use of the holistic systems thinking approach in because the focus is too often on the symptoms only, which results in reoccurrence of the problem. The symptom of the observed problem at stake (dysfunctional referral system) is the low level of quality care provided to mothers in the Kabarole district. Here it should be mentioned that this research applies a holistic approach to this specific problem only. There are of course more influences on the quality care than solely the dysfunctionality of the referral system. Senge states that any kind of problem is generated by a system and never by a single object or individual (Haraldsson, 2000). Thus multiple variables are responsible for the malfunctioning referral system and its influence on quality care delivery. Figure 20 (see next page) maps how the state of the functionality of the referral system is established and how this influences quality care. Figure 21 shows what the influence on the functionality of the referral system would be if law enforcement was practiced and leadership would occur.

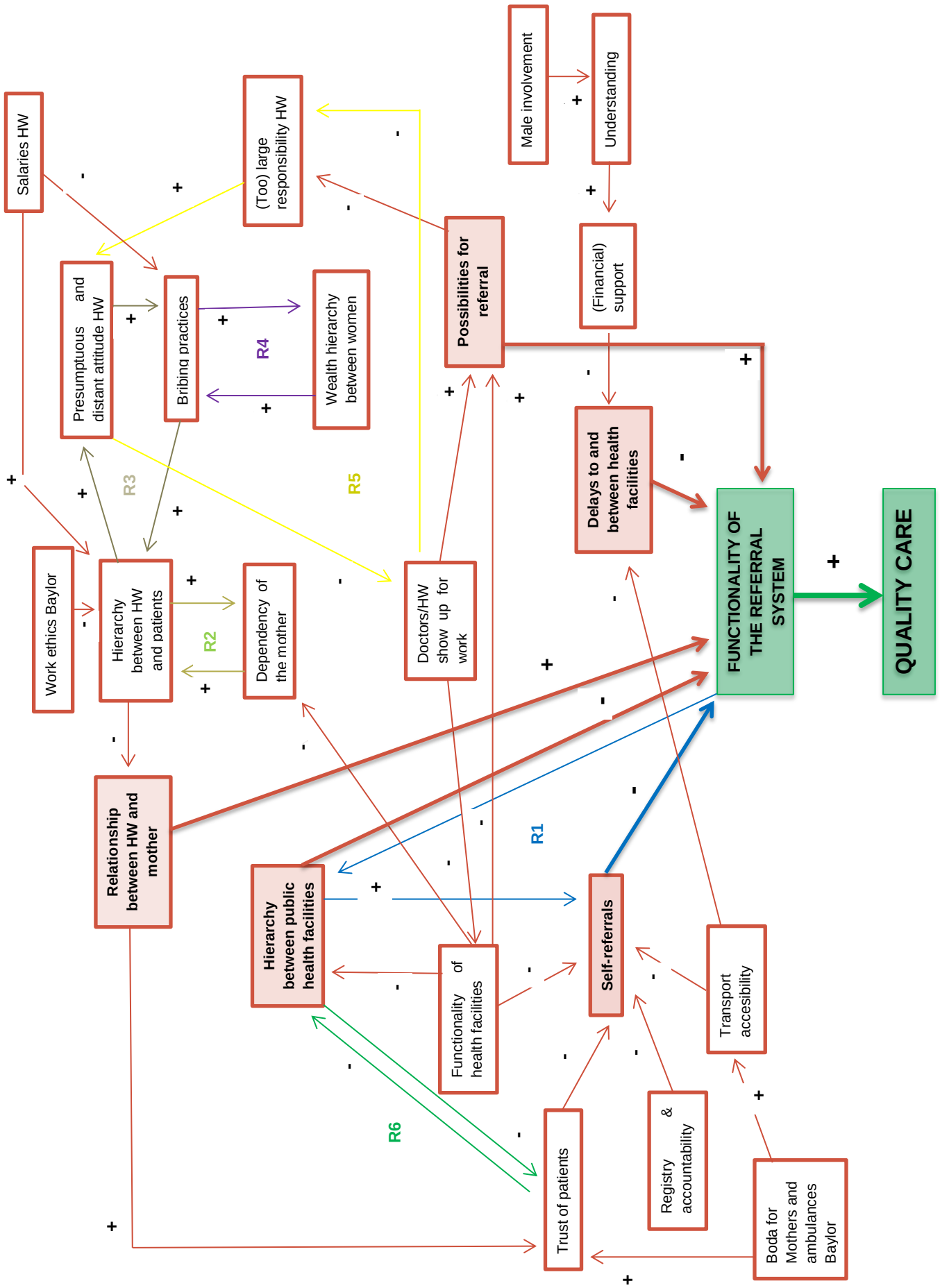
8.1 Clarification of the CLD

The CLD on the next page depicts all the variables with an influence on the functionality of the referral system. The outcome of this is a certain level of functionality and this has a positive influence on the quality care. As is explained in chapter 4, a positive sign (+) implies that both the variable at the head and the tail of the arrow change in the *same* direction. If the functionality of the referral system improves, the quality of care improves as well. A negative sign (-) implies that both the variable at the head and the tail of the arrow change in the *opposite* direction.

The light-red shaded variables have a direct influence on the functionality of the referral system. They are as follows:

- Self-referrals (-): if the number of self-referrals increases, the functionality of the referral system will decrease, because this means that lower levels are by-passed;
- Hierarchy between public health facilities (-): if the hierarchy between the levels of public health facility is intensified, then the functionality of the referral system will decrease due to bigger differences and less collaboration between the levels. Also the trust of mothers will influence this negatively;

FIGURE 20: CLD INFLUENCE OF THE FUNCTIONALITY OF THE REFERRAL SYSTEM ON QUALITY CARE



- Relationship between health worker and mother (+): if the relationship between the health worker and the mother improves, the functionality of the referral system will improve as well due to a higher level of trust from the mother;
- Delays to and between health facilities (-): if the delays to and between health facilities decrease, the functionality of the referral system will be increased;
- Possibilities for referral (+): if the possibilities for referral increase, the functionality of the referral system will be increased as well. An increase in possibilities means that health facilities are upgraded, that the transport between health facilities improved or something else with a positive influence on the referral system.

These five direct influences are all shaped and influenced by various variables. There is no need to describe all the links here, but it is interesting to take a closer look at the reinforcing feedback loops.

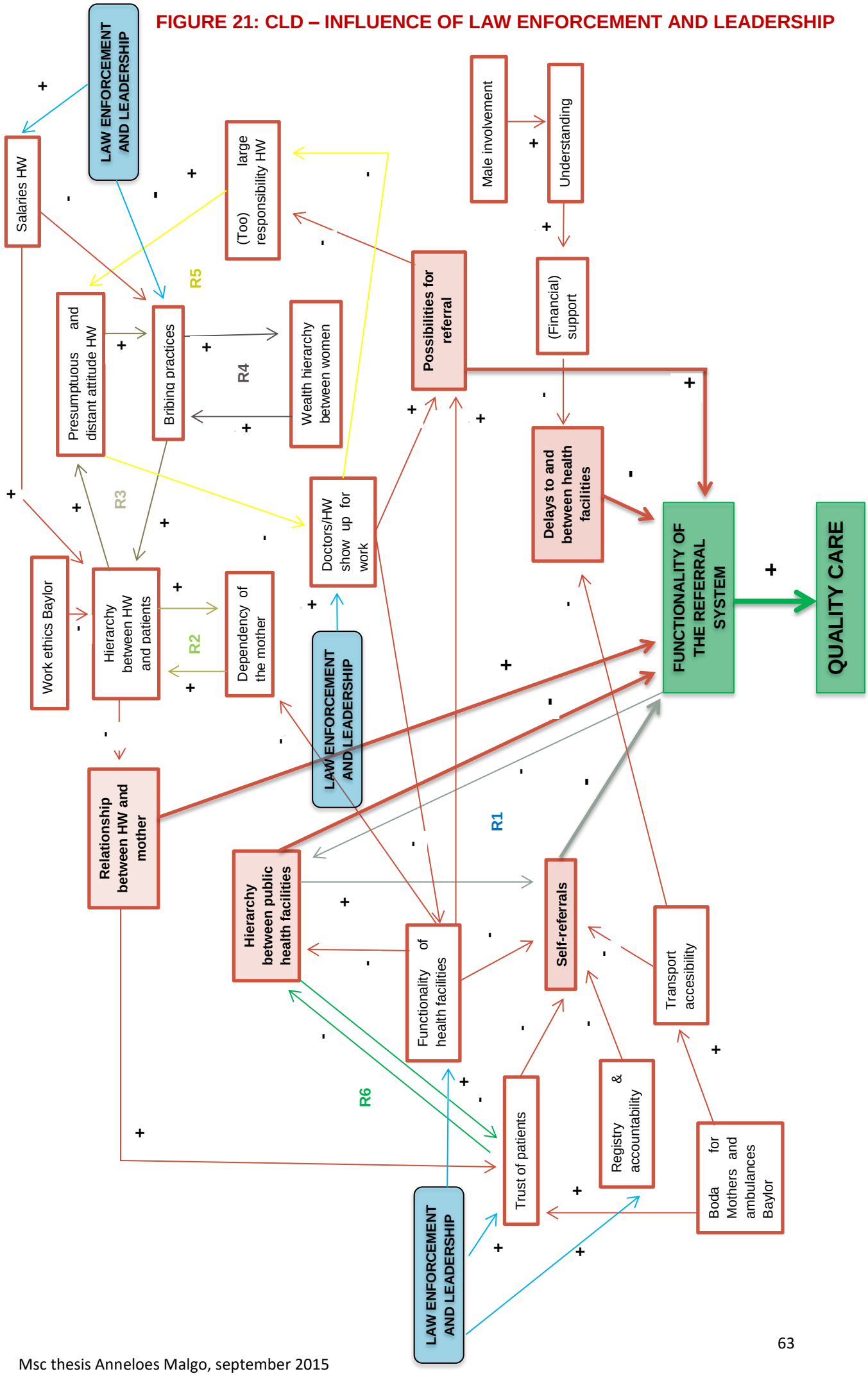
R1: Self-referrals (–) Functionality of the referral system (–) Hierarchy between public facilities (+) Self-referrals etc.

Once the number of self-referrals decreases, the functionality of the referral system increases because lower level facilities are by-passed less by the mothers. This means that the lower level facilities apparently became more attractive and now have more opportunities to provide services and refer if necessary. This increase in the functionality causes a lessening of the hierarchy between public health facilities. If the referral system is more functional the different level facilities improved their functionality and are cooperating. This lessening of the hierarchy then leads to a decrease in the number of self-referrals and so the loop continues to reinforce itself.

R2: Hierarchy between health workers and patients (+) Dependency of the mother (+)Hierarchy between health workers and patients etc.

If the existing hierarchy between health workers is intensified, the dependency of the mother is increasing as well. This is due to the fact that the mother depends heavily on the health worker: she needs care and the health worker can provide it if he/she is willing. The mother can (in principle) not offer anything in return. If this dependency increases, the hierarchy will only intensify more and the loop reinforces itself. *R3: Hierarchy between health workers and patients (+) Presumptuous and distant attitude health workers (+) Bribing practices (+) Hierarchy between health workers and patients etc.*

FIGURE 21: CLD – INFLUENCE OF LAW ENFORCEMENT AND LEADERSHIP



facilities. If patients visit the lower level facilities as well, they have more reason to keep their improvements up to date and serve the patient properly. Again also this loop reinforces itself.

These six reinforcing loops are a visualization of the processes that take place in establishing the functionality of the referral system. All of the reinforcing loops can result in a positive or a negative reinforcement. A negative reinforcement will (directly or indirectly) lead to a decrease of the functionality of the referral system, because all variables are linked to each other in some way. If we look at R5 then this will lead to an ever increasing negative attitude of the health worker which leads to the direct influences of less possibilities for referral and a worsened relationship between the health worker and the mother. These two variables directly influence the functionality of the referral system.

8.2 Explaining the influence of law enforcement and leadership

The reinforcing loops described in the above section have to be interrupted by an external variable to change their course. It is described in chapter 7 how proper law enforcement and good leadership create a positive change with regard to the functionality of the referral system. The progress is still slow, but promising.

Figure 21 depicts the influence of law enforcement and leadership on the processes that establish the functionality of the referral system. If law enforcement and leadership increase, this will increase the salaries of the health workers because they do not earn what they should for the hours they work. Also bribing practices will be persecuted, which will decrease them. Both these influences make sure that R2, R3 and R4 cause positive reinforcement. An increase of law and leadership will also lead to more doctors showing up for work which causes positive reinforcement in R5. Other influences of an increase of law enforcement and good leadership are more accountability and better registries, an increase of trust from the patients and higher functionality of the health facilities. If the law is applied, then all health facilities should move more and more towards their intended functionalities. This external interruption also causes positive reinforcement in R1 and R6.

9 DISCUSSION

Before coming back to the research questions in chapter 10, this chapter will discuss the empirical outcomes of the research. The theoretical framework of chapter 2 is discussed in relation to the outcomes and implications for policy are addressed.

9.1 Outcomes of the research in perspective of the theoretical framework

The available theoretical knowledge on the organizational capacity of maternal healthcare in developing countries is limited. The only two useful models are the 'Three Delays Framework' (Thaddeus and Maine, 1994) and the 'Access model' (Peters, 2008). As mentioned in chapter 2, both these models do not provide enough foundation to analyse and understand the dynamics behind the dysfunctionality of the referral system. Therefore the systems thinking theory has been applied in chapter 8, to create a holistic perspective on the problem at stake.

If a close look is taken at this CLD (figure 20), it can be seen that one of the direct influences are the 'delays to and between the health facilities'. The delays are definitely a determining influence on the functionality, but they do not include all the influencing variables. Important influencing variables found in this research are the different hierarchies described in chapter 6. The social relations between mothers themselves and between mothers and health workers have a large influence on the functionality of the referral system. This is partly in line with what Thaddeus and Maine (1994) say about the influence of socioeconomic factors on the first delay, the decision to seek care. The socioeconomic factors do however influence more things than solely the decision to seek care. They influence the position of the mother, her attitude towards the health facilities, her possibilities to reach the facility or to be referred and also the level of influence she has on the decision where she wants to be assisted.

Another important influence on the functionality of the referral system are the corrupt practices taking place in Buhinga especially. The Access model of Peters (2008) describes the relation between poverty and the access to healthcare. It is confirmed by this research that this relation indeed exists, but it is important to include the corrupt practices that take place. They influence the relationship between poverty and access to (certain) healthcare fiercely. It changes the mothers' decision-

making about where to seek healthcare and it also influences the relationship between health workers and patients, which on its turn are both of great influence for the functionality of the referral system.

The two models described in chapter 2 do not clash with the outcomes of this research in any way. It is however the case that the relationship between the functionality of the referral system and the level of quality care is too complicated to be realistically analysed by these models. The systems thinking approach provides a more complete method of analysis.

9.2 Policy implications

The biggest finding with possible consequences for policies is the finding that law enforcement and leadership can cause influencing positive reinforcement and consequently have a positive influence on the functionality of the referral system. The MoH would be well advised to increase law enforcement and persecution of those who break the law. Also empowering good leaders can have a positive influence on breaking the negative reinforcement loops. It is of great importance to punish those people who break the law. Only by applying one rule for all can hierarchies be overcome and trust be regained.

This is not only a job for the government, also NGOs can have a positive influence on this. Baylor Uganda sets a good example by promoting strict work ethics and showing leadership which both reduce inequalities and improve the access to healthcare. This has a positive influence on the functionality of the referral system. An NGO can however not enforce the law, since this is a government job. A bottleneck can be found here with regard to the relationship between NGOs and the MoH. Uganda is a breeding place for NGOs, and also many of them target the maternal and child health, since this is a major problem in Uganda. However, NGOs are operating on foreign money, which can create a dependency on the side of the MoH who is originally responsible for these problems.

A Dutch article from the magazine One World draws attention to the ‘evils in African healthcare’. They target the presence of corruption as the main evil. According to the authors the MoH is not fulfilling their duty due to insufficient tax incomes of the government. be preserved due to the NGOs who enter the country and spend foreign donor money. Big question marks are raised with regard to the effectiveness of foreign NGOs, if so less seems to have changed over the past 20 years. Are the corrupt practices and lousy law enforcement

not just sustained if NGOs keep filling the gaps which the MoH is supposed to fill? (Bruin, 2015).

Proper law enforcement in all areas of the healthcare system will target the corrupt practices immediately with large consequences for the whole healthcare system including the referral system. Law enforcement also means upgrading the health facilities and increasing the salaries for the health workers to the determined level. The problem is that this all requires money which is not present or which disappears due to bribing and a lack of law enforcement on the higher levels as well. Again the importance of organizational capacity cannot be emphasized enough. Also on higher levels within the MoH is it important to start a firm reorganization and perhaps indeed start collecting enough taxes to provide proper healthcare to the nation (Bruin, 2015).

10 CONCLUSION

This concluding chapter will discuss the findings in terms of general implications. The chapter aims to answer the main research question.

The introductory chapter of this research described the current problems perceived with regard to the dysfunctionality of the referral system. Due to the many things that go wrong in the maternal healthcare provision, especially within the organizational capacity, the referral system experiences difficulties to cope with. This leaves its mark on the level of quality care that is delivered to the mother. The following main research question was composed:

What is the influence of the functionality of the referral system on the delivery of quality care to local women in the Kabarole district (Uganda)?

The following sub questions were dealt with in chapter 5, 6 and 7:

1. How is the referral system intended to function and what goes wrong?
2. How do inequalities on different levels in Uganda have an influence on the referral system?
3. What are the consequences of the dysfunctional referral system?
4. What is the position of 'the referral system' in an analysis based on the systems thinking approach for the quality of maternal healthcare in Fort Portal?

This chapter will briefly discuss the main findings to the sub questions. In doing so, we work towards answering the main question.

1. How is the referral system intended to function and what goes wrong?

The preliminary literature research together with the gathered data showed what the intended functionality of the referral system is. The referral system was introduced in line with the decentralization of the healthcare system and was supposed to distribute the burden of disease among the different levels. Healthcare was supposed to become more accessible for Ugandans. Unfortunately, many bottlenecks are observed with regard to maternal healthcare. The mothers experience a high lack of trust, which is among other things caused by the non-functionality of many health facilities. Also transportation at the moment of referral is perceived as an issue. Many referral cases have to transport themselves due to limited

availability of ambulances. Also the maternity registry is perceived to be a bottleneck. Due to a lack of proper registration no one can be held accountable when something goes wrong. Besides that it also restricts the possibilities for improvement of referrals or health facilities dramatically, because the problems cannot be traced back. The result of all this is a high amount of self-referrals which create a barrier for improvement. As long as the self-referrals are not reduced, not much will change within the functionality of the referral system.

2. How do inequalities on different levels in Uganda have an influence on the referral system?

Different hierarchies with an influence on the functionality of the referral system have been observed in this research. Two hierarchies are found within the healthcare system itself: the hierarchy between public and private facilities and the hierarchy within the public facilities itself. Mothers tend to self-refer to higher level facilities (and if possible to a private facility) to avoid referrals as much as possible. These self-referrals are, as sub question one also concludes, a negative influence on the functionality of the referral system.

Social hierarchies are also of influence on the functionality of the referral system. Hierarchies between men and women limit the possibilities of women to receive the necessary care; hierarchies between women themselves reinforce bribing practices and promote inequality within the healthcare system. Also the hierarchy between health workers and patients promote inequality and decrease the trust of mothers in the healthcare system. All these social hierarchies reinforce the dysfunctionality of the referral system, mainly because the mother loses her trust and the lower level facilities are being downgraded.

3. What are the consequences of the dysfunctional referral system?

Multiple issues are observed as causes for the dysfunctional referral system. This dysfunctionality requires methods of coping. These methods differ for health workers and patients. Due to the non-functionality of many health facilities the health workers' possibilities for referral are limited. Besides that the doctor is also often not available, which means that the health worker makes the decisions. For health workers the coping mechanisms are mainly reflected in the increased responsibility they have.

The mothers tend to adopt an accepting attitude with regard to the dysfunctionality of the referral system. Most of them cannot think of ways to improve the offered maternal

healthcare, it is as if they accept the situation and search for ways to make it most bearable. There is no urge to strive for improvements and improve their position. This is probably also influenced by the social hierarchies which determine the position of the mother. The only observed active influence mothers show is self-referring to higher level facilities. This of course only aggravates the overall problem, but it is a way in which they can ensure reasonable care for themselves.

Corrupt practices (in Buhinga) are also a consequence of the dysfunctional referral system. The number of self-referrals due to the dysfunctionality cause congestions at the hospital. This creates opportunities for the health workers to take advantage of the situation. They have the luxury position of working in a hospital which provides all the necessary care. Because of the crowdedness, they cannot provide the necessary care to everyone in time. This means that those who are willing to pay can receive the care first. At the same time, the corrupt practices also reinforce the dysfunctionality of the referral system.

4. What is the position of 'the referral system' in an analysis based on the systems thinking approach for the quality of maternal healthcare in Fort Portal?

The systems thinking approach has been applied to all the gathered data from this research and this resulted in the large CLDs in figure 20 and 21. The functionality of the referral system should be analysed from a holistic perspective to understand its formation. The CLD shows which variables have a direct influence on the functionality of the referral system and how they are influenced themselves. The functionality of the referral system changes the quality care in the same direction (+); if the functionality is improved, the quality of care will improve as well.

Six reinforcing feedback loops are identified in the CLD. These loops came into existence after analysing all the data and bringing them back to meaningful variables. The outcome of the reinforcing loops create negative direct or indirect effects on the functionality of the referral system.

After elaborating on the findings for the four sub questions, the main question comes close to being answered. To understand how the functionality of the referral system influences the level of quality care it is insuperable to understand the dynamics behind it. This influence can be either positive or negative. It was shown that the functionality is largely restricted by

several bottlenecks which result in self-referrals. Inequalities in the form of hierarchies play a big role in the level of healthcare people receive and mothers appear to have a rather powerless position in these hierarchies. They are confronted with a dependency towards their husband and a dependency towards the health worker. Only money seems to be able to cause a change in this dependent position.

The CLD creates the opportunity to see which of all the influencing variables have a direct influence on the functionality of the referral system: self-referrals; the hierarchy between public health facilities; relationship between health worker and mother; delays to and between health facilities; and the possibilities for referral. These central variables can be traced back to find out what influences their status. Understanding the interlinkages between variables shows where changes should be made to eventually improve the quality care.

In terms of a way forward, the data showed how health workers share positive experiences with regard to law enforcement and good leadership. This is depicted in the second CLD, figure 21. It shows how law enforcement and good leadership can drive the necessary spoke into the wheel of the dysfunctional referral system and improve the level of quality care delivered to the mother.

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12 APPENDICES

12.1 Interview guide patients at health centre

- *Consent of the participant*

  Information about the aim of the research (find ways to improve the functionality of the referral system for maternal and child care)
  Interview is completely anonymous; okay with audio recording and note taking?
  Importance and appreciation for participation

- *General information participant*

  Age:
  Parish:
  Relationship status:
  Occupation:
  Highest attained level of schooling:
  Religion:
  Nr. of pregnancies (incl. current):

- *Current visit to health centre*

  Reasons for current visit (visited all necessary ANC? All in Kagote?)
  Time to reach health centre
  Means of travel to health centre
  Is this health centre the closest health facility to your home?

- *Current pregnancy*

  Why do you choose to come to Kagote today?
  Why do you come to antenatal visits?
  Where do you want to deliver?
  Can you describe to me what you will do when your contractions begin?
  If she goes to Kagote: Did you think about the risk of being referred if complications occur?
  Did you make any costs during you ANC visits, or during former deliveries?
  What kind of costs were that?
  And how did you pay for it? Support of father of the child/husband/family?
  Do you save money so that you can afford coming to the health center?
  Does your husband come along with you for ANC visits? For delivery?
  How do you feel about that?
  Do you make decisions with regard to your pregnancy and delivery by yourself or with your husband?

- *Experiences with the health system (and referrals)*

  1. Can you describe to me what you understand as ‘a referral’?
     Explain: what do we mean by ***referral***

Own experience with being referred when pregnant?
Former pregnancies? Any changes in decision-making?
Other people's experiences with referral?

- Reasons for referral (Doctors available?)
- Referral pathway (Were you asked where you wanted to go?)
- Visited ANC?
- Followed protocol during referral – consent of the patient?
- How did you/she feel?
- Transport between health facilities (How? Costs involved?)
- How were you/the person you know received after referral? Did the receiving staff know about your conditions and how were you helped? Costs involved?
- Outcome (obstetric/ non-obstetric causes?)
- Influence on future decision making? (self referral)

2. Resources available at health centre/receiving facility (*capability* of the health center). Do you have any experience with resources/medication/doctors not being present at the health center or hospital?
3. We are now in a public health facility. What can you tell me about private health facilities? Any experience with that?
4. Have you heard about Baylor's Boda's for mothers?
5. What can you tell me about the attitude of health workers? Do you know anything about their salary? Comparison health workers in different facilities?
6. Do you count on making any costs when you go to a public health facility? What can you tell me about 'bribing' health workers?
7. How do you feel about delivering at home/TBAs or at a health facility? Why?
8. Do you know (other) people who choose to deliver at home? Can you think of any reasons why people want to deliver at home?

- *Closing up*

  Any questions or anything to add that would be interesting to share with regard to the research?

  Thank participant

12.2 Interview guide patients Buhinga

- *Consent of the participant*

  Information about the aim of the research (find ways to improve the functionality of the referral system for maternal and child care)
  Interview is completely anonymous; okay with audio recording and note taking?
  Importance of and appreciation for participation

- *General information participant*

  Age:
  Parish:
  Relationship status:
  Occupation:
  Highest attained level of schooling:
  Religion:
  Nr. of pregnancies (incl. current):

- *Current visit to Buhinga*

  Time to reach hospital
  Means of travel to hospital
  Is this hospital the closest health facility to your home?
  Reasons for current visit (visited all necessary ANC? All in Buhinga?)
  How about former pregnancies (deliveries and ANC where)
  Why are you in Buhinga today?

- *Experiences in pregnancies*

  Can you describe to me what you will do when your contractions begin?
  Where do you want to deliver and why?
  Visited ANC? Importance of ANC/PNC?
  Did you make any costs during you ANC visits? Former deliveries?
  What kind of costs were that? (Bribing?)
  Do you pay for the costs that you make yourself? Support of father of the child/husband/family? Saving money?
  Does your husband come along with you for ANC visits? For delivery? Why/why not?
  How do you feel about that?
  Do you make decisions with regard to your pregnancy and delivery by yourself or with your husband?
  Can you describe to me what you understand to be 'quality care'?

- *Experiences with the health system (and referrals)*

  1. Explain: what do we mean by ***referral***
     Own experience with being referred when pregnant?
     Former pregnancies? Any changes in decision-making?
     Other people's experiences with referral?

- Reasons for referral (Doctors available?)
- Referral pathway (Were you asked where you wanted to go?)
  To what extent did the risk of being referred play a role in your decision to visit Buhinga?
- Followed protocol during referral – consent of the patient?
- How did you/she feel?
- Transport between health facilities (How? Costs involved?)
- How were you/the person you know received after referral? Did the receiving staff know about your conditions and how were you helped? Costs involved?
- Outcome (obstetric/ non-obstetric causes?)
- Influence on future decision making? (self referral)

2. Resources available at health centre/receiving facility
   Do you have any experience with resources/medication/doctors not being present at the health centre or hospital?
   Do you think there are enough health facilities in the Kabarole district?
   Women who live in remote areas?
3. We are now in a public health facility. What can you tell me about private health facilities? Any experience with that?
4. Have you heard about Baylor's 'Boda's for mothers'?
5. What can you tell me about the attitude of health workers?
   Comparison health workers in different facilities?
   Do you know anything about their salary?
6. How do you feel about delivering at home/TBAs or at a health facility? Why?
7. Do you know (other) people who choose to deliver at home? Can you think of any reasons why people want to deliver at home?
8. If you could change anything in the maternal health care for women in Fort Portal, what do you consider to be the most important thing that needs to be changed?

- *Closing up*
  Any questions or anything to add that would be interesting to share with regard to the research?

  Thank participant

12.3 Interview guide health workers

- *Consent of the participant*

  Information about the aim of the research (find ways to improve the functionality of the referral system for maternal and child care)
  Interview is completely anonymous; okay with audio recording and note taking?
  Importance of and appreciation for participation

- *General information participant*

  Age:
  Parish:
  Relationship status:
  Occupation:
  Highest attained level of schooling
  Religion:
  Nr. of pregnancies (incl. current)

- *Being a midwife*

  How long have you had this job (former work experience at different health facility?)
  Why did you became a midwife/nurse
  Why are you working in Bukuuku
  Can you describe your daily/weekly activities
  What is Bukuuku supposed to offer? Is that the case? What improvements do you see?
  Do you experience any limitations to your possibilities as a midwife?

  - Salary
  - Resources
  - Doctors present
  - Training

- *Referrals*

  Explain what I understand to be a referral
  What would be a reason for you to refer a mother
  Description of a referral that you remember
  Followed protocol during a referral (where do you refer to)
  What is a HC IV (like Bukuuku) supposed to offer – and is that the case?
  Receiving referrals?
  What kind of improvements could you think of for the referrals?
  Transport between health facilities

- *Opinion*

  Can you describe to me what you understand to be 'quality care'?
  Would you consider that care to be accessible for local women in FP area?
  Do you think there are enough health facilities in the Kabarole district?

Women who live in remote areas?
Baylor's: Boda for Mothers
How do you feel about delivering at home/TBAs or at a health facility? Why?
Collaboration with government? With Buhinga? With other HCs?
If you could change anything in the maternal health care for women in Fort Portal, what do you consider to be the most important thing that needs to be changed?
What do you observe in Bukuuku about relationship between husband/wife?

- *IF own children*

  Own experiences with pregnancies
  Own experiences with referrals
  - Where ANC
  - Where delivery
  - Influence of own job on decision-making

- *Closing up*
  Any questions or anything to add that would be interesting to share with regard to the research?

  Thank participant