

OSLOMET

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What is Respectful Maternity Care? **An Ethnography Study of Mothers and Midwives in Fort Portal, Uganda**

ABSTRACT

Globally, the maternal mortality rate is high at 216 deaths per 100,000 live births. Within Sub-Saharan Africa the rate remains much higher at 546 deaths per 100,000 births. Uganda makes up two percent of the global maternal mortality rate signaling much needed improvement to the implementation of maternal health within the country. The highest indicator of maternal mortality is whether or not she has a facility based delivery in the present of a skilled birthing attendant. There are many factors hindering facility based deliveries. One reported factor is the lack of respect women feel in maternity wards and experience of mistreatment and disrespect & abuse by midwives and doctors.

To explore the experiences of respect within a maternity ward, this study aims to understand how Ugandan women defined respectful maternity care within two health centers located in/about Fort Portal, Uganda. Two components of the respectful maternity care charter were the focus of the study: privacy and informed consent/information sharing. Participants included pregnant women and recently delivered mothers, midwives, and doctors. Interviews, focus groups and observational data were collected over a three month period.

Ugandan women, in this study, presented no interest in critiquing or praising the services provided to them within the maternity ward. Privacy and informed consent/information sharing did not appear to be an important aspect of their care. Generally no woman voiced complaints or praise on services they received. Upon further analysis the researcher believes that an unequal balance of power between patient and provider exists that dissuades women from become active players in the experiences at a health facility. If an unequal balance between patient and provider exists respectful maternity care cannot exist.

In order for respectful maternity care to even be an option for birthing women, there must be a shift of societal power dynamics that value all women and must ultimately be replicated within the health care system. Patient center care will facilitate respectful maternity care to emerge and only then will women be able to make reflections on their experiences and definitions of respect.

Key words: Maternal Mortality, Respectful Maternity Care, Patient-Provider Relationships,
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DEFINITIONS

For the purpose of this study few terms have been defined to convey their meaning as used in this study. These terms may have one definition in generally but for the purpose of this study they take on a slightly different meaning. When these terms of used in this paper, please refer to these definitions.

Privacy means physical privacy of the body and information about one's health and privacy of health documents. The most common forms of physical privacy would be a curtain of some sort, and sometimes a door. Others included window protection. Privacy of health documents means protection of a person's files, in this case files kept in locked filing cabinets. Also files constantly monitored.

Informed consent- a patient understands and agrees to any health services needed and understands and agrees to potential observation.

Information Sharing- the free provision of health information to patients in an understandable way.

Emotional support meaning the midwife make adequate provisions to provide the patient with a comfortable and friendly environment.

UK Midwife/Midwives- UK Based midwives sponsored through Knowledge 4 Change.

Ugandan Midwife/Midwives- Uganda midwives specific to the health centers included in the study. Not to be confused with all Ugandan midwives in the country.

Acronyms

ANC=Antenatal Care

ART- Antiretroviral Therapy

D&A= Disrespect and Abuse

HCIII= Health Center III

HCIV= Health Center IV

HSSP=Health Sector Strategic Plan

MDG= Millennium Development Goals

MM= Maternal Mortality

MoH= Ministry of Health

PCH= Primary Health Care Concept

PNC=Postnatal Care

RMC= Respectful Maternal Care

SBA= Skilled Birth Attendant

SDG= Sustainable Development Goal

SMI= Safe Motherhood Initiative

SVD= Standard Vaginal Delivery

TBA= Traditional Birth Attendant

VHT= Village Health Team

WHO= World Health Organization

I. INTRODUCTION

All over the world, pregnancy and childbirth is an exciting time in the lives of women and their families. It is also recognized as a very vulnerable time in a woman's life both physically and mentally. It is especially a vulnerable time for pregnant women in Africa. Globally the maternal mortality rate is 216 deaths per 100,000 live births. In 2015, low income countries account for 99% of maternal mortality. Sub Saharan Africa accounts for 66% of the maternal mortality rate (Trends in Maternal Mortality 1990-2015, WHO, UNICEP, UNFPA, World Bank Group, United Nations Population Division, xi). The largest causes of maternal mortality are sepsis, hypertension, and hemorrhage (WHO 2016, 113).

In Sub Saharan Africa, women are dying from preventable complications during pregnancy and delivery. Uganda is impacted from high maternal mortality rates that are slow to decrease. In Uganda, poor maternal and perinatal health outcomes measure for over 20% of the total disease burden (The World Bank, 2012). The government and the Ministry of Health recognize the need to push for more reform to guarantee safe, accessible and affordable maternal care services.

To address the dangers to pregnancy for women worldwide, specifically preventable maternal mortality, the Safe Motherhood Initiative (SMI) was introduced in a series of conferences in 1987 Nairobi. SMI quickly spread to surrounding countries, including Uganda, where it was incorporated in health policy initiatives. This initiative strived to tackle every aspect of pregnancy, childbirth and the postpartum period such as, good prenatal care (early detection and referral), birth attended by a skilled birth attendant, and necessary obstetric care for high risk mothers (Mahler, 1987). Despite these efforts maternal mortality rates continued to remain high in many developing countries moving into the 21st century.

According to the WHO "Mother-Baby Package" the SMI uses a broad implementation approach to encompass the "4 Pillars of Safe Mother Hood": Family Planning, Antenatal Care, Clean/Safe Delivery and Essential Obstetric Care (WHO 1996, xi). The mother-baby package gives a number of recommendations for changes in implementation before and

during pregnancy, during and after delivery for mother and baby. Maine & Rosenfield argue that only “essential obstetric care” (one of the four pillars of essential obstetric care) truly significantly reduced MM rates and must be made a focus as opposed to the broad goals defined (Maine & Rosenfield 1999, 481).

While it is widely acknowledged that simply having access to obstetric care is a direct and impactful way to combat poor maternal health outcomes, another emerging explanation for stagnant MM rates point to the quality of care given to women. A growing acknowledgment of the importance of quality care has emerged over the past two decades. The World Health Organization recognizes quality of care as a “critical aspect of the unfinished maternal and newborn health agenda, especially care during and around labor and delivery in the immediate postnatal period” (WHO, 2015). Lack of quality care and disrespect & abuse within health facilities leads to underutilization of health services which contributes to preventable maternal mortality (Kujawski et al. 2015, 2247).

The respectful maternal care movement was borne out of a need to systematically articulate and identify factors that can lead to higher rates of facility based delivery and eliminate the prevalence of disrespect & abuse during the laboring period. Respectful Maternity Care (RMC) advocates for a patient-centered care approach that focuses on the respect for women’s basic human rights and is based on clinical evidence (Manning & Schaaf 2015, 3).

The importance of gender cannot be overlooked when discussing maternal health and the goal to widely accept and implement RMC. Disrespect & Abuse (D&A) is deeply rooted in discourse of undervaluing woman’s experience when institutional powers such as the health sector is involved, this phenomena is also duplicated in a woman’s daily lived experiences. In order to understand the dimensions of RMC within a Ugandan setting one must look at the role of women within Ugandan culture, specifically their role as patient *and* provider.

The remaining chapters will delve into the health indicators that measure maternal health. Quality of care, specifically the respectful maternal care initiatives will be examined including its benefits, challenges and approaches. Privacy and informed consent will be the starting point in examining respectful maternal care. This initial point of interest will move

the research to further question, patient/provider relationships and impact of gender relations on the RMC movement.

Purpose of Study

Respectful maternal care has been largely neglected, until recently, and deserves more in depth research to explore what can be done to decrease maternal mortality rates. To add to the growing literature on respectful maternal care practices, I thought it important to gain an understanding of what Ugandan women' definition of respectful care. An understanding of what Ugandan women, and women from similar backgrounds, refer to as respectful, disrespectful and abusive can affect positive change that is contextualized to the health profile of that region. The importance of finding problems and solutions within the accurate context is more important than prescribing outside definitions to very complex, subjective terms.

Research Question(s)

This study asks the overarching question of “How do Ugandan women define Respectful Maternity Care?” with three sub questions:

1. How important is the role of privacy and informed consent (two of the seven RMC categories) to Ugandan women receiving maternity health services?
2. How does the relationship dynamic between patient and provider shape the implementation of respectful maternal care?

Hypothesis

The hypothesis for this study were as follows:

1. The role of privacy and informed consent will be fairly important to women received services in the maternity wards

Study Limitations

Preparation, execution and written analysis of this study occurred over a 19-month period from (April 2017- November 2018. The data collection was conducted on site during a three-month period from September 18, 2017 to December 11, 2017. 18 days of observations were conducted in two health centers and five interviews were conducted. The

first two weeks of the field assignment was used to construct an understanding of the health care system, and gain a general culture context.

Language

Officially, English is one of the languages of Uganda, but in reality, many people do not speak or understand the language. In and around the Fort Portal area the native population speak a local language known as Rutooro. Those who spoke English were somewhat recognized as the middle class as English is learned from 3rd grade and up. Most pregnant women seeking services at the public health facilities were lower classes farming women who had no access to education, therefore did not speak English.

The language barrier made it difficult to sometimes understand interactions. To remedy this I employed a translator to help me conduct interviews. My translator was a local student studying at university, not an professional translator. Due to the nonprofessional status of the translator, it is unclear on the quality and accuracy of translating the meaning and tone of responses. Sometimes long dialogues between translator and participants were summarized shortly for my understanding. Some nuances were surely lost this way.

During observations I was able to ask Ugandan midwives to translate interaction's in Rutooro. This was not already possible if the maternity ward was extremely busy. Again, in some instances long dialogue between mother and midwife would occur and a midwife would very briefly explain the interaction. In this way nuance is lost in these interactions as well. I relied on body language to piece together the meaning of interactions and asked questions at a more appropriate time.

Insider/Outsider Effect

Even though I am African American, my blackness does not erase the consequences of the outsider effect. Many Ugandans initially thought I, too was Ugandan, specially from the Rutooro kingdom but my style of dress, language and differing cultural ideas made it apparent I was not Ugandan, therefore I was classified as an outsider. I believe my presence sometimes confused Ugandans whom I interacted, within my study and outside of my research.

I was neither white, like tourists or aid/health workers that many Ugandans are used to seeing, nor was I a midwife/doctor which made up a large percentage of foreign nationals at the health centers. I could neither be classified as a white foreign aid worker or a Ugandan national. As a black researcher I stood as an “other”; the categories used to classify most people in that setting did not apply to me.

Insider

Insider research refers to research conducted with populations that the researcher is also a member (Kanuha 2000, 444). Group membership can be recognized as age, gender, religion, language, nationality, race and a combination of many more identities. Conducting research when one identifies as an insider has advantages, such as trust in the researcher resulting in more transparency during a study leading to greater depth to the data (Dwyer & Buckle 2009, 55). There are disadvantages afforded to the insider. Participants may feel a bond of similarity and fail to explain experiences fully or simply the research could unknowingly assert their own experiences into the research skewing their data (Dwyer & Buckle 2009, 57).

Outsider

As an outsider researcher, participants may have not been as open or transparent with me during interviews and observation. Discussed above, the language barrier made it difficult to have free flowing conversations. Although an outsider researcher more easily can stay objective while analyzing data.

One disadvantage is that as an outsider participants may feel inclined to answer based on their perceptions of what the researcher wants to hear. This phenomena is called the researcher effect. I believe the researcher effect could have affected the responses received during my interviews with mothers, this will be explained further within the analysis and discussion chapters.

Time Constraints

Initially all fieldwork was to be conducted within three months, September 2017-December 2017. This short period of fieldwork collection was further shortened due to

labor strikes throughout Uganda. On November 6, 2017 members of the Uganda Medical Association (UMA), comprised of doctors, began a nationwide strike over the government's failure to address their needs for salary increases and a review of medical supply and other equipment needed in health centers (Okiror 2017). From that date onward, doctors did not show up to work in public hospitals, and health centers. On November 25, 2017 the government and the Uganda Medical Association reached an agreement and the strike was temporarily called off. Dr. Edward Obuka, the president of UMA, ask that doctors resume work between November 25th and December 16th.

Even though the UMA only consists of doctors, many other medical professionals including midwives (specially midwives working at the two health centers covered in study) participated in the strike to show solidarity with the doctors grievance. Many of the grievances they expressed directly affected midwives and nurses ability to work as well. The two health centers covered in this study re-opened their doors the first week of December 2017. Due to the strike, I was only able to conduct fieldwork for two months instead of three.

Large Variance in Statistical Data

When finding statistical data to present as facts on numbers such as population size, literacy rates and maternal mortality rates. I noticed a large variance in numbers from year to year when reading through reports from the Ugandan government such as the Household Surveys. For instance within the surveys there is a large difference because literacy rates from the 2012/2013 and the 2016/2017 survey. The reports notes the variance in reporting is due to "cleaning the data" that occurred for the most recent survey. For this reason, I primarily used figures from the World Health Organization and other global organizations because there was less variance and there was greater consistence from organization to organization on the same rates.

The Ugandan Household Survey was used for literacy rates as the national survey gave more country specific details, such as breakdown of literacy rates by region. The survey was also used to report on the country urban and rural populations. This information is not recorded with global organizations.

Outline of Thesis

This thesis is divided into eight chapters. Chapter one, the introduction chapter, briefly presented issues facing maternal health such as maternal mortality and introduces the scope of the study as well as the objectives and research questions used to guide the study. The second chapter, literature review, presents facts and data on maternal health reports, globally, region specific (Sub-Saharan Africa), and within the country context (Uganda). More details are given on the history of Uganda's health sector and how it operates currently. Key terms were introduced that position respectful maternity care within the larger conversation of maternal health. Such key concepts included disrespect & abuse and Too Little, Too Late.

Within the third chapter, grounded theory was outlined as the theoretical framework guiding the data collection and analysis of this study. Gender and Development framework, symbolic Interactionism, and intersectionality are also briefly discussed as theories that framed my analysis. In chapter four, the study's methodology is discussed in detail, given explanation to all research methods used, to help the reader understand why specific methods were chosen over others. Within the methodology chapter ethical considerations are outlined in detail and well as the method of gaining informed consent from all participating parties.

Chapters five and six present the findings on privacy and informed consent/information sharing extensively taken from interview, focus groups and observational data. Chapter five highlights the concept of privacy within the respectful maternity care charter discussing the use of curtains and screens, and speculation on the importance of privacy to Ugandan women. Chapter six, highlights the concept of informed consent/information sharing, primarily from data collected from a focus group and speculates if informed consent can exist between patient and provider.

Chapter seven, the discussion chapter, emerging ideas from the data are discussed such as "complacency", "advocacy as an exception", and "appearance to indifference to respectful maternity care". These emerging ideas along with a few others accumulate to answer the initial guiding research questions on RMC. The initial research questions and answered, as

more questions are raised on RMC in Uganda and countries similar. Provider-patient relationships are analyzed from data collected as well as from other relevant studies.

In the final chapter, chapter eight, a general summary of the thesis is outline, pertaining to the flow of information that lead to its conclusion. Concluding statements and observations are made on the findings of this study but also its place within the growing literature on respectful maternity care, maternal health and patient-provider relationships within Sub-Saharan Africa. Recommendations are made on the improvements that is needed within social hierarchy and within health care system- specific to patient-provider relationships that would better facilitate the immersion and lasting power of respectful maternity care.

II. LITERATURE REVIEW

Sub-Saharan Africa Maternal Health Report

While maternal mortality (MM) has been virtually eliminated in high income countries, middle and low income countries are facing maternal mortality rates that are slow to decrease and relatively high. In Sub Saharan Africa (SSA) the numbers are staggering. The death of pregnant women are an unnecessary burden on households and communities and given the relative ease of prevention, when proper inventions are made, it's devastating that many countries still have high rates.

A woman dying from childbirth leaves her subsequent child/children in an extremely vulnerable position. When a mother dies from delivery a children's likelihood of survival drops severely. A study conducted in rural Tanzania, found that 46.28% of children whose mothers died during or near birth subsequently died, and 40.73% of children who experienced late maternal death before their 10th birthday also died. Children affected by early maternal death have a 51.54% chance of surviving until their first birthday, compared to 94.42% chance for children with surviving mothers (Finlay et al. 2015). This further proves that maternal mortality affects the lives of everyone around.

Due to its implications, the United Nations included MM as an issue to be focused on among the eight Millennium Development Goals (MDGs). Signed in on September 2000, all 189 UN member states agreed to combat global problems such as poverty, hunger, disease, illiteracy, environmental degradation and discrimination against women. Millennium Development Goal 5 made the declaration to improve maternal health, specifically MDG 5.A and 5. B's goals were to cut maternal mortality by $\frac{3}{4}$ and to achieve this by 2015. This declaration by the UN strongly encouraged many African countries with high maternal mortality rates to focus on this issue and began implementing polices and delegating resources to quell the problem. As this was an UN based objective/goal, MDG 5 was met with fortitude from domestic governments, local and international non-profits and other countries- all working to reduce maternal mortality rates

Although much progress was made, that progress was consistently low, and MDG 5 was not met in 2015. The mortality rate was cut nearly in half but many challenges lie in the way. For example, 25% of deliveries globally happen without a skilled birth attendant and

only about 50% of women received the recommended four antenatal visits during pregnancies (United Nations, 2015). Below highlights the trend in MM rates by region from 1990-2015.

Table 3.3. Comparison of maternal mortality ratio (MMR, maternal deaths per 100 000 live births) and number of maternal deaths, by United Nations Millennium Development Goal (MDG) region, 1990 and 2015

MDG region (in bold)	1990		2015		% change in MMR between 1990 and 2015 ^e	Average annual % change in MMR between 1990 and 2015	Average annual % change in MMR between 1990 and 2000	Average annual % change in MMR between 2000 and 2015
	MMR ^a	Maternal deaths ^b	MMR	Maternal deaths				
World	385	532 000	216	303 000	44	2.3	1.2	3.0
Developed regions^d	23	3 500	12	1 700	48	2.6	3.3	2.2
Developing regions	430	529 000	239	302 000	44	2.4	1.3	3.1
Northern Africa^e	171	6 400	70	3 100	59	3.6	4.1	3.2
Sub-Saharan Africa^f	987	223 000	546	201 000	45	2.4	1.5	2.9
Eastern Asia^g	95	26 000	27	4 800	72	5.0	4.8	5.0
Eastern Asia excluding China	51	590	43	380	16	0.7	-3.0	3.1
Southern Asia^h	538	210 000	176	66 000	67	4.5	3.6	5.1
Southern Asia excluding India	495	57 800	180	21 000	64	4.1	2.5	5.1
South-eastern Asiaⁱ	320	39 000	110	13 000	66	4.3	4.7	4.0
Western Asia^j	160	6 700	91	4 700	43	2.2	2.7	1.9
Caucasus and Central Asia^k	69	1 300	33	610	52	3.0	3.1	2.9
Latin America and the Caribbean	135	16 000	67	7 300	50	2.8	3.1	2.6
Latin America ^l	124	14 000	60	6 000	52	2.9	3.1	2.8
Caribbean ^m	276	2 300	175	1 300	37	1.8	2.5	1.4
Oceaniaⁿ	391	780	187	500	52	3.0	2.9	3.0

Figure 1 Maternal Mortality Rates 1990-2015

(Trend in Maternal Mortality Rate 1990-2015, Estimates by WHO, UNICEF, UNFPA, World Bank Group and the United Nations Population Division, 17)

The Sustainable Development Goals, another declaration by the UN, continues to fight for maternal health in SDG 3 “ensuring healthy lives for all ages” SDG 3.1 aims to reduce MM rates to 70/100,000 by 2030. In 2015, the global MM rate was measured at 216/100,000 (World Health Organization, 2015). The UN, and the World Health Organization defines

maternal mortality rate and the proportion of births attended by a skilled health work as indicators for this goal.

There is great importance in the indicators named by the UN for Sustainable Development Goal 3.1. The first indicator, the MM rate, is obviously imperative and needed to know how MM fluctuates over the years. The second indicator is more telling, “proportion of births attend by a skilled health work”. Pregnant women are at an alarmingly rate at higher risk of death when they deliver without professional care, and this phenomenon happens disproportionately in low income countries. These deaths are preventable, the majority of pregnancy related complications if detected in the antenatal, intrapartum and postpartum stages by skilled health workers could save many lives.

Midwifery

There is much ambiguity on exactly who is providing maternal care services to pregnant women. Within this study and the research written about in this literature review, midwives bear the majority of the role on providing services to pregnant women. But in many countries some aspects of midwifery care is under taken by a number of others such as obstetricians, family doctors, nurses, auxiliary midwives, community health workers, traditional birth attendants, nurse-midwives, well trained, by international standards, midwives and unsupported or inadequately trained midwives (Van Teijlingen, Wrede, Beniot, Devries 2009, 14).

When writing on midwifery this encompasses all the above listed entities and not just trained midwives. Analyzing women’s own perceptions of respectful maternal care or lack thereof it’s important to have a base understanding of how the practice of midwifery is defined. Renfrew et al (2014) define the practice of midwifery as “skilled, knowledgeable, and compassionate care for childbearing women, newborn infants, and families across the continuum throughout pre-pregnancy, pregnancy, birth, postpartum, and the early weeks of life. Core characteristics include optimizing normal biological, psychological, social, and cultural processes of reproduction and early life; timely prevention and management of complications; consultation with and referral to other services; respect for women's individual circumstances and views; and working in partnership with women to strengthen

women's own capabilities to care for themselves and their families” (Renfrew et al. 2014, 1129).

Too Little, Too Late (TLTL)

Much of the maternal health challenges can be characterized as “Too Little, Too Late” (TLTL). TLTL is referred to as a number of system deficiencies that prevent healthcare providers from delivering even the simplest and most cost effective evidence based interventions (Miller et al. 2016, 2177). The system deficiencies are complex and very broad. They range from issues surrounding, inadequate numbers of skilled providers, insufficient training, lack of commodities or an absence of guidelines for evidence based care when commodities are available (Duysburg, 2013). Access to health care due to geographical, social and economic factors also can prove to be barriers facilitating TLTL. (Bohren, 2014). These factors lead to easily preventable maternal health issues to not be treated leading to unnecessary maternal deaths. A few of challenges facing maternal health will be outlined in the following sections.

Factors Contributing to Utilization in Low Income Countries

Why is it then that so many women low income countries, specifically African countries, still are not delivering their children with the help of a skilled health worker? There are many compounding factors that act as barriers to birthing in a health facility; some are structural, such as lack of transportation and money, and other are more subjective denoting personal choices based on the influencing societal values of the woman’s environment. In a study conducted in the Amansie District in Ghana, a district similar to the one studied based on its rural location and Ghana’s similar MM rate- 319 per 100,000 live births (WHO, 2015). Women reported the following factors as to why they prefer a home birth, in order of importance: verbal abuse by health workers in hospitals, lack of transportation, confidence in traditional birth workers, and sudden labor (Nakau et al. 4, 2015).

The most consistently found determinant to the use of reproductive health services is a woman’s education level (Campell 2009, 34). Other determinants are socioeconomic indicators such as urban/rural residence (Agadjanian et al. 2016, 25) (Mekonnen et al. 2015, 376), household living conditions (Bohren et al. 2014, 71), household income (Amponsah-Nketiah & Moses 2009, 474) and occupational status (Kusuma et al. 2018, 163). More factors that affect utilization of health services are community beliefs and

norms in relation to health behaviors (Stephenson et al. 2006, 87). Kifle et al. writes “these community beliefs and norms are reflected in an individual’s health decisions because behavior is influenced by how a person thinks the community views his or her actions. As such, women make delivery decisions within a community and national context” (Kifle et al. 2018, 22).

Women living in rural areas face unique factors that influence their decision on utilization of services. Globally, rural areas tend to have less access to health care by way of less resources: proximity to physical health centers, medication/supplies, and human resources (International Labor Organization, 2015). The highest resource gap for rural populations are found in Africa; up to 77% of the population have no access to health care due to a shortage of health workers (International Labor Organization, 2015).

Aside from lack of resources, distance had been recognized as a factor hindering utilization, especially in rural areas (The White Ribbon Alliance for Safe Motherhood, 2011).

According to the 2008 Ghana Demographic and Health Survey 33% of rural mothers reference distance as the most significant facts for not seeking birth services (Ghana Statistical Service et al., 2009). Travel time means distance but also the mode and difficulty of travel.

It is important to note that the most vulnerable population of women are women living in rural areas. Rural women are more likely to be less educated and as discussed earlier a woman’s level of education is a contributing factor to utilization of health services, especially seeking facility based delivery literacy rates for women living in rural areas are, on average, 30% lower than women living in urban areas.

According to Uganda’s 2016/2017 National Household Survey, the national literacy rate is 74%. 76% of the population lives in rural areas, compared to 24% of the population that live in urban area (Uganda Bureau of Statistics 2017, 21). The literacy disparity is evident for those living in urban areas and those living in rural areas. 87% of urban residents are literate compared to 69% of rural living people. 64% of women in rural areas were literate compared to 85% percent of urban women. This shows about a 20% different in literacy

rates based on geography. When specifically comparing the literacy percentage of Kampala, the capital, to the Tooro region, where HCIV and HCIII were located, the rates for women is nearly a 30% difference. Kampala’s female literacy rate is 92% and the Tooro region’s female literacy rate is 64% (Uganda Bureau of Statistics 2017, 41).

Persons Aged 10 Years and above who are literate (%) year 2016/2017

Residence	Male	Female	Total
Rural	73.6	64.4	68.8
Urban	89	84.6	86.6
Region			
Kampala	93.3	92.3	92.8
Tooro	70.6	64.2	67.3
Uganda	77.5	69.9	73.5

(Uganda Bureau of Statistics 2017, 41)
 Contents of table condensed for relevance

At the UN’s 2010 human rights convention, the committee on the elimination of all forms of discrimination against women, expressed concern “ at the disadvantaged position of women in rural and remote areas (who form the majority of women in Uganda) which is characterized by poverty, illiteracy, difficulties in access to health and social services and a lack of participation in decision-making processes at the community level” (CEDAW 2010, 11)

In reviewing the literature, these logistical challenges to access care were constantly referenced: poor roads, long travel times and lack of quality care. Women also report widespread lack of resources such as lack of supplies, medicine and literal bed space, but also lack of human resources (staff) that lead to long wait time and untimely care (Mugo et al. 2018, 6). Lack of quality care can greatly influence a women’s decision’s as to where she wants to give birth. In a situation where no practical challenges stand in a woman’s way of delivering under a skilled birth attendant perceived lack of resources compounded with the risk of mistreatment will easily deter a woman.

Disrespect & Abuse- What is it?

An increasing volume of research reports that mistreatment of women during childbirth is widespread and is systematic (Bohren et al. 2015). The mistreatment including physical abuse, such as pinching or slapping (McMahon et al. 2014; Moyer, Adongo, Aborigo, Hodgson, & Engmann, 2014) and verbal abuse. (Chadwick, Cooper, & Harries, 2014; D'Ambruoso, Abbey, & Hussein, 2005; Hatamleh, Shaban, & Homer, 2013) but also extends to feeling ignored/neglected, discriminatory treatment, and a demand of money between provider and patient (McMahon et al. 2014, 4). In addition to verbal and physical abuse, the lack of supplies and facility constraints can be perceived as unwelcoming. This “mistreatment” can be more accurately be defined as disrespect & abuse while seeking pregnancy related health services.

Disrespect and Abuse (D&A) is a human rights issue and has deep implication for health outcomes. When a woman feels D&A during a routine trip to a health facility she will lose trust and satisfaction towards health care providers (Kujawski et al. 2015; Kowalewski et al. 2000; Bohren et al. 2014; Turan et al. 2008.) Satisfaction and trust rates of patients is linked to the likelihood and timing of utilizing those services in the future. (Kujawski et al. 2015) Untimely utilization of services and the lack of utilization all together jeopardizes a woman's chances of surviving childbirth.

In a study done on the barriers to utilization of facility based delivery in the Karamoja region of Uganda many women and men reported “bad staff attitude” as a reason to delivery at home (Wilunda et al. 2014, 7). Participants reported that health workers did not attend to them with respect, very rude to them which scared mothers away from seeking a facility based delivery (Wilunda et al. 2014, 7).

Even in a context when facility based maternal health services were utilized preventable maternal deaths are reported. Miller et al. (2003) investigated high rates of maternal mortality in the Dominican Republic. The Dominican Republic is an interesting case because even though 98% of births happen in health facilities attended by skilled health workers the country's maternal mortality rates still remained relatively high. Conducting a multisite qualitative study, they found:

“women were not informed of the results of their examinations, women with complications labored together with those labeled ‘normal’ in the one large, brightly lit and noisy ward. Some women were naked, most were lying on bare plastic mattresses, the one sheet having been soiled with urine, feces, or drenched in amniotic fluid. There was no privacy, no dignity, and no attempt to honor the human and reproductive rights of the laboring women” (Miller et al. 2003, 96)

Comprehensively D&A can be defined as “interactions or facility conditions that local consensus deemed to be humiliating or undignified, and those interactions or conditions that are experienced as or intended to be humiliating or undignified” (Freedman et al. 2014, 916).

Normalization of Disrespect & Abuse

Disrespect is also difficult to identify due to the normalization of this phenomenon in women’s child birthing experience. A study conducted in Abuja, Nigeria questioned the acceptability of mistreatment of women during childbirth and generally found that physical and verbal abuse were deemed acceptable if the outcome was to lead to a safe and normal delivery for baby and mother, or if the mother had been disobedient in some way, for example not listening to the doctor or midwife (Bohren et al. 2015, 645). Verbal or physical abuse, that came seemingly unwarranted (or without good reason) were deemed unacceptable.

During many interviews done during the Bowser study, a theme of the “normalization” of D&A appeared. One respondent commented

“I think most of our women don’t know they have the rights to respectful treatment. If we do a patient satisfaction survey now, you will find [patient satisfaction] is high. Because women [in my country] by character...they never say they are mistreated...maybe that is the fact, but they never speak the truth. They don’t object or speak out. They accept what they get” (Bowser 2010, 15).

Another older woman participating in a focus group expressed sentiments that speak to the treatment of pregnant women as a cultural norm. She thought that younger women now expect too much currently and “women should be beaten” to reflect her own life experiences (Bowser 2010, 15). Similarly an observation team observed a series of “very forceful, rough deliveries”; when interviewing the women recipients of this care expressed gratitude at the opportunity to deliver there (Miller et al. 2002).

D&A is grounded in the belief that health is a human right as stated in the UN's Universal Declaration of Human Rights in 1948, which leads D&A to be classified as a human rights issue. A definition for D&A must encompass individual D&A, such as provider behavior that was experienced as disrespectful or humiliating and structural- systematic deficiencies that set up an environment for D&A. Freedman et al. has laid out some "experimental building blocks" in defined disrespect and abuse. These include, "behavior that, by local consensus, constitutes disrespect and abuse", "subjective experience" and "intentionality" (Freeman et al. 2014, 916).

There many recorded incidents of D&A reported by researchers, though relatively recent as D&A incidences were not formally documented by human right organizations as a systematic problem until 2007. In a review of 65 qualitative, quantitative and mixed methods studies conducted in 2015 reported a 7 category model classifying instances of D&A including: physical abuse, sexual abuse, verbal abuse, stigma and discrimination, failure to meet professional standards of care, poor patient/provider communication, and health system constraints (Bohren et al, 2015).

Another comprehensive review was undertaken under USAID- funded "Translating Research into Action" project. A review of available evidence of D&A as well as interviews with expert informants as well as group discussion on the top of D&A were gathered. Some of the categories identical to the ones outlined in Bohren's study, such as physical abuse, stigma and discrimination. The others identified were similar in nature but were described differently, including "Abandonment of Care", "Non-Dignified Care", "Non-confidential Care", "Non-Consented Care", and "Detention in Facilities". With this knowledge a broad definition of disrespect & abuse is "interactions or facility conditions that are experienced as or intended to be humiliating or undignified" (Freedman et al, 2014). Although this is the definition I choose to use there is still much debate on a definition and there has been no general consensus on any definition. D&A is mostly understood in categorized incidences.

Recently there have been several initiatives and suggestions that have been adopted to combat D&A to restore trust and satisfaction to patients. But it's important to note that the

absence of disrespect and abuse doesn't equal respectful maternity care. RMC requires a conscious effort and should be the priority of health providers and health systems

Respectful Maternity Care

The White Ribbon Alliance for Safe Motherhood created the first and widely accepted respectful maternity care charter for the universal rights are childbearing women. This charter legitimizes Respectful Maternity Care as a “hard” issue steeped within the context of human rights, and grounded in multiple multinational human rights declarations and charters, some including: the Universal Declaration of Human Rights, the Declaration of the Elimination of Violence Against Women, and the Convention on the Elimination of all Forms of Discrimination Against Women. This charter was developed by drawing upon the 7 categories of D&A identified in and Bowser & Hill study. The charter lays out seven rights of childbearing women:

1. Freedom from harm and ill treatment
2. The right to information, informed consent and refusal, and respect for choices and preferences, including the right to companionship of choice wherever possible
3. Confidentiality, privacy
4. Dignity, respect
5. Equality, freedom from discrimination, equitable care
6. Right to timely health care and to the highest attainable level of health
7. Liberty, autonomy, self-determination, and freedom from coercion

(White Ribbon Alliance, 2011, 2)

Working towards the categories that outline RMC can prove to be a successful mechanism to combatting preventable maternal mortality. The WHO released a statement “Every woman has the right to the highest attainable standard of health, which includes the right to dignified, respectful health care” (WHO, 2015). Within the statement the WHO lays out suggested actions to eliminate D&A, including: advocating on a strong focus on respectful care as an essential component to quality care, generated data on respectful care and D&A, and including women in efforts to improve quality of care to eliminate abusive practices. (WHO, 2015).

Challenges to Respectful Maternal Care

Challenges to RMC are closely tied to the basic challenge of getting mothers to have a facility based delivery. Bohren et al. (2014) conducted a qualitative evidence synthesis on facilitators and barriers to facility based deliveries. By compiling and analyzing 34 studies they were able to identify facilitators and barriers by a broad theme. Some of the broad themes included: cost, transportation/access, policies, perception of risk, and perceived quality of care.

Each theme relates heavily on one another. “Perception of risk” and “perceived quality of care” are one example. “Perception of risk” means “awareness of risks associated with childbirth, influence of previous birth experiences on future delivery choices, and influence of ANC on delivery choice” (Bohren et al. 2014, 3). “Perceived quality of care” can be influenced by past interactions with health providers during a previous pregnancy and/or ANC. Alternatively “Cost”, “Transportation/access” and “Policies” are very much intertwined with one another leaving a barrier that could be categorized as all or one of the following themes.

Bearing this idea in mind it is easy to see how a barrier to simply having a facility based delivery also serves as a challenge to RMC. Some barriers to facility based delivery and RMC include: effects of previous birth experiences on subsequent delivery locations, facilities perceived as providing low quality of care, mistreatment and abuse by health workers, neglect and delays in receiving care at the facility, and lack of privacy in a facility.

When attempting to implement RMC systematically and consistently even just throughout one health facility or hospital. One must ask why? Why is respectful maternal care practices absent from health delivery services. Just as the prevalence of D&A is a detriment to access health care RMC faces challenges in its implementation. D&A and the absence of RMC is a systematic problem, one that cannot lay the entirety of the blame on “mean” or “uninterested” health personnel or personality characteristics. There are many real limitations preventing the RMC from being adopted in sub Saharan maternal facilities.

Evidence shows that challenges on the micro (personal) and macro (organizational) level contribute to D&A and the lack of RMC. (Warren 2017, Bowser & Hill 2010). For example, on an organizational level, the right to privacy may be fortified if a midwife is short of staff and is required to care for multiple patients, placing a curtain between patients to ensure privacy may impede on the health providers' ability to give care (Ndwiga et al., 2017, 8). It has also been found that providers, specifically, midwives vs clinicians, who have attended a higher number of births in the last month is less likely to provide RMC, particularly non-abuse and kindness, compared to providers who have performed less births (Dynes et al. 2016). This "burn out" is common in many social service professions. A high workload, in this case, deliveries, could decrease a nurse or midwife's ability to provide RMC on a daily basis.

Providers who carried the perception that they were paid fairly for their work provided significantly better RMC relating to friendliness, comfort and attention compared to providers who felt underpaid (Dynes et al. 2016). It seems that the perception of pay equity positively influences interactions and care provisions. Providers may feel appreciated and motivated to work, when they perceive their pay adequate. This hypothesis seems feasible as several qualitative studies show that low pay has been described as a particularly stressful aspect of their work environments and lead to unprofessional behavior (Bohren et al. 2015, Human Rights Watch 2011, Rahmani et. al, 2013). In particular a study conducted in Tanzania found that inadequate pay for long hours, ineligibility for overtime and lost opportunities to pursue other income generating endeavors were described as a contributing factor to providers' dissatisfaction with their working environment (Mselle et al. 2013).

Generally, societal attitudes also effected the implementation of RMC. To name a few: ageism, stigma surrounding HIV status, socioeconomic status, and sexual history affects the likelihood of a patient receiving certain aspects of RMC. Another study conducted in Tanzania found that patients' age mattered. Higher levels of RMC were reported in patients in their 30s-40s compared to women in their teens and 20s (Dynes et al. 2016). One possible explanation is that the providers themselves treat younger patients differently because they are just younger than them; or because they are younger than them providers feel that they are too young for motherhood. Lower levels of RMC could be a sort

disapproving mechanism adopted by providers. Abuya et al., also found that younger patients were less likely to received RMC, specifically, the RMC category of confidential care. Younger patients were experiencing non confidential care as a higher rate than older women. (Abuya et al, 2015) In general, younger women, specifically adolescents are more vulnerable to disrespect & abuse (Bohren et al. 2015, Bowser 2010, Ndwiga et al. 2017).

Background Information

Country Health Profile

Uganda appears to be wholly committed to improving the health care services provided to its inhabitants. The country is a member of the United Nations (UN), the African Union and the East Africa Community. This means that Uganda is in active agreement with the constitutions of these organizations that health is a human right and prioritize the development of a quality health care sector. Well intentioned, Uganda still faces challenges unique to developing countries.

Uganda is a fast growing country with 34.9 million and an annual growth rate of 3.03% (WHO Regional Office for Africa 2016, 5). It is estimated that 72% of the population live in rural areas and the remaining 28% in cities. Poverty has decreased significantly to 19.7% in 2012 with the majority of the percentage found in rural areas (WHO Regional Office for Africa 2016, 5). As of 2015 the fertility rate averages at 6 children per woman (WHO 2016, 124) and 48% of the country consist of youth (15 and under). 18.5% of the population is under five and only 2.3% of the population is 65 and older.

On the supply side, there is just one doctor and thirteen nurses for every 10,000 people (IRIN GLOBAL, 2011) and there is a massive inequality to services available in rural v urban areas. Urban areas (27% of population) have access to 70% of the medical services country wide. This significantly limits the quality of care and accessibility available to most households. Accessibility is also limited because of poor infrastructure as well as social-cultural factors that still advocate for the use of traditional healing patterns as a primary treatment course.

Uganda possesses one of the youngest and fastest growing populations globally; this can be a great opportunity for a developing country if proper investment is put into the upcoming

generations. This population demographic also speaks to the many risks (health related, natural and man-made disasters) that Ugandans are subjected to little protections. HIV/AIDs, lower respiratory infections, and malaria are the three leading causes of death (Uganda: WHO Statistical Profile, 2015). Although maternal mortality rates and under 5 child death rates are decreasing they still remain pressing issues for Uganda to reach its full potential. To obtain positive outcomes focus needs to be put on health promotion during the life course such as reproductive, maternal, neonatal, child, and adolescent health, as well as addressing social determinants.

History of the Health Care Sector

Uganda strives for universal health care by using the primary health care concept. (PHC) The primary health care concept developed in the 1970s attempted to tackle predominant health problems in developing countries by broadening the concept of health and by understanding other causes of ill health such as poverty, literacy and sanitation. (Tashobya, 2004). The five main themes of PHC are: the importance of equity as a component of health, community participation in decision making, multi sectoral approach to health problem, adoption and use of appropriate technology, and emphasis on health promotional activities. (Tashobya, 2004). Through a series of trial and error from the 1970s-upward Uganda has implemented reform after reform to achieve PHC in practice.

Between independence in 1962 and the implementation of PHC Uganda's health care system was established via a large network of health units and hospitals (one in each district) with preventive services and home hygienic run by health inspectors. Care was centered around the doctor whose main focus was providing curative care. This system worked relatively well with free and easy access to health care. This system relied on extensive funding from the government in order to be sustainable. The global recession of the 70s, compounded with the bad governance of the Idi Amin era, made the health care system collapsed and become highly corrupt and ineffective.

PHC came as a welcomed innovation to Uganda. Ultimately, instead of applying a comprehensive approach, selective PHC took hold instead. This meant that several various and overlapping health projects were adopted all at once instead of a holistic

implementation. Tashobya & Ogwal (2004) illustrate the confusion of taking the selective approach to PHC.

“The Control of Diarrhoeal Diseases (CDD) programme was introduced around 1983, and about the same time, UNICEF introduced a programme emphasising :Growth monitoring, Oral rehydration therapy, Breast feeding, Immunisation, Food security, Family planning, and Female education. In 1986, the Expanded Programme on Immunisation (EPI) was relaunched; the Maternal and Child Health (MCH) programme; Family Planning and the AIDS control programmes were also introduced. Over the period 1989 to 1993 a further expansion of vertical programmes/projects took place, and by 2000, there were 57 programmes in the health sector” (Tashobya & Ogwal 2004, 1).

Services were left uncoordinated and completely fragmented and distant from one another, some of these programs were virtually lawless as they received external funding.

Adopting selective PHC as well as the popular Structural Adjustment Programs (SAPs) of the 1980s and 90s lead to disastrous outcomes for many poor countries. SAPs ran under the idea that social services were not universal human rights. Simply this meant preventive services should be provided but the state and curative services should be covered by the individual (user fees). This lead to a severe cut in public expenditure on health, scarce public resources, and poor usage of the system-both on the demand side and supply side. The World Bank/IMF organized another set of reforms, still rooted in the philosophy that SAPs were built on, to address the problems within the health sector that were adopted in Uganda in 1986. These reforms still upheld the idea that government should reduce its responsibility to finance social services to free up resources that could be spent on the poor.

Clearly PHC was not able to be reached through the selective approach selected by Uganda because of the popularity of SAPs in developing countries at that time. The two approaches contradict each other. In Uganda PHC had the goal of reaching “Health for All” by the year 2000, when it was adopted in the late 1970s. In the mid 90s reforms that re centered “Health for All” resurfaced as decentralization took hold. This strategy was outlined in the ten-year National Health Policy (NHP) and a five-year Health Sector Strategic Plan (HSSP). The government introduced a minimal package that was to address major causes of disease, the main issues were the control of communicable diseases, the integrated management of childhood illness, and sexual/reproductive health and rights. Realizing the failure of the last two decades this reforms were to propel PHC to a priority in the 21st century.

In the new millennium many more health reforms have been implemented in the betterment of achieving universal health care. In 2001, user fees were abolished, this was a major success as for the last few decades user fees weren't regulated and mostly serviced to supplement health workers salaries (Okech 2014, 57). User fees also, kept many Ugandans from utilizing services due to lack of income. The abolition of user fees has promoted health equity among the rural, poor population. It still comes with its challenges. The abolition of fees did not abolish the corruption found within the health sector. Informal charges are still common and the incidences of out of stock drugs/resources have become normalized.

Structure of Health Care System

The structure of the health care system is outlined in the Health Sector Development Plan (HSDP) and incorporates the public and private sector, with the public sector covering 44% of the services available. (WHO Regional Office for Africa 2016, 6) The private sector is made up of non-profit health care providers (PNFPs), private health practitioners (PHPs), and traditional and complementary medical practitioners (TCMPs).

Public health care services are provided via decentralized actors with include facilities managed by 112 local government institutions, 22 municipalities, 181 counties, 1, 382 sub counties, 7,241 parishes and 66,036 villages (Uganda Census Report, 2014). The Ministry of Health (MoH) is responsible for the general leadership and governance of the sector. Their duties include policy formulation, strategic direction, definition of standards, disease surveillance, quality assurance and resource mobilization. Local governments are responsible for district level planning, budgeting and resource appropriation, passing health related by-laws, recruitment and management of health staff and service delivery.

The health sub county level strengthens the management of health services, improves equity of access to essential health services and provides the actual medical services (promotive, preventative and curative). All health facilities are organized in a tiered based referral system within each health sub country with patients starting at a health center II (HC II) level and finishing at a national referral hospital (NRH). It is estimated that 75% of the population lives within 5 km of a health center (WHO Regional Office for Africa, 7). The

community health system comprises of village health teams (VHT) that promote primary health care, encourage their neighbors to seek help at a health center.

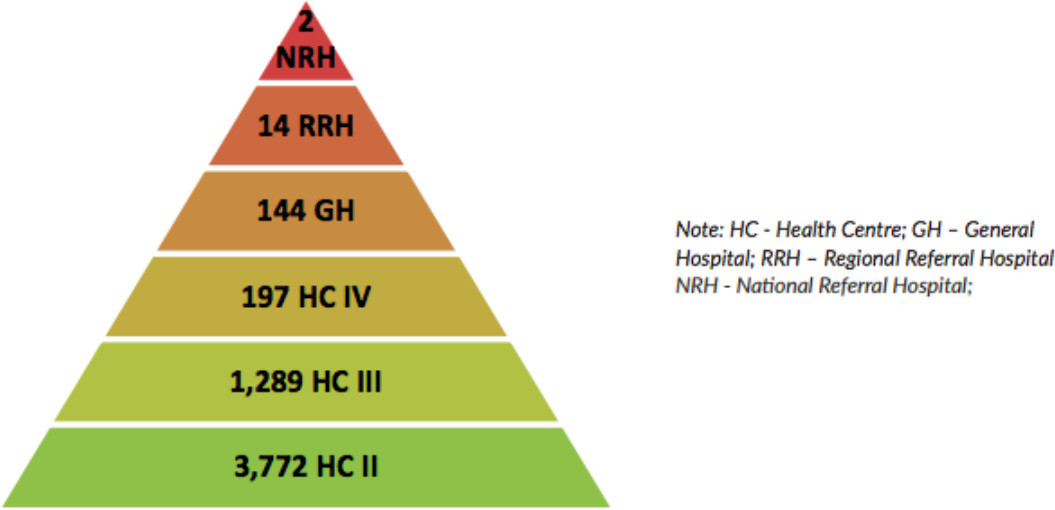


Figure 2 Organization of Health Services in Uganda
(WHO Regional Office for Africa 2016, 7)

In this tiered referral system, health center II is the next step for a villager after contact with a VHT and is located in each parish. HC II treat common illnesses such as malaria. HC II are staffed with a nurse, midwife, two nursing assistants and a health assistant. It runs outpatient clinic that run various basic preventative and curative services such as antenatal care, immunization, reproductive services, and HIV services. HCIII is locate in every sub-country and staffed with 18 staff who operate a general outpatient clinic and a maternity ward. HCIV serves a county and is basically a miniature hospital. It performs all the services found at a HCII and III but also has separate wards for pediatrics, maternity etc, it also admits patients. It also has a theatre for emergency operations led by a senior medical officer and another doctor. There are 13 regional referral hospitals in the country with Mulago Hospital in Kampala serving as the main referral hospital.

Maternal Health in Uganda

The maternal mortality (MM) rates has decreased significantly over the pass 25 years, in 1990 the MM rate was 780 deaths per 100,000 births, in 2015 the rate was 343/100,000

(WHO 2016, 27), but fell short of achieving the Millennium Development Goal 5. The Ugandan Health Sector Development Plan of 2015 marks MDG5a of having a marking of “slow” on the progress scale. Most of these deaths are easily preventable with women dying from postpartum hemorrhage, sepsis, pre-eclampsia/eclampsia, abortion complications and obstructed labor.

The Ugandan government and other large non-profits has launched several programs outlining various plans and initiatives to combat the challenges to quality maternal services. Some include the Boda for Mother Voucher Project funded through Baylor College of Medicine, Uganda’s “Maama Kits” program, and the Safe Motherhood Initiative.

The “Boda for Mother” Voucher Project is simply a voucher expecting mothers can give to motorcycle taxi drivers (locally known as “boda men”) as payment. The “boda” drivers can then report to Baylor to receive compensation.



Figure 3 Boda for Mother Vouchers

Uganda’s “Maama Kits” program was launched in 2003 with support from the WHO and funding from the US based non-profit “Links Inc. of United States of America”; the

program is operationalized through the Ministry of Health. The “Maama Kit” is a practical kit stocked with a plastic sheet, sterile gloves, razor blades, cord ligature, cotton, sanitary pads, tetracycline and soap. The “Maama Kit” initiative emphasizes the need for clean deliveries (“making child birth clean and safer) with sterile supplies that aren’t reliant on whether or not a woman can afford it.

Many maternal initiatives focus on access to care and the quality of medical services provided. Few focus and prioritize the emotional treatment women receive during care and how that may influence their decision to deliver in the presence of a skilled birth attendant. As discussed earlier many have studied the effectiveness of poor respectful care and its effects on woman coming to deliver at a health facilities. Overcoming many obstacles to be able to receive treatment, such as the monetary commitment of traveling to a health facilities and the geographical challenges of traveling on poor infrastructure, women may choose to stay home if they believe they will receive disrespectful care.

Challenges

Poor utilization of services account for a high percentage of poor maternal health outcomes. MM rates remain high partly most women don’t deliver in the presence of skilled birth attendant (SBA). In Uganda, just 58% of mothers deliver in health facilities. (WHO 2016, 28) the largest number of mothers mostly in rural areas deliver at home giving an estimate of more than 60% of the new born each year. (Mukasa, 2012). Another key predictor in perinatal death is the utilization of maternal health services, especially antenatal care (ANC). Whether a woman uses maternal services are dependent on a number of factors such as the woman’s occupation, the number of pregnancies/ children, and the partners’ socio-economic status, occupation and education. Simply it is also determined by if the woman even knows these services exist.

Other challenges include physical and mental accessibility to a health facility; some women lack money for transportation, or the health center is inaccessible due to a lack of suitable road. In one study conducted on utilization of maternal services 44% of the study proportion cited distance a barrier to utilization of health services (Rutaremwa et al., 2015, 3). Some women choose to deliver at home for cultural reasons, or the perceived lack of a quality care one may receive at a health facility.

Perceived lack of quality care systems from systematic inefficiencies most common, the lacking of supplies. This leads to poor attitudes from patients and providers. Often mothers are required to bring in their own maternity necessities leading to higher rates of sepsis or infections (WHO & MoH, 2006, 6). In addition, providers working under supply shortages are often perceived by patients are rude (WHO & MoH 2006, 7).

III. THEORITICAL FRAMEWORK

A few frameworks were applied in this study. Grounded theory practices were used to approach the analysis of data collected as well as form theory around the data. Furthermore, two other theories/approaches were also fundamental in framing the study. Based on previous research done disrespect and abuse and respectful maternity care conducted prior to data collection, the theory of intersectionality and the Gender and Development approach were used to frame the research.

Grounded Theory

The use of grounded theory fits with the nature of this exploratory study. Grounded theory can be loosely defined as “an abstract theoretical understanding of the studied experience” (Charmaz 2006, 5). Grounded theory is a useful approach to take when a researcher is studying empirical events and experiences.

Grounded theory methods consists of systematic, but flexible guidelines for collecting and analyzing qualitative data, to devise theories that are grounded in the data (Charmaz 2006, 2). The key word in understanding the application of grounded theory is *guidelines*, I applied grounded theory methods as a set of principles and practices, but not rigid rules. Grounded theory is flexible and is not a based on a set of methodological requirements (Charmaz 2006, 5).

Glaser and Strauss (1967; Glaser 1978; Strauss 1987) developed grounded theory practice and identified its defining concepts as:

- **Simultaneous involvement in data collection and analysis**
- **Constructing analytic codes and categories from data**, not from preconceived logically deduced hypothesis
- Using the constant comparative methods, which involves making comparisons during each stage of the analysis
- **Advancing theory development during each step of data collection and analysis**
- **Memo writing to elaborate categories, specify their properties, define relationships between categories and identify gap**
- Sampling aimed toward theory construction not for population representativeness

- Conducting the literature review after developing an independent analysis

As grounded theory is inherently based on flexible guidelines I choose to follow Glaser and Strauss' defining concepts that were relevant to this study and which are bolded above. Focusing on these four defining concepts guided my analysis and development of theory. In this chapter, I will explain how to approach my analysis based on collected data.

One of the concepts defined by Glaser and Strauss' grounded theory is: "conducting a literature review after independent analysis". I deemed it important to gain some knowledge of the larger discussion on respectful maternity care so a literature review was partly conducted prior to data collection. I believe this was an important step as a researcher, to gain context any issues they wish to study.

Women's perception of respectful maternity care was chosen as the focus of the study. I used initial data collection as a way to guide what were the relevant components of RMC, and use those components as a focal point of the study. From initial data collection, first privacy and informed consent/information sharing first emerged as relevant topics within RMC to be analyzed. Due to a context building literature review conducted prior, I was able to locate the language on key topics that I wanted as the focus the study.

Privacy became a topic of interest as I noticed the interesting use of curtains and screens as well as the openness or lack of privacy afforded to patients, within the maternity ward and also to HIV services offered. Curtain and screen use and openness of services are extensively discussed/analyzed within the data analysis and discussion chapters. Informed consent/information sharing also became a guiding topic of interest. The RMC concepts of privacy and informed consent/information sharing initially guided my analysis.

As I began conducting interviews, an idea emerged that women were not being transparent or fully open in their responses. This is were, the research effect became to emerge. I became to rely on my observational data in addition to interviews to guide my analysis further. From the observational data, detailed memos were written to document common threads and themes. Memo writing was identified by Glauus and Strauss as a key component to grounded theory methods. Common threads pulled from observational and

interview data were complacency of women, lack of advocacy, and the dynamics between patient-provider.

Charmaz (2006, 3) says that grounded theorists “study events and experiences and pursues their hunches and potential analytic ideas about them”. In this way, the study evolved immensely, from a guiding topic of interest to slowly solidifying emerging themes to shape theory. The journey between data collection and analysis, felt as piecing together a puzzle, linking them together to understand the full picture- meaning the theory. Fitting these “puzzle pieces” together is bases of applying grounded theory, and gaining and analyzing meaning from studying the experience of participants. Studying participants’ experiences is based in the understanding of how the participant interacts with other people or institutions. For example: how women interacted with midwives, doctors and even myself, as an researcher. Studying these interactions is deeply rooted in the sociological approach of symbolic interactionism, that serves as one of the theoretical foundations of grounded theory.

Symbolic Interactionism

Symbolic interactionism can be loosely defined as a theoretical perspective that “assumes society, reality, and self are constructed through interaction and thus rely on language and communication” (Charmaz 2006, 7). Following the guidelines of grounded theory methods, I conducted simultaneous data collection and analysis and this principles of grounded theory is directly linked to the symbolic interactionist understanding of “action and interaction”.

According to Mead (1934), who is credited with developing symbolic interactionism, actions arise out of social interaction. There are two forms of social interaction: non-symbolic and symbolic. Non symbolic interaction is a “conservation of gestures” (Mead 1934, 167), a process in which individuals directly respond to another’s actions (Blumer, 1969 cited in Chamberlain-Saluan, Mills & Usher 2013, 6). Symbolic interaction is “ a cyclical and fluid process, in which participants continually adapt or change their acts to fit the ongoing act of one other... interactions become symbolic when individuals interpret and define their own or another’s actions and act on the basis of assigned meanings” (Chamerlain-Saluan, Mills & Usher 2013, 6). Symbolic interaction is an interpretive

process that directs the actions of the one doing the interpreting and conveys to the other, or to one's self, how he or she "is to act" (Blumer 1969, 66).

According to symbolic interactionism, every action has meaning. Within data analysis, the interactions between patient and Ugandan midwife/doctor, patient and Ugandan student midwives and even the interactions between patient and myself have meaning that is applied to the analysis of the data. This means that reading "between the lines" at action and not just verbal language was a part of understanding women's role and perception of respectful maternity care.

The use of symbolic interactionism is apparent in concluding explanation of women's perceptions of respectful maternity care. The analysis of participants interactions with me, doctors and midwives made apparent, the power hierarchy existent within the patient-provider relationship with patient, specifically pregnant/recently delivery women, assuming the lower status. These women played the role of submissive based on the actions of midwives and doctors.

Gender and Development Approach

The gender and development approach (GAD) also guided the data analysis and development of theory in this study. GAD was another approach known as women in development (WID). WID shifted in GAD as international development professionals began to recognize the relational unequal balance of power between men and women. Where WID specifically focused on women's issues, GAD focused on the social relationships between men and women in which women were systematically facing discrimination (Moser 1993, 3).

Whitehead writes on the position of women in development as such that aligns for the GAD approach "our first assumption was that any study of women and development... cannot start from the viewpoint that the problem is women, but rather men and women and more specifically the socially constituted relations between them" (1979)

The GAD approach takes a look at women in relation to men, and ways in which these social constructs of gender have been conducted and how they are negatively affected by these unequal relationships. This approach focusses on the subordinate status of women in relation to men (Moser 1993, 4). Dominant and subordinate status is especially relevant in this study, in relation to patient-provider relationships.

Intersectionality

In 1989 Kimberle Williams Crenshaw developed the sociological term “intersectionality” to map how several socio-economic identifiers can simultaneously perpetuate discrimination. Crenshaw has primally wrote on intersectionality within the lens of race and gender, specifically how black women’ experience of discrimination must be, minimally, framed through the lens of their race and gender. She uses the practical image of a traffic intersection as a way of explaining this phenomena,

“Consider an analogy to traffic in an intersection, coming and going in all four directions. Discrimination, like traffic through an intersection, may flow in one direction, and it may flow in another. If an accident happens in an intersection, it can be caused by cars traveling from any number of directions and, sometimes, from all of them. Similarly, if a Black woman is harmed because she is in the intersection, her injury could result from sex discrimination or race discrimination.” (Crenshaw 1989, 149)

Since the introduction of the term, intersectionality has been used to explore many phenomena not just centered around race and gender but have been used to study ageism, ableism, xenophobia, heterosexism. The intersection of class, and gender, I believe, shaped many aspects of this study, not only the quality of care given but also the quality of care some perceived has adequate based on these identifying markers. Maternal health is a woman dominated field, from patient to provider. The location of this study was in a rural setting where most people work in the agriculture field, far from a large city and would be considered lower class. Most women receiving services would be identified at lower class, rural women.

Therefore before data collection became I became aware of how location, and socioeconomic status could intersect with each other to influence the perception of respectful maternity care from pregnant woman. Location, means physical location of rural vs. urban but also the location that has an influence on culture. The area is symbolically

ruled by a specific kingdom that carries its own cultural values and traditions different from area in Eastern Uganda like Kampala or Jinja for example. The intersections of quantifiable components such as income level and unquantifiable components like one's identity must be considered as components that can affect that study's results.

IV. METHODOLOGY

The following chapter will highlight specific research methods that were employed to complete this study. I sought to gain an understanding of what woman wanted out of their care specifically during and after delivery, therefore a qualitative study was deemed most appropriate.

Through studying at Oslo Metropolitan University, I connected with Professor Louise Ackers, founder and chairperson of “Knowledge 4 Change” (K4C), a charity based in Manchester and Fort Portal, Uganda. K4C organizes ethical student-nurse placements and professional medical staff placements in several health centers in and around Fort Portal. Through this organization I received placement in two health centers (HCII, HCIV), specifically the maternity ward, alongside a few student nurses and midwives from K4C. There I was able to conduct active and passive observations, and well as interviews with recently delivered mothers, midwives, and doctors that spanned over a 10-week period.

Gaining Access

Formally, the Uganda program manager for K4C acted as a gatekeeper for me to gain access to the health centers. Once placed there I received a more informal introduction to medical staff via one of the UK midwives who spent a few weeks working alongside HCIV midwives prior to my placement. From there I had access to pregnant women or recently delivered women. From these introductions it was my responsibility to make connections with pregnant or recently delivered women.

Ethnography

Ethnography was chosen as a methodology in this study. According to Schwandt, adopting an ethnographic methodology is ideal “for generating and analyzing qualitative data that is grounded in a commitment to firsthand experience and examination of some particular social or cultural phenomena. (Schwandt 2007, 93). Ethnography draws on a number of methods including directed and constant contact with participants in the context of their daily routines, watching what happens, listening and asking questions. (O’Reilly 2009, 6). Because this study focusses on mothers’ perceptions of respectful maternity care, it felt

important to capture the “unsaid”, the energy between woman and midwife/doctor and of course patterns in behavior.

Method: Participant Observation

Participant observation is the main method employed in this ethnographic study. It added a great deal to my study that otherwise would’ve been unidentified with just interviews. By conducting observations one can focus on how social and interactional processes occur in a specific setting. (Clarke 2009, 363). Observational data can thus help to illuminate, understand and explain behaviors observed, making sense of out their outcomes. (Clarke 2009, 363) Systemic observation, in this study over 10 weeks, will allow the researcher to identify individual, unit and organizational culture/context that influence outcomes.

Participant observation is useful for a few reasons; it helps to gain an understanding of things from the “native’s” point of view, to blend into the setting as unnoticed as possible, and to truly understand the setting so you can make sense of it. (O’Reilly 2009, 11). As I examined a facet of maternal health but held no background in a medical related field it was important for me to spend time learning and understanding the basic structures of a maternity ward. I received a crash course in antenatal care, deliver and postnatal care. Even though I was not a medical professional, blending in proved easy as there was a class of student midwives participating in observation and instruction during my 10 weeks there. I blended in with them.

During participant observation the researcher takes on two roles as a participant and as an observer. A participant is a member of the group, joins in on activities and shares experiences, emotions etc. Generally she, takes part in daily interactions. An observer is an outsider, someone who watches and learns, and doesn’t fully engage. The role of the participant observer is to participate in order to observe. This involves the ability to stand back to reflect, analyze and objectify interactions. Over time this will lead to the research asking more directed questions, the researcher will become more directed in the way observation is collected, thus observation becomes more of the focus as the study progresses. (O’Reilly 2009, 11)

Semi Structured Interviews

Initially only semi structured interviews were to be used as research data but as I spent a few weeks in the health centers observing, I realized the need to include observational data. I encountered difficulty generating participants who were willing to be interviewed. When I did interview mothers I felt that their responses/opinions on the quality of care they were receiving was not entirely truthful. I will discuss why I felt that way and why I believe this to be true within the discussion chapter.

Even though semi structured interviews served as the primary method of interviewing, I employed several interview strategies throughout the study. Unstructured conversations took the form of asking questions to midwives or mothers in an informal context or conversations that happened after particular incidences. These were unplanned sessions that added to the depth of the study.

I engaged in semi structured interviews with a recorder and note pad. The interview would begin with an outline or guide to loosely follow. If the interviewee veered off topic no attempt was made to steer the interview back to an outline. What the interviewee deemed relevant to discuss is what I deemed important. As O'Reilly (2009) states "an ethnographer is usually attempting to learn about participants from their own perspective, to hermeneutically understand the other's view, and this will not be achieved by imposing one's own line of questioning on people" (O'Reilly 2009, 13).

Focus Groups

During the course of this study one focus group was conducted with 4 UK midwives who worked along myself and Ugandan midwives and pregnant women from a range of two months to two years. This was an informal planned discussion that took place over afternoon tea at a frequented nearby café. We were all familiar with one another from working/living with one another. I took an active part within the discussion. I was able to say things and/or subtly bring up topics to test out responses and spend time on topics of particular interest. This method is known as something in between a natural conversation and a focus group; Katie O'Reilly (2005) defines that is an "opportunistic discussion". The advantages of planned discussions is that they bring up conflicting idea, cause others to

think about things that they haven't and cause them to question assumptions and maybe even change their minds (O'Reilly, 2009 7).

Setting

I was able to conduct my study in two different public health centers in and around Fort Portal. Each health center is categorized in a different tier in the referral system; one was a midwifery led, HC III and the other HC IV. During my time at these two health centers, active/passive observations were conducted and also served a main place to pool respondents for interviews and focus groups.

The Health Center III (HCIII) consisted of a maternity ward, a lab, an outpatient facility. The most common services provided include, antenatal, family planning services, immunizations, basic curative measures, delivery services (n; an antiretroviral therapy (ART) clinic is also held there. The maternity ward appears as one flat structure with 5 rooms and a main hallway area. The biggest room, the postnatal room, contains 6 beds. There is also a small room for antenatal visits. The second largest room is the delivery suite that also functions as an area for small procedures such as in inserting birth control.

The one room is an administrative office as well as medicine dispensary and sometimes even as a counselling room. The last room serves as a break room for health staff, there is a bed for overnight midwives and often health staff will take their tea breaks in this room. About 4-5 midwives are employed and regularly work in the maternity ward doing not just midwifery work but also outreach in neighboring villages due to the high HIV ratio in the area. During the period of my study for were also 2-3 volunteer midwives working at HCIII.



Figure 4 HCIII Maternity Ward

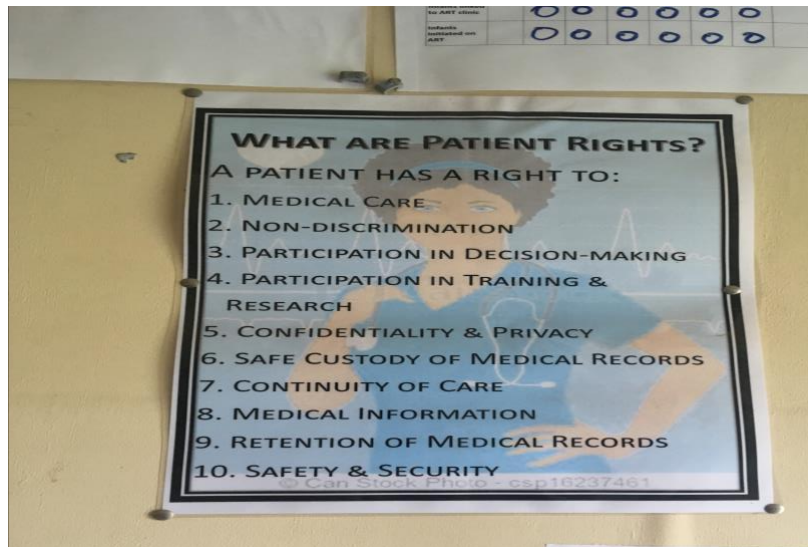


Figure 5 Patient Rights Charter in Lobby of HCIII

Health Center IV (HCIV) sits on a larger plot of land and had a few more services available than HCIII, including an operation theatre. The maternity ward enjoyed more services, like access to an operating theatre, and resources than found in HCIII; the delivery suite had three bed instead of two. There, women can be admitted during active labor and the antenatal ward housed eight beds. The postnatal ward also boasted 8 beds.

There was also a health staff break room with two beds and a desk, a stock room, two indoor toilets (as well as outhouses), one antenatal room, and one consultation room for family planning, and an office. There is a NICU/ newborn services ward as well. When

entering the maternity ward there is a large lobby area for women waiting for antenatal services with about 7 rows of bench. The amount of staff varied and it proved difficult to get an approximate number, but around 20 health staff were employed in the maternity ward of HCIV. This includes midwives, doctors, and NICU nurses.



Figure 6 Delivery Room- HCIV



Figure 7 Waiting Room/Lobby HCIV

Interview Setting

Since I met most women at HC III or HCIV this served as the location for our interviews. I quickly learned it became very difficult to follow up with women once they left due to a lack of transportation and/or of a mobile phone; basically lack of infrastructure made follow up nearly impossible. For example if it rained, many people simply would not show up to a pre-planned meeting, including their place of employment, due to the deterioration of dirt roads that made travel difficult.

The location of the interviews proved a difficulty as I did not want the women to feel they could not freely express themselves while physically sitting in the health centers. Because of this the interviews were conducted on the lawns of the health center or at the local canteen that was located about 100 yards away from the health center. In this way we were able to give some privacy and lounging on the grass or grabbing a soda at the canteen gave our interview an informal feel.

Confidentiality & Consent

To ensure the confidentiality and anonymity of the health center patients, midwives and doctors in this study all names remain anonymous, names used in the privacy, informed consent and discussion chapters are names that have been changed. Health information is a

very sensitive and personal topic. In this study protecting other's information was of the utmost importance. The health centers are only referenced as "HCIII" and "HCIV".

In order to ensure understanding of my study and the choice of participation on every level I will outline the steps I took to ensure informed consent was given. Allan, the program manager, in Fort Portal was able to deliver an information letter to the head of the hospital explaining my study, the scope of my research, who and what I wanted to talk to. This information was basically a permission request to the administrator to gain access to spending time at "HCIII" and "HC IV".

Informally once I began going to the health center. I was introduced to HCIV midwives through a UK midwife who had been working alongside them for a few weeks. Being introduced by someone who they knew eased my transition. Our interactions and gaining consent from the midwives was a very informal ordeal. Consent was gained in several conversations with several midwives and one doctor. The midwives were curious about me, asking me many questions, such as "are you a nurse?" "what do you study?" "where do you study?". In this way it was easy to communicate a lot of the information about my study and if my presence was wanted or not. The general information shared was that I was a student from Oslo Metropolitan University, affiliated with K4C and my observation/ interview were for research purpose on a school assignment. I made it known that the study was completely voluntary and participation could stop at any moment. Every midwife and doctor consented to be involved with my study.

When observing pregnant women, I asked the midwives to briefly explain who I was, what I was doing and ask them if it was okay if I sat in on antenatal visits, deliveries, and postnatal visits. This often happened while I was present, in the local language of Rutooro. Often I would have to prompt the midwife to remember to ask the woman. In this way I was at a disadvantage as most of the women did not speak English.

When interviewing women after their birthing experience I employed a translator. The translator was a student at the local university studying IT, and was completely unaffiliated to the health centers. I initially meet her and had a conversation about the scope of the

study. I gave her a copy of my information letter and consent letter. I wanted her to have an idea of the study and her role within the study.

I asked her to translate my information letter and consent form into Rutooro. Ultimately this proved fruitless; the women who didn't speak English also could not read in Rutooro. Because of this verbal consent became the method in which consent was recorded. My translator would speak with the woman on my study, ask for consent, tell them participation is voluntary and they could withdraw at any moment and also ask them if they had further questions. She would often use my consent form, glancing down to ensure she gave a full range of information when asking for consent.

Ethical Considerations

This study received ethical approval from the Norwegian Center for Research Data (NSD) in Bergen, Norway on 15th of August 2017. The approval form can be found below in the appendix. When participate observation was added to my study I re-contacted the NSD agent processing my study to update NSD on the changes, so it would be reflected in the approval form.

Collecting data during medical procedures exposed me to many bits of information about my participants, such as HIV status, the nature of their home life, pregnancy and a host of other identifying factors that are deeply personal. In order to ensure that no physical, emotional, long term or short term harm was done by my study. I employed a number of methods. Even if a woman consented to my presence and participation in my study if I felt they were uncomfortable with my presence I would excuse myself and discredit their participation. I reached the decision to excuse them from the study if I noticed, uneasy looks, constant glances towards me, and speaking in a low/soft tone.

O'Reilly (2012) discusses the idea of power and status as an ethnographer. She states "some people feel that as researchers they are in a powerful position in relation to their research participants. They choose the topic, direct the research, decide what to record and how, decide what to ignore or overlook, and determine what is written and where it is

published” (p 10). In some cases, I felt that women gave consent to participant in (and to many other things dictated to them from medical staff) due to the idea that these groups (myself as a research, and medical staff) held power over them. During my study I was very familiar with the UK midwives (affiliated with K4C) who working alongside of HCIII/HCIV midwives whom I became acquainted. Women saw me interact with them and accompany them to meals and medical visits. In this way the assumption that I was affiliated with HCIII/HCIV may have been made by some women participants.

During the interview process participants received information verbally and were asked to give their consent verbally. They received information on the purpose of the study, the responsible institution, the methods used for the research and how their information would be treated confidentially. I also informed them on the voluntary nature of the study and that they can withdraw at any time without giving a reason. They were asked if the interview could be recorded, explaining to them that once the interview was recorded it would be transcribed and used for analysis. Once the study concluded all data would be deleted.

Validity and Reliability

Validity within the social sciences means that one is arguing that the findings of a certain study is true and certain. (Schwandt 2012, 309). True meaning that the finds represent the phenomena being studied. Certain meaning that the findings are supported by good evidence backing up the asserting and conclusions made within a study.

Reliability with the social sciences can exist without validity. Reliability within a qualitative study means the consistent and stable interactions can occur repeatedly over a time of span. Just because a repeated outcome is reached doesn't necessary prove validity. Consistency and stability are two components to defining reliability.

Consistency can be measured by the number of times results can be independently recreated within a certain margin of error. Stability refers to the degree in which the results can be replicated independently at a later date. Basically can the study be examined later in time and reproduce the same results (Ward & Street, 2010, 801).

There are two types of reliability recognized within the social sciences: external reliability and internal reliability. External reliability exists if researchers are able to generally recreate a study and produce similar results. Proof of external reliability is in how can the results of a study be founded in similar situation. Internal reliability refers to the consistency and rigor undertaken for data collection, analysis and interpretation.

Data Analysis

Two approaches to of data analysis were used: a thematic analysis approach and a conservation analysis approach. Within this chapter I will delve into more detail of each approach. The interviews and focus groups were recorded and transcribed. The observations were recorded by hand in a notebook and typed into a Word document at the end of each observation day.

Thematic Analysis

More specifically in this study a thematic analysis approach was used in the analyzation of data. Thematic analysis is an approach that involves identifying themes, classifying data according to those themes; and interpreting those themes by searching for commonalties, relationships, patterns, theoretical constructs or explanatory principles. (Lapadat 2010, 926). Richard Boyatzis pulls five purposes of thematic analysis: as a means of (1) seeing (2) finding relationships, (3) of analyzing, (4) systematically observing a case and (5) quantifying qualitative data (Boyatzis, 1998).

Conservation Analysis

Conservation analysis was most important to understanding the relationship between HCIII/HCIV midwives and the pregnant women whom they interacted with. This approach to analysis views social actions as worthy of in-depth examination, the belief is that at the core of these social actions patterns of order can be discovered that can produce overarching patterns, resulting in themes (Grandy 2010, 239).

Both conservation analysis and thematic analysis worked alongside one another during the analysis process. Conservation analysis allowed me to gaining a more rich and in depth understanding of the relationship between patient and provider. Thematic analysis

facilitated a way to track emerging themes and ideas that were identified through the social actions of participants.

Coding

All data was then coded into a few main themes and then into sub themes. The main themes identified were: privacy, informed consent, and information sharing,

Coding is a “process that disaggregates data, breaks them down into manageable segments, and identifies or names those segments.” (Schwandt 2012, 32). Within this study a grounded, posteriori, context-sensitive scheme was used for coding. A grounded coding scheme begins with setting some simple codes but refining and tweaking the terminology as the study progresses and data collection requires the codes to reflect the nuances of the themes.

This inductive approach to coding is common when using a thematic approach to analysis. Themes are derived from grounded data. This process is ongoing throughout a study; it is a process of noticing patterns, and being cognizant on how participants label events. The researcher must constantly compare data to codes/categories and revise codes and interpretations as data is collected and overarching patterns are identified. In this way the researcher builds a rich, complex, exploratory and explanatory case (Lapadat 2010, 297).

V. PRIVACY

“Doing a Show of Privacy” & It’s Significance

In the early stages of passive observation, the RMC category of “the right to privacy” glared out to me as a route a focus for my study, simply because their seemed to be a lack of privacy. One October when a UK based midwife came in for her first day in maternity the very first comment she made to me was on women’s naked bodies. The glaring lack of privacy in the physical form (women undressed on tables without a curtain) to confidentiality of medical history, lead the focus to this topic. Studying privacy patterns or lack thereof seemed practical. This is something that can be easily monitored in a systematic way. For example, I made a checklist of privacy components that were easy to quantify:

Date: 10/2/17	Cloth covering delivery suite window?	Curtains separating women (during med procedures) in delivery suite	Screen usage during antenatal/postnatal patients
Arrival- Morning	Y/N	Y/N	Y/N
Noon	Y/N	Y/N	Y/N
Departure- Afternoon	Y/N	Y/N	Y/N

Notes:

This covered the most basic interventions “built in” the maternity ward: most commonly consisting of hanging curtains in the delivery suite, in which two bed operated as delivery bed and one as an office table. The delivery suite also had fashioned multicolored curtains over the window on the entrance/exit door so no one could peek in. The windows in the delivery suite has blurring window panes. There were also two sets of screens used, one located in the antenatal room and the postnatal room. These interventions covered the basic built in privacy mechanisms at HCIV.

Curtain Usage at Health Centre IV

The idea behind establishing “built in” privacy interventions is that providers will automatically use them because a) it is easy b) it is there. This proved to be wholly false in the situation with the Ugandan midwives. Use of curtains, screens and other physical privacy methods that are meant to put a woman at ease are adopted in a very exceptionally based method. Specifically, Curtain/screen use proved to provide a lot of information on the role that physical privacy plays in the maternity ward. From curtain use, I was able to really begin to understand if Ugandan midwives deems physical privacy an important service to provide.

During my two months spent conducting my observation I rarely witnessed curtain use within the delivery suite. Midwives didn’t really bother to use them, nor did expecting mother or attendants request for it’s use. When used in the delivery suite this would happen right before the baby was born, during active “pushing” time.

The importance of curtain usage as relating to privacy comes up early in my focus group with the UK midwives group.

I’ve definitely seen (privacy) in isolated examples that have stood out because it’s a surprised. So I’ve been surprised when sometimes a midwife will pull a curtain around (the delivery bed) for example. Doing a show of privacy... she’s asked people to leave but that’s definitely been the exception.

-UKM1

During the focus group while discussing the exceptionally of the usage of privacy mechanisms we had an interesting exchange, that shed more light on the significance of privacy:

***Interviewer:** So what I noticed at Bukuku is that the use of the curtain, like you said, you’d be surprised if the curtains were used and it’s seem super arbitrary so like for example I had a UG Midwife come in and she was examining a woman and she put the curtain down in between me and the woman like by where the desk area is which I thought was really strange and it kind of made me think perhaps they don’t really understand why they should use the curtain but they know that they should sometimes so they just do it sometimes and it’s very bizarre.*

***UKM3:** It’s a very task oriented thing rather than a like...*

***Interviewer:** Having comprehension as to why you should use this?*

***UKM3:** Yeah*

Curtain use, when used was seen as more of a one step in a line of midwife related things, but the comprehension of why the curtains should be used where not.

UKM2: So actually those curtains weren't up at Bukuku until the American ambassador came to open the unit. So they hadn't been there at all and that's why they got put up.

UKM3: But then I think like the other day- the day there was an inspection and it was when the strikes were happening. But we went in and the room (delivery suite) was spotless, it was clean, it was tidy, it was well organized and was in stock and all the curtains were down so they know that..

UKM2: That's what they want.

UKM3: They recognized what the expectation is however it's only adopted when they would have consequences.

The use of curtains only was adopted because of a visit from the American ambassador. In a sense privacy was most likely “cared about” when “the boss” would be watching.

Negative consequences strongly encouraged the usage of curtains instead of a patient centered approach that place emphasis on the woman's preferences.

Several UK based midwives who work alongside Ugandan midwives noticed this themselves.

The needs and wants of the woman sometimes seems to get lost when discussing health care but it's important to always position the patient first and center care around them.

Which can prove to be difficult. One UK midwife commented:

“I think we've all talked before with each other about how it's much more community living here. So for women it's extremely normal that other women can overhear their antenatal check or they will come to clinic which is for women who are HIV positive and their babies and there all sat outside basically on a public road, they all know each other and they, you know, often people will be giving out antivirals to women through an open door. There's like- there isn't even- I think- an expectation of privacy.” -UKM1

Do the rural Ugandan women, even care about their physical privacy before, during and after giving birth? There could be at least three difference answers that all overlap with one another: disinterest, the appearance of disinterest, or a systematic complacency. Certainly, the majority of the time I spend observing deliveries, antenatal and post-natal rounds many, many women seemed completely fine laying naked on bed in a room surrounded by multiple medical staff. Some were quiet, some stared a myself and the groves of student midwives with curious eyes, but absolutely no one voice any type of discontent with any part of their care, at least in my presence.

Observation of Mary

This phenomenon was quite puzzling and became even more troubling when *Mary was found in the postnatal ward. Mary is a 20 year old first time mother who delivered her baby via cesarean section. I was able to conduct an interview with her in the native language (Rutooro) with the help of my translator. I was unaware that Mary spoke English until later. During the interview Mary said she was generally satisfied with the care she was receiving in the maternity ward. Later on that evening I was speaking with UKM3 about her day in maternity. She stated that for the past few days she was caring for a woman who lost a stitch in her stomach after a c-section and was suffering from sepsis. This woman had asked that UKM3 treat her wound because in her words “The other (Ugandan) midwives were too rough”. The next morning in maternity UKM3 points out the woman whom she was referring to and it was Mary.

The day before when I interviewed Mary she never mentioned anything about rough care, pain and/or a preference for UKM3 even when asked questions relative to her situation:

1. Are there any improvements that could be made to care on the ward?
2. Were providers empathic to your pain/relief?
3. Do you feel like your physical privacy was protected when you received care in the maternity ward?

The next morning and for a few days after I directly observed Mary. In a very casual manner I'd sit with her, chat, hold her newborn and watch as every few hours UKM3 would come and change the bandage on her wound. UKM3 used a screen while caring for Mary. UKM3 indicated to me that Mary *asked* for the screen to be used. One Monday she told UKM3 that nobody had changed her bandages the day before. With UKM3, Mary was very vocal (privately) to make sure she received the type of care she wanted.

I asked Mary for a second interview which she consented to but declined to be recorded (she consented to being recorded during her first interview). I found this interesting and after the interview we chatted a little bit and I asked her why she declined to be recorded. She expressed to me that she was skeptical of me. She asked “Why me? Why are you interested in speaking with me again?” She also expressed her fear that I would put the recording of our interview on the internet. This indicated to me that Mary cares deeply about her privacy not only her physical privacy in maternity but the use of her intellectual property via the interview with myself.

Student Midwives

The presence and sheer number of medical staff took on a life of itself within the maternity ward that could not be predicted. During a three-month period there was around 40 student midwives completing training. This maternity ward of relatively small size could not accommodate such large numbers. Often this would result in an interesting dynamic for mothers, midwives and the student midwives. The student midwives mostly accompanied by themselves (sometimes with a teacher) would be responsible for conducting rounds on women admitted in the antenatal ward, and the postnatal wards. They would also conduct antenatal clinic. Most of their activities were unsupervised, sometimes they would receive instruction from Ugandan and UK midwives alike.

When the student midwives did get instruction they would eager crowd around a woman and watch, take notes and answer questions coming from the teacher or midwives. In not one instance where I witnessed this did I see any women asked if the student midwives could observe. I neither, saw the women object to this. In instances when it was a routine check the women seems a little excited to have so much attention on them. This created a situation most would classify as uncomfortable. There would be between 6-15 student midwives plus a teacher and/or midwives plus myself observing. If rounds were being conducted in antenatal and postnatal ward stares from other women admitted or their guests would follow.

During one particularly hectic day where about 20 student midwives were training. A woman was in active labor (around the last hour until birth) and it was a particularly stressful labor experience for all involved. It had been many hours and baby's head hadn't dropped far enough down for mother to begin pushing, even though she was fully dilated. It was a tense few hours as the Ugandan midwife and UK midwife disagreed on what should be done to get the baby to drop further.

The Ugandan midwife decided that the mother should begin pushing at the disagreement of the UK midwife. The mother begins pushing and in these moments the student midwife group were due to switch shifts. The morning students were scheduled to leave and the afternoon students were scheduled to arrive. Signing in and out was done in a book located in the delivery schedule, during these tense pushing moments of the mother, in the course

of 5 minutes, about 30 student midwives rushed in and out of the delivery ward to sign in/out of the log book. All of these happening as this woman attempted to give birth; it was very chaotic. One out of two curtains were drawn but you could still very easily see the woman.

In most cases where I witnessed any number of student midwives conducting observations the woman could, at any moment, object to their presence. In this situation this woman was in the stages of giving birth, the most vulnerable time, during pregnancy, physically unable to express her wishes. During this time the energy in the room was not optimal due to a disagreement between midwives and further sullied by an exuberate number of people entering and exiting the delivery suite.

On one side, the student midwives seemed to be a hindrance and annoyance. They were many; anywhere one went there would be a number of them. Why did the women seem enjoy their presence or simply accept them as the final medical opinion on their pregnancy? After all they are just second year students.

Absenteeism among the doctors and midwives appeared to be high. This was not scientifically measured because it was difficult to get a count on how many midwives/doctors were employed but also because that wasn't the focus of this study. Often in the morning there would be one Ugandan midwife from the night shift waiting for the morning shift to relief her. Sometimes they showed up other times they didn't. On the instances when a midwife was not present, a number of student midwives would be present and effectively run the ward until someone else would show up. It may be a stretch of an hour or a few hours but they would pick up the slack. In this way mothers depended and appreciated their work as they were consistent, more consistent than most employed there.

This proved to be most helpful in the weeks of the doctors' strike. Even though only doctors were striking many midwives began to strike in solidarity with the doctors. Many midwives stopped showing up to the ward. When they did they were to act only in emergency cases/births. If they were present within the health center's vicinity, physically, they wouldn't be present in the ward. Student midwives were able to stay and do a few

basic things. Their skill set was very under developed but it gave the mothers comfort to know someone checking on them.

This dynamic relationship between student midwife a patient makes it impossible to predict a privacy violation or not. The student midwives developed a sort of trust and kinship between patients, maybe even better than the midwives themselves. They weren't quite used to the workplace culture of the health center. Because they were students they are inquisitive and attracted to learning new things. They would question anything and everything. They were more likely to change or challenge a behavior because they were developing what type of midwife they would be themselves. For example they would be more willing to clean up the ward when prompted. Because of this they were more likely to be "kind" to patients, therefore winning over trust.

Culture of Transparency or Lack of Privacy?

Briefly discussed above by one UK based midwife was the idea that privacy does not factor into a woman experiences of respectful maternity care. Women may be more comfortable in shared community spaces so lack of curtain/screen use does not bother them. I began analyzing observation data taken from Friday September 23, 2017. Every Friday two events occur: mother bring newborns for post-natal appointments, they usually entails vaccinations, baby weigh in and addressing anything else concerning baby and mother. The second service is the HIV clinic where HIV+ patients come, collect their medication, hold support groups and address any needs they may have.

Mothers arrive and sit outside awaiting the start of the postnatal clinic. The postnatal clinic is conducted outside including: vaccinations, examination of baby and a weigh in, at minimum. Similarly for the HIV clinic, HIV+ patients begin lining up outdoors and health clinic staff will come outside to give instructions etc. Simply, it is very easy for the community to know the status of other's health or the status of the health of someone's baby with the current clinic set up.

Yet there are no patient complaints clinic set up may be reflective of the dynamics of an individual and their respective community as a whole. Even though these patients lack privacy, this is not presented to me as an issue they had. This could be a culture of

transparency, or it could actually be a concern from participants, but they do not articulate during this study. These two perspective will be further analyzed within the discussion chapter.

VI. INFORMED CONSENT/INFORMATION SHARING

Midwives Perspectives

“Stop asking her because she’ll just say no! And I’m like that’s the whole point!” - UKM3 in UK Midwife Focus Group

Are women receiving services or are services being performed unto them? That’s one of many questions that arose as observations and interviews progressed within the study. As reported in the previous chapter, women do not reject the presence of the student midwives, rather they welcomed it. But if the student midwives weren’t so accommodating and kind would the women voice their objections? Did they feel as though the maternity ward was a space for their voice, opinions or rejections to be heard?

These observations and topic brought up during a focus group with UK base midwives, drew the researcher to another theme within the RMC charter pertaining to information sharing and informed consent. Within the RMC charter the second right is “the right to information, informed consent and refusal, and respect for choices and preferences, including the right to companionship” (Respectful Maternity Care Charter p.2, 2011). From observations and interviews the right to information sharing and informed consent appeared to be a relevant RMC to explore. Apparent was the ambiguity on the place of informed consent/information sharing. It was difficult to gauge the use/prevalent of it, and if women deemed it to be an important part of RMC. In an excerpt taken from a transcribed interview below a mother felt that refusal of a service from a midwife could not happen.

Interviewer: *So did they tell you they were going to cut you before they cut you?*

MI: *Yes, they did. And you can’t even disagree because you have to push. After that I have to push immediately. After that cutting. I had to push. Immediately the baby was outside. (laughter)*

Whether or a conversation took place prior to the delivery stage about the possibility of a episiotomy is unclear. It is clear that the mother above felt certain that one could not refuse.

Within the focus group for UK midwives a few instances were recalled on refusal or allowance of information sharing/ informed consent. UKM3 explains a situation in which Ugandan midwives actively refused to share information and/or receive consent from a woman in labor who required an episiotomy:

So I- there's a lady who I think was a primate who was in prolonged second stage, poor fetal heart, thick meconium (meconium) and so I decided to do an episiotomy and so before I numbed her or did anything I asked Susan and Mercy* was also in the room to explain why and what I wanted to do and they wouldn't explain it to her because they said that she will be more fearful if I tell her now then if I just do it and tell her afterwards. And I was like well if I come at her with a blade and she doesn't know what I'm doing is she not going to be more fearful?*

And it took quite a bit of time to actually get them to explain what I was going to do and why. Then, obviously, I gave her local anesthetic, did the procedure and then afterwards explained why I did it again but it was kind of like, sort of, quite a difficult- it was almost like a battle between me and the midwives to get them to translate that because they thought, like one of them said (I think it was Susan) they said like I wouldn't want to be told if you were going to do that to me and I was like if I came at you with a blade you're going to know really what I'm going to do. People talk; people know what's going on, they're not stupid. The reasoning to why I would tell them was very different from their reasoning for why they wouldn't.

The idea that information sharing and allowing a woman to give informed consent on a procedure seemed common and came up quite often. UKM2 comments on two separate occasions about the resistance to information sharing/informed consent:

I was working in the antenatal clinic once with the Ugandan midwives and we're saying to them like you need to explain to this woman what medication we're giving her and why and they just think it's hilarious.

I've had that experience like that again with student midwives at Buhinga and I was like can you ask the woman. I want to do this, this and this for this reason can you explain to her and ask her and they're like [name removed], stop asking her because she'll just say no! And I'm like that's the whole point! Like it's informed consent, she has the right to say no. They're literally just like "just do it otherwise she wouldn't let you do it.

In these instances, recalled by the UK midwives, the resistance to information sharing/informed consent are consistent for at least two separate types of services: an episiotomy and explanation of medicine use.

Why is there such an implementation gap between understanding information giving/informed consent and practicing it on a daily basis? UKM2 says:

I don't think they really understand, informed consent. Well they do! Because we talked about it in one of my lectures that informed consent is about ethical stuff like doing research and they totally get that. So I'm like do you all practice that day to day in midwifery? No."

UKM2 was referring to the interaction she described above between herself and the student midwives. The effectiveness of her lectures are also in competition with what student

midwives see in practice during their training. Are they more inclined to remember a lecture or follow their superiors in the hospitals?

Patient Perspective

On the patient side, are patients emphasizing the importance of informed consent/information sharing through their actions and words? Observation notes taken on November 9th illustrate the relationship dynamic between Mary and UKM3, and Mary's advocacy for patient centered care including the right to informed consent and information sharing:

- *She's been at Bukuku for about a month now and her wound is healing quickly.*
- *UKM3 cleans wound. They are very friendly. UKM3 takes a picture of wound to show Mary the progress she's made.*
- *UKM3 takes the time to explain to her the medicine she is taking. She explains it once. Mary says she doesn't understand. She explains again. Mary says she doesn't understand. UKM3 then asks "Do you know what an antibiotic is?" Mary says no.*
- *UKM3 explains to her what an antibiotic is and this seems to open up a line of communication; she becomes more inquisitive. Mary follows up with "What does the sugar do for my wound?" (They are using sugar to help the skin heal properly, it is an excellent, and cheap tool) UKM3 explains the use of the sugar. Mary asks who will be here on the following days to treat her wound. She's interested and cares about exactly who will be here. She thanks UKM3.*

Mary is curious for information on her wellbeing and wound only after UKM3 shows interest in explaining to her the situation. Advocacy for the right to proper care, which the patient is comfortable with, seems to be the exception to the rule, instead of the rule.

A lack of information sharing was evident in an interaction with a woman who recently miscarried at home and came to the maternity ward to make sure all of the fetus was removed from her womb. Taken from observation notes December 4th:

Woman thinks she is delivering placenta's 2-3 times before giving birth. In actuality she is having a few abortions (miscarriages) between pregnancies. She tells this to a UK midwife with the SM translating it to English. UK midwife cannot explain the actual situation to her. So Dr. Smith makes an assessment of her health (if the fetal was fully removed from*

her uterus) she explains what she thinks again to him. He respectfully listens to her but never fully explains what is happening with her pregnancies. This woman continues to believe she is delivering the placenta before birthing. Is anyone going to telling her she is aborting?

**Name Change*

It's unclear if in prior abortions medical personnel explained to her that she was aborting but in this situation Dr. Smith does not correct her misinformation.

Besides information sharing of a medical nature, in an interview with Dr. Smith, about the recollection above, he provided some insight into the level of expectations for respectful maternity care. Dr. Smith was one of the "better" doctors at the ward, more personable and kind to patients and a general amicable person professionally, and appeared to be most liked by health staff and patients.

He spoke, on average, more to patients than observed by other doctors or midwives. He asked his patients many questions pertaining to health, but he even admits that it's not a part of his routine to introduce himself to his patients or explain what he's doing. He noted that within his training there was not a priority in learning how to effectively communicate with patients socially, with simple introductions or greeting, or communication of medical related information. Which lead me to consider the student midwives again.

In one instance after cleaning the delivery ward on a slow day. The student midwives and UK midwives started an informal Q&A session; most of the question were strictly health related. Then a student midwife asks "Sister, how do we know when to ask for consent?" The UK midwife responds well certainly when you conduct an internally examination. She challenges them to think about if they're were the patient and didn't have any information on medicine. UK midwife says "You would want someone whose touching you and with you when you're in pain to tell you what's happening and why right? Just put yourself in their position".

The student midwives nod. Interactions like that lead to hopefulness but similarly, one must be realistic on the idea that a few lessons taught by a foreign midwives who only spends limited amount of training time with them would illicit a behavior change. The student

midwives watch other midwives and imitate those actions. I've seen them demonstrate that for better and for worse.

Considering the observational material, interviews and focus group conducted for this study the right to information sharing and informed consent still appeared not to be a concern for patients or providers. Providers did not routinely fulfill this right and patients did not demand or advocate for this component of respectful maternity care.

To be explored in the discussion chapter is what is fueling the appearance of indifference to privacy, informed consent and information sharing? Could the appearance reflect what women deem important or unimportant or is there fear or apprehension on voicing their wants and needs out of their maternity care experience?

VII. DISCUSSION

This chapter pinpoints how observational material, interviews and focus groups relates to addressing the guiding research questions that served as the basis of this study. This chapter also examines how the findings unearthed more questions as some research questions appeared as “unanswerable” but sparked a deeper understanding of women’s interactions with health institutions, specifically maternity care. These revelations somewhat broadened the study and challenges the conversation around respectful maternity care.

To review, the research questions originally posed at the start of the study were:

1. How important is the role of privacy and informed consent (2 of the seven RMC categories) to Ugandan women receiving maternity health services?
2. How does the relationship dynamic between patient and provider shape the implementation of respectful maternity care?

Role of Privacy

Women receiving maternal health services did not seem to deem privacy as an important factor in their experience. This was demonstrated by the lack of practice undertaken by the midwives and doctors of insuring women’s privacy. Hospital staff did not routinely provide privacy for patients. Alternatively, on average, women did not demand or advocate for their privacy to be ensured.

On average, women did not appear to be distraught or uncomfortable with the lack of privacy provided. This disproves the initial hypothesis that privacy will play an important role in a patient’s respectful maternity care experience.

But as a research of a qualitative nature, one must “read between the lines”. Using grounded theory methods, that have symbolic interactionist roots. Gaining mean from non-actions and actions is imperative. Past research shows that lack of privacy is an important factor mentioned by women. Women shared real concerns on how lack of privacy affects their experiences at a clinic. Women felt like that could not talk freely on their concerns; speaking openly make them vulnerable to being the subject of community gossip (Yakong et al 2010, 2439).

Role of Information Sharing/Informed Consent

Just like the role of privacy, information sharing/informed consent did not appear to be important to patients. The right to information and informed consent was a more contested aspects of respectful maternity care for Ugandan midwives. Some providers actively refused to provide information to patients in an attempt to “help” them. This help was presented as emotional help. The Ugandan midwives definition of emotional help, in this case, was to spare a woman the fear associated with having knowledge of a medical intervention to be performed on her. For example, in one instance recounted by a UK midwife, Ugandan midwives did not want to tell a woman her delivery required an episiotomy in order to save her from fear.

But I question the intention behind the emotional help? Are the Ugandan midwives trying to spare her the fear of knowing her will need a episiotomy? Or our they unwilling to handle the patient if she becomes agitated at the idea of having an episiotomy? In other cases, providers simply did not provide information or have conversations with women where understanding or consent could be easily gained.

On the patient side, from observational data no women requested information or expressed refusal of a service, intervention or medicine. Women unanimously did what was requested by the provider, never questioning the objective of an intervention or asking questions on the intervention itself. This, also, disproves the initial hypothesis that information sharing/informed consent will play an important role in a patient’s respectful maternity care experience.

The Appearance of Indifference to Respectful Maternity Care

It appears that privacy and information sharing/informed consent does not play an important role to Ugandan women regarding their facility based delivery experiences. Making judgements such as this proves difficult due to the indifference generally shown by pregnant women to access of quality care. Women never truly spoke out on care whether it was good or bad. This leads to considerations that maybe women weren’t truly expressing their preference for care while they were receiving services and/or they were not truly

expressing their opinions on their experiences to me. These statements will be reviewed further.

During a follow up interview with Mary, I was able to ask her questions more specific to her situation.

Interviewer: Who has been treating your wound?

Mary (paraphrasing): Student Midwives, doctors, everyone. Everyone is treating me well.

UKM3 was the first to treat her. She makes no indication that UKM3 treats her “better” than other providers.

Secretly Mary prefers UKM3 to treat her, she has told her this privately. But she refuses to praise one midwife’s work over another or criticize.

After the interview (we spoke) in the antenatal room that wasn’t being used. Roberta (NICU nurse & midwife) came in and pinched her cheeks and briefly chatted and laughed with us. I realized then that Evelyn wouldn’t criticize the care from the UG midwives and equally praise she receives from UKM3 because she is friendly with the UG midwives. Even though they may be rough with her, even if they didn’t treat her wound on Sunday. She likes them. The care is okay because she gets along with them and they like her. It’s rare/hard to criticize people who you like.*

In Mary’s situation it was clear she had developed a good relationship with some of the midwives in maternity ward. Her experience was out of the norm from the observational data, because she spent just over a month in the ward.

When interviewed other women reported trust and high satisfaction rates, making no suggestions on midwives changing their behavior. Noting satisfaction with their maternity experience.

Complacency

Initially it appeared that complacency was masked as disinterest from mothers. But complacency seems to be the underlying “emotion” in most women’s pregnancy experience from start to finish. One of the most drastic situations witnessed on December 4th:

UG Midwife brings a MAMA KIT to mother and baby (this is one of the few things offered to women when they come into birth babies). It contains useful things like a razor, blanket, tarp to cover the bed with, washing soap to wash birth out of sheets like, gloves, a roll of

cotton and a data sheet to mark baby's weight gain. Because this woman hasn't delivered at the hospital. She opens the MAMA KIT and removes the gloves, cotton, tarp, and razor. She does this in front of the mother and all the student midwives. The mother says nothing when she is handed a half empty MAMA KIT. When UG midwife leaves UK midwife gives all the items back to the mother.

A MAMA KIT is one of the few things that mothers can receive free of charge; they are often out of stock and very much coveted by delivering mothers. The woman watches as the Ugandan midwife takes from her kit and provides no reaction, equally when the UK midwife returns the lost items to her so also doesn't respond other than accepting the materials. Things are consistently happening *to* them, without their involvement. This interaction couldn't be explained as disinterest. The act of the UK midwife intervening and advocating on the behalf of the patient is not recognized, rather, I hypothesize, the patient understood the UG midwife to do one action that lead to her depleted MAMA KIT, and understood the action taken by the UK midwife to be absent of the purpose of advocacy.

Advocacy as an Exception

All evidence of women asking for tailored care that they were comfortable with seemed to be antidotal this includes what has been witnessed during observation and through the focus group. UKM1 commented:

We had one lady... In antenatal clinic as she had, she'd come to get family planning and myself and my colleague both from the UK were there and the midwife was out of the room at the time and she- we were trying to say, "do you want family planning?" and she said "oh I don't understand" so we went and got the midwife and the midwife reported that she'd said "I don't feel safe here because, I wouldn't come here again because, they don't understand what I'm saying and I don't want to come and have my baby here because I'd be scared because they can't understand me" Which I thought was great but she actually wasn't Ugandan. She was Kenyan. She'd come from somewhere else.

The only person who've I've seen is Mary, the lady who had the wound infection. I think when we initially met her- when we were sorting out her wound, we put the curtains up for her, and she was- again- the kind of typical, submissive patient but I think as we got to know her more and built relationships with her she became more- advocating for herself and more vocal about what she wanted. So for example, say we'd put the curtain and obviously the beds are kind of hard to get around (the curtain). For her, the bit that was seeing, she'd be like can you bring that curtain in or she'd do it herself. She would ask us to clean the wound rather than the Ugandan midwives. She would ask us not to go and get the doctor. She was a bit more, as we got to know her, she became more vocal in what she wanted. Whereas initially she was submissive...She's a unique case because we spent a lot*

of time with her, as opposed to all the other women we kind of see and then they deliver and go home. –UKM2

Advocacy didn't not seem to be a component to study as it seems so difficult to find consistent examples of it. This seemed to invalidate my initial thesis question, of how Ugandan women would define respectful care because advocacy of one's own care was seen in isolated cases that were few and far between. Lack of patient advocacy presented itself as a more consistent and accurate representation of maternal health services.

Why did there appear to be a lack of advocacy or agency between patient and provider? Based on the study's observation one hypothesis is that low advocacy rates with mothers is due to the hierarchical nature of relationship between patient and provider.

Patient-Provider Relationships: Shaping Respectful Maternity Care

The analysis of privacy and informed consent/information sharing and the subsequent themes that emerge from the data including: advocacy as an exception, complacency, and appearance of indifference, lead to questions on the patient, a pregnant women's, degree of freedom of expression within a maternity ward. Do these women feel they occupy a space where their concerns and opinions will be positively accepted and legitimized? Do they feel as though they have the currency to engage in conversations with their doctor or midwife? The lack of communication recorded in interviews and observations may be because women don't feel comfortable speaking up.

In a typical interaction between health staff, a woman comes in, the midwife/doctor reads her "passport" asks a few questions for clarification and instructs the woman how to lay/what to do depending on the examination. During antenatal checks, fetal heart rate is taken, a women weight, and other vitals such as blood pressure. Women answer when spoken to; but hearing a woman ask her own questions seems rare, and I cannot recall a time when a woman did. Most of the interactions are conducted in silence, the health personnel, doing their job, writing down health information in their file. Never explaining what they're doing, and why.

Alternately during my interviews, when women were asked about their experiences with health personnel their relationship with the provider seemed to be a dichotomy of authority vs. submissive. Many women stated that “the midwife told me to do this and I did it”. The kind of care you deserved to receive seemed to depend entirely on the patient’s behavior rather than a standard of quality care.

Interviewer: *They were nice? They didn’t use force?*

MI: *They don’t...also they can slap you but when you are well disciplined, they don’t use force.*

Translator: *So it depends on the attitude of the patient?*

MI: *Yes, it depends on the attitude of the patient.*

Interviewer: *When you say well disciplined, what does that mean?*

Translator (MI’s words): *I mean those women who come to produce they (the nurses) say “you do like this” and they do like this. (they don’t listen to the nurse) They have to apply force. So that you don’t kill your baby.*

If a woman does as she is told or if a woman is “well disciplined”, generally speaking the service will be to her benefit. Being “well disciplined”, as the respondent above mentions, can normalize disrespect & abuse. In a qualitative study conducted in north central Nigeria, women, midwives and doctors were presented with four scenarios of mistreatment prioritized by a systematic review of mistreatment acts. The four scenarios included pinching or slapping a woman; shouting at a women; refusing to help a women; and physically restraining a woman.

The results pointed towards a normalization of mistreatment. The intend behind the actions rationalized what most may consider bad behavior from doctors and midwives.

“Some women felt that if they were shouted at, then the healthcare provider was doing their job and served as a reminder that the woman should also do her job and cooperate” (Bohren et al. 2016, 646).

“By slapping their laps, the patient will know that truly you care for her. After the delivery, you would tell the woman the reason that you did it for her, even some women will tell you, I’m sorry, thank you” (Bohren et al. 2016, 645).

In conclusion, male and female doctors recognized that mistreatment happens but equated actions as a tactic to gain compliance from women. One remark from the researcher particularly stood out:

It is of great concern that both women and healthcare providers commonly blamed a woman's "disobedience" and "uncooperativeness" during labor and delivery for her experience of mistreatment" (Bohren et al. 2016, 674)

Alternatively, in a study conducted in Kenya on the patient-provider relationship of patients living with HIV, researchers identified a similar perceptions on power dynamics of provider and patient. In the patient's and provider's mind practice mistreatment in the form of verbal abuse or admonishment is okay because it actually expresses care from the health staff.

On the justification of mistreatment:

"Some people living with HIV interpreted the 'abuse' and the disciplinary actions taken by the providers as a sign of heightened care and concern for their health, which encouraged conformity to the engagement rules" (Ondenge et al. 2017, 3).

Gaining compliance from patients is another emerging theme from other studies:

"Many providers reported that they appreciated patients who were proactive, did not question 'the rules given to them', 'kept their clinic appointment dates', 'came to the clinic on time' and 'took their medication'. The providers perceived such patients as 'good patients' who they appreciated as worthy of their help, and gave them privileges" (Ondenge et al. 2017, 3).

A study conducted on women's experiences of seeking reproductive health care in rural Ghana found unequal power dynamics between patient and provider stunting the utilization of services. They found that dominant practice in Ghanaian society devalued women and reinforced power relations (Amoakohene 2004, Ampofo et al. 2004). This practices replicated themselves between women's interactions with nurses. Women reported being treated "like children", they felt ignored and disrespected (Yakong et al. 2010, 3).

More interesting is the conclusion that the women drew from this treatment.

"Women believed that they needed to accept the disrespect, intimidation and scolding they received from nurses in order to obtain the care needed. Therefore they sought to avoid conflict with nurses by not expressing their feelings" Yakong et al. 2010, 5).

These studies provides some reasoning in favor of women remaining corporative. The studies referenced above represent similar settings found in HCIV/HCIH and were conducted in rural areas, faced with constraints common to rural health systems. The study

conducted in Ghana reflected part of power dynamics within a maternity ward and the study conducted in Kenya presented a similar Sub Saharan context.

The Ugandan midwives have a very dominant role within the maternity ward. If a Ugandan woman wants a relatively easy facilities based delivery is may appear in their best interests to cooperate rather than suffer from further mistreatment, by acting disobedient. I witnessed a birth on December 1st that illustrates the extensiveness of the power of Ugandan midwives:

UKM4 stays ready in the delivery suite for almost 2 hours waiting for baby. UKM4 wanted mother on all fours, dog position, to push the head further down. It takes a while and much explanation for the mother to comply because the only position mothers birth in is on the back. Ugandan midwife comes in occasionally. On one particular visit to the delivery suite, mother is up walking and a contraction hits. Because UKM4 wants her on all fours, instead of climbing up on the (delivery) bed she begins moving the tarp to the floor so mother can get in position there. Ugandan midwife says she must be on the bed. Why? No idea, we watch as mother struggles on the bed.

According to UKM4, moving a laboring mother, so close to delivery was unnecessary. In this situation “laboring mother” issues no compliant but does struggle back unto the bed, in which she must lay on her back. Another hour passes.

Ugandan Midwife breaks her waters, before she does this she decides the mother must have another tarp on the bed and makes the mother get up to lay down another tarp and has her climb herself back on the bed without any help.

Deemed by UKM4, has was another unnecessary task that the woman must perform on her own, but performs it without objection. Because of my observations and evidence from past study I questioned whether true informed consent can exist in this maternity ward. If a woman feels that the provider is above them in authority, can they truly feel comfortable voicing complaints or preferences? They cannot.

Respectful Maternity Care: A Concept that isn't Fitting?

Doctor talks about if privacy and consent isn't discussed in medical school and if it's not practiced during your training then you are not going to have that respectful care skills.

Doctor talks about that when they watched videos on respectful care from western doctors, it just doesn't “fit” here. The western doctors introduce themselves to the patient (something he admits he doesn't do).

From my observations, interviews and focus groups I'm questioning whether some categories described in the respectful maternity care charter are applicable. Striving for physical privacy appeared to be a non-issue; on the patient side women don't seem to be too concerned with it. Naked bodies play a different role there than in a western culture. The idea of privacy is other aspects of life are missing so why would it play an important role during a woman's pregnancy. On the provider side physical privacy can impede on a midwife's able to provide care when they are often short of staff and overworked. Displaying curtains and screens with the American ambassador visiting further illustrates the uselessness of this mechanism.

The concept of respect is altered in Uganda. Just from spending a brief three months in Uganda I noticed the hierarchical structure of their social systems. Not just in the health care system but in my daily actions. I once bought the daughter of the hairstylist who was braiding my hair cookies and as a statement of gratitude the mother instructed her daughter to get down on her knees and bow to thank me. This action was done multiple times in different situations. The waiter/patron dynamic was similar in a dominant/submissive dichotomy. The idea of respect is quite often paid to the person who is seen "above" someone else. For example, a UK doctor (female) explains to me a situation with a male doctor in maternity.

I was examining a woman in the delivery ward while a male Ugandan doctor was present doing some paperwork (one of the delivery beds is used as an office table). I pulled the curtain down between my patient and the doctor. And he say "why are you pulling the curtain down" I asked "to give the woman some privacy". The Ugandan doctor answered, "I am a doctor, I have a right to see." The doctor felt disrespected because as a doctor he should be allowed to be treated differently.

The order of hierarchy is that the person in a space with the highest status must be respected primarily. This clearly doesn't represent the patient centered care the RMC movement is based in. The hierarchy in the maternity ward was stark and very much gender based. All the midwives were women, including the head midwife, but all of the doctors were men, as was the director of HCIV. Following the logic of respect that I've observation duplicated in the social structures in this region, in order for patient center care to be relevant, there would have to be a complete shift in gender roles as well as a destruction of the hierarchy system. That calls for a radical social movement to change culture. That is a

tall order and slightly unrealistic; as a change in behavior and attitudes takes generations to shift.

Gendered dynamics of the larger culture are illustrating within the health system as well. The idea that only men are doctors and women are nurses/midwives are women stands largely to be true (I did meet one Ugandan woman studying to be a doctor and one male NICU nurse). These dynamics are self-policed and enforced by women midwives. No men were ever present in the delivery suite, aside from doctors. On one occasion when I was observing antenatal checks a couple were seen first. When I asked the midwife why this couple were given priority she stated that a man couldn't wait too long to accompany his wife for an appointment because he had other things to do with his day. A man's time was respected and deemed more important than the woman's. A woman's time was not respected.

Alternately it can be argued that the RMC movement can encourage a woman's autonomy and a shift in at least the birthing culture in this region. If the standard of care upholds RMC categories and the D&A categories considered to be the most pressing issues than RMC would "fit" more within Ugandan health care culture. For instance, within D&A issues of physical abuse, and abandonment of care and non-dignified care and their corresponding components within the RMC charter of "freedom from harm and ill treatment", "dignity and respect" and "right to timely health care and to the highest attainable level of health" are more relevant. On a structural level, organizational flaws need to be addressed that could contribute to impeding the RMC and interpreted as D&A. For instance, order, space and manpower can affect a woman's judgement of care.

Interviewer: Were your needs attended to and were they attended to in a timely fashion?

Translator: translates into Rutooro

MI: *There (midwives) are few, There are many (patients)*

Translator: *So like it's not really possible for you to get attended in a timely manner because there's so many people and few nurses but if the nurse is free then the time- they will take care of you in a timely manner. So it depends on how many people are there and she's free then yes if not then you will just have to gesture and wait for the nurse*

MI: *The nurses? Eh After they had to go. So after producing they had to go to the others, so didn't give me a lot of time to talk to them. Because after producing well others are just*

there crying. They also want to produce so they just go. They give you your baby and say go and sleep with your baby and you go.

Translator: *Not so much time.*

Interviewer: *So little time but when they were there, they gave advice.*

M1: *Because they had to go. I stayed for 4 hours and then I had to go because there was no space for sleeping. There are many women. The smell there is not good. There is no space.*

M1 illustrates the need for more nurses in maternity as an improvement on respectful maternity care practices.

It appeared that for true advocacy to be a part of health care culture there needs to be a consistent use of other rights with the RMC charter. If women had an exception of care, if they were accustomed to certain procedures during a routine check such as consistent curtain use, or explanation of procedures if would be more vocal to ask for them when they aren't provided for.

The Intersection of Rural Living and Gender

As discussed in previous chapters, women's experiences of living in rural areas has effects on their socioeconomic status and education level. These factors are directly linked to their status within Ugandan society. Poor rural women are generally rank as a low status within Uganda. Their status are poo rural women has effects on the ways their interact with institutions. They may been less inclined to speak up and advocate for oneself.

It is not coincidence that the two women within the study that spoke up were women who spoke English. Speaking English denotes a higher status because it means you have some level of education and literacy. Within HCIII there were many posters and information graphs on the walls within the lobby. This is a great initiative to encourage women to understand services. A patient's rights poster is display and a photograph of this poster is included in the settings section in the methodology chapter. Unfortunately most of these poster were in English, so only educated women would be able to absorb this information. The patient rights poster was also posted into the native language of Rutooro but this study required women to be able to be literate in this language.

It's important to note that although all women experience a loss of status due to their gender, having an education and middle/upper class status can protect a woman from suffering the full weight of discrimination that may be faced by a poor woman.

Middle/upper class women are afforded their luxury of birthing in private clinic or have connections with doctors that could make their experience positive at a public facility.

The intersectionality is important to recognize because the women's experiences presented in this study aren't representative of all women's struggles or experiences in Uganda.

Socioeconomic status, education level, tribal affiliation, age and region all matter in accounting with a woman's experience. The women studied do represent women who have the least amount of protections but their experience is not a monolith.

VIII. CONCLUSION

General Summary

In this study I aimed to explore the definitions of respectful maternity care using two guiding questions.

1. How important is the role of privacy and informed consent (2 of the seven RMC categories) to Ugandan women receiving maternity health services?
2. How does the relationship dynamic between patient and provider shape the implementation of respectful maternity care?

First presented in this study was the academic conversation about respectful maternity care specific to low income countries in Sub Saharan Africa. Terms like, disrespect and abuse, midwifery, too little too late were discussed to position this study appropriately within that conversation. Facts and statistics were presented on maternal health and maternal mortality to stress the grave importance of improvement to maternal health. Studies on gaining an understanding on why and how maternal mortality rates fail to fall faster were explored as well.

Prefaced with this discussion, respectful maternity care was defined by the White Ribbon Alliance's Respectful Maternity Care Charter, and the operationalization of two charter rights, (1) privacy, and (2) informed consent/information sharing was presented a focus of this study. Outlined within the methodology section was the steps taken to best retrieve data on privacy and informed consent/information sharing.

As reviewed in the findings and discussion chapter, privacy and informed consent/information sharing did not appear to play an important role in Ugandan women's perception of respectful maternity care. The key word was "appear". Although no one raised praise or negative opinions on any of the services rendered, women may not feel comfortable to do so. As one mother said, he agreed that midwives and hospital staff should smile more and speak more kindly to mother, but also this mother expressed, one cannot say no to a procedure done by a midwife.

Discussed was the question of whether women feel comfortable enough to speak out. Examining that requires more research, even though from the research done in this study it appeared that way. Not enough evidence was collected to definitively say this was the case. Further observation on patient-provider relationship needs to be studied including further interviews to fully answer this question.

This study ends by picking up where previous research left off and furthering the conversation while also posing new questions on topics that need further research. It is my hope that this study can further the growing knowledge of quality of care within maternal health that can help global health professionals in the way care is given. Increasing quality of care will certainly have a positive effect on lowering maternal mortality rates.

Key Observations

My initial hypothesis that: “the role of privacy and informed consent/information sharing will be fairly important to women received services in the maternity wards” was an unfounded claim after analyzing the data. But key observations was the appearance of indifference to facility based care and a forced complacency that existed for women receiving maternity services.

No participants raised positive or negative claims on the services provided. This first gave the impression of indifference but another explanation presented itself through the data and previous research, like the studies done in Nigeria, Ghana, and Kenya outlined in the discussion chapter. Women needed to appear cooperative to avoid further possible mistreatment. Women remained submissive and obedient to services, replicating the dominant-subordinate relationship that exists between patient and provider but also exists within the wider Ugandan society.

The patient provider relationship present is one in which patients must appear to be obedient to providers in order to lower the likelihood of an unpleasant experiences. Women must do as they are told, and not speak up for fear of verbal abuse and mistreatment.

The current relationship between patient and provider outlined in this study is not a model that is conducive to patient center care that facilitates respectful maternity care. Patients do

as they are told out of obligation to the hierarchal system that exists at large in Ugandan society. Like the Ugandan doctor who thought it his right to observe a naked patient being observed by another doctor, the prioritization of respect is different.

Doctors, specifically male doctors, receive the primary share of respect, the rest trickles down to midwives, nurses and other health staff. The priority is never place on the women to receive respectful maternity care. The “respect” hierarchy reflect the status quo presented in larger Ugandan society. The RMC framework is based in the theoretical approach of patient centered care. RMC cannot be considered as a point of interest until an equal balance exists between help staff and patient.

Recommendations

A holistic approach must be applied in order to work towards implementing an operationalized respectful maternity care charter. Medically there is a constant push to improve rates of women to have four antenatal visits and scheduling facility based deliveries. But as research shows one reason women choose home birth without an skilled attendant is because of mistreatment experienced by the hands of health staff personally or through stories circulated within their network. Basic improvement to mistreatment and the elimination of disrespect & abuse, will greatly encourage women to seek services that saves lives.

Elimination of disrespect & abuse does not equate to respectful maternity care. Health systems should focus on patient center care that supports the themes represented in the respectful maternity care charter. Prioritization on a patients care experiences also requires a shift in the hierarchal place of women in society, especially poor, uneducated rural women. Within a deeply hierarchal system in Uganda, women routinely face discrimination and violence. Within that hierarchy age, tribal affiliation, socioeconomic status and geographical location also can strengthen or weaken your status. The women in these study overwhelmingly represented poor, uneducated rural women, this further deepens their low status.

Rural women, poor women, women in general need to been recognized as valued member of society in relation to men. When this occurs, equal status within larger society will

trigger down to many institutions, including the health sector. Women' medical needs as well as their thoughts and opinions on their experience of care will be legitimized. This can prompt a movement of advocacy that will strengthen the importance of a patient's experience leading to big push to apply respectful maternity care efficiently.

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Appendix I: Ethical Approval



Randi Wærdahl
Postboks 4 St. Olavs plass
0130 OSLO

Vår dato: 15.08.2017

Vår ref: 55126 / 3 / LAR

Deres dato:

Deres ref:

Tilbakemelding på melding om behandling av personopplysninger

Vi viser til melding om behandling av personopplysninger, mottatt 14.07.2017.
Meldingen gjelder prosjektet:

55126	<i>What is Respectful Care: A Qualitative Study on women receiving intrapartum care in Fort Portal, Uganda.</i>
Behandlingsansvarlig	Høgskolen i Oslo og Akershus, ved institusjonens øverste leder
Daglig ansvarlig	Randi Wærdahl
Student	Gyasi Gomez

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i melde skjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget [skjema](#). Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en [offentlig database](#).

Personvernombudet vil ved prosjektets avslutning, 01.11.2018, rette en henvendelse angående status for behandlingen av personopplysninger.

Dersom noe er uklart ta gjerne kontakt over telefon.

Vennlig hilsen

Dokumentet er elektronisk produsert og godkjent ved NSDs rutiner for elektronisk godkjenning.

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Appendix II: Interview Guides

Interview Guide For Mothers

General

1. If you would like, could you please describe your most recent childbirth experience?
2. If you have had multiple deliveries, can you describe the most pleasant birthing experience and why was it pleasant?
3. If you have had multiple deliveries, can you describe the most negative birthing experience and why was it negative?
4. Did you feel respected during your time in the health care center. Yes/No and in what way?

Within the flow of our discussion, I wish to ask me follow up questions while the respondent is speaking about their experiences. Those follow up questions are as follows:

1. Would you describe the health care workers as kind and friendly? (friendly)
2. Were they empathic to your pain/relief? (friendly)
3. Were your needs attended to in a timely fashion? (timely)
4. Were you allow to practice cultural rituals at the facility?
5. Were you spoken to in a language they was understandable to you?
6. Were you yelled at your physically hurt during your stay?
7. Were you or your companions insulted in any way during your stay?
8. Do you believe your HIV status influenced your care?

Interview Guide For Health Care Workers

1. How would you describe the type of care you provide during childbirth?
2. Besides the health of mother and child, what is the most important characteristic of care that you provide? Privacy and Respect
3. Do you think privacy and consent is upheld where ever you've been working? Why or why not.
4. What do you think consists of care work during labor, beside the physical care?
5. How would you describe respectful maternal care?
6. How well do you think you are at providing respectful care?
7. What are some barriers/challenges that you face in delivering optimal respectful care?
8. How have you (have you?) been trained/encouraged to provide respectful care?
9. Do you think the patients care?