

THE SOCIAL ORGANIZATION OF MATERNITY CARE AND BIRTH IN AMURU SUB-  
COUNTY, NORTHERN UGANDA

by

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A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF  
THE REQUIREMENTS FOR THE DEGREE OF

DOCTOR OF PHILOSOPHY

in

THE FACULTY OF GRADUATE AND POSTDOCTORAL STUDIES  
(Gender, Race, Sexuality, and Social Justice)

THE UNIVERSITY OF BRITISH COLUMBIA  
(Vancouver)  
December 2014

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## **Abstract**

High maternal mortality rates throughout sub-Saharan Africa attest to the critical importance of comprehending barriers to health care during pregnancy and birth. This study examines how maternity care and birth are socially organized in Amuru sub-county, northern Uganda, a rural setting recovering from two decades of conflict. To conduct this study, I spent seven months undertaking fieldwork in Amuru, northern Uganda. In addition to observations, I interviewed and held focus groups with childbearing women, and in a second study stage spoke with health care providers and health care administrators. My research methods draw from institutional ethnography.

The challenging context for maternity care and childbirth in Amuru was exacerbated by poor infrastructure and ongoing social distress in the aftermath of the protracted conflict between the Lord's Resistance Army (LRA) and government forces that ended in 2006. Findings drawn from the data illustrated that approaches to care and birth among participants were shaped by everyday challenges associated with poverty and lack of infrastructure, the most prominent of which were accessing transportation, avoiding arduous physical work while pregnant, and ensuring adequate nutrition. Couples' HIV testing, which was positioned as compulsory and wherein women were responsible for husbands' participation, also challenged participants access to antenatal and delivery care. Childbearing women's approaches to maternity care were also shaped by the mama kit project (distribution of a non-profit 'gift' of baby-care basics to mothers), and its associated discourses of deservingness, scarcity, and uncertainty. Imbued with power, all these factors affected access to care. This dissertation contributes to scholarship on the social constitution of maternity care and childbirth in northern Uganda.

## **Preface**

This dissertation is the original work of the author, Sarah Elizabeth Ellen Rudrum. She identified the research program, performed the research activities working with a translator, and analyzed the research data.

At the University of British Columbia, the Behavioural Research Ethics Board approved the research proposal. It was titled “Women’s Approaches to Childbirth in Northern Uganda” The certificate number is H11 – 02573.

Within Uganda, this project received ethics approval via The Lacor Hospital Ethics Review Board, The Uganda National Council for Science and Technology, and The Office of the President (file number SS 2846).

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## List of Acronyms and Abbreviations

ANC: Antenatal Care  
DHO: District Health Officer  
HIV: Human Immunodeficiency Virus  
HSM: Holy Spirit Movement  
IC: Invisible Children  
IDP: Internally Displaced People  
LC I: Local Councilperson (level I)  
LRA: Lord's Resistance Army  
MDG: Millennium Development Goal  
NLA: National Liberation Army  
NGO: Non-governmental organization  
NUMAT: Northern Uganda Malaria Aids and Tuberculosis Project  
TBA: Traditional Birth Attendant  
UMOH: Uganda Ministry of Health  
UNAIDS: The Joint United Nations Program on HIV/AIDS  
UNFPA: United Nations Population Fund  
UPDF: Uganda People's Defense Force  
VHT: Village Health Team  
WHO: World Health Organization

## **Glossary of Acholi (Luo) Words**

Boda-boda (or simply boda): Motorcycle taxi

Cen: A spirit or apparition, usually evil; a polluting spiritual force

Co: Co-wife (who shares the same husband) or sometimes sister-in-law

Ot yat: Hospital or health centre

Panga: Machete

Pime: Measurement

Simsim: Sesame

## **Acknowledgements**

I extend my deep appreciation to my supervisors, Dr. Helen Brown and Dr. John Oliffe, and to the members of my advisory committee, Dr. Patti Spittal and Dr. Patti Janssen. Their dedication, time, and expertise have contributed much to my studies and to this dissertation. For Dr. Brown's mentorship throughout my doctoral studies, and for Dr. Spittal's guidance on research and life in northern Uganda, I am particularly grateful.

I have also benefitted from the friendship, support and collaboration of colleagues at the Institute for Gender, Race, Sexuality and Social Justice, at the Liu Institute for Global Issues, and at the Institute for Intersectionality Research and Policy (SFU). In particular, Anika Stafford, Beth Stewart, Natalie Clark, Daniel Grace and Alycia Fridkin shared the journey, and Dr. Olena Hankivsky and Dr. Thea Cacchioni provided valued mentorship, advice, and collaboration.

In Uganda, Dr. Martin Ogwang and Dr. Grace Kyomuhendo lent their enthusiasm and expertise to this project. I am also indebted to all those at Lacor Hospital and Lacor Health Centre III who welcomed us so warmly, and particularly Godfrey Ojok.

I'm thankful for all my friends: those who also lent an edit or an audience include Steph, Mia, Jess, and Jude. I owe you one!

I have been lucky to have the support of my family. First and foremost, Omar Bhimji, who said that of course I should do a PhD and stood by that, and by me, throughout this process. Also my Sachaa Pyar, who has successfully kept me engaged with life outside the academy. My parents, June and Alan, and sister, Katy, whose pride, interest, and encouragement has been invaluable. Many thanks and much love to all of you.

I gratefully acknowledge the support of the University of British Columbia for funding my studies and the Liu Institute for Global Issues for support with fieldwork expenses.

## Chapter One: Introduction and Literature Review

### Introduction

A recent case brought before the supreme court of Uganda by a group of civil society organizations appealed the loss of a constitutional challenge alleging that the government violated the human rights of two women who died in childbirth (CEHURD, 2014). Spearheaded by *The Center for Health, Human Rights and Development* (CEHURD), this landmark case was the first to test the government's legal obligation to provide care to birthing women. The legal struggle drew attention to the dire state of maternity health care in Uganda and attempted to catalyze change in a setting of mounting frustration and anger as maternal deaths continued unabated. One of the women who died was an elected official, the other a subsistence farmer; both bled to death in state hospitals. A lack of supplies and the absence of skilled staff were alleged to have contributed to these preventable deaths.

The stories of these women and the appalling hospital conditions that led to their deaths exemplify a personalized face of maternal mortality in Uganda. Many other women, among the approximately 58 percent who give birth without a formally trained attendant,<sup>1</sup> die alone or in family settings. The maternal mortality ratio is “the number of deaths due to pregnancy related causes, when pregnant or within 42 days of delivery per 100,000 live births and provides an internationally accepted marker of the safety or otherwise of pregnancy” (O’Hare & Southall, 2007, p. 565). The incidents brought forward in the CEHURD case background Uganda's

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<sup>1</sup> In sub-Saharan Africa, approximately 58% of women delivered their first child outside of a health facility (Rogo, 2006). Many of these births are attended by a Traditional Birth Attendant (TBA). In Uganda, Grace Kyomuhendo’s study in a rural area of western Uganda also found that 58% of women gave birth outside a health facility (Kyomuhendo, 2003). Poor women throughout the region are more likely to give birth at home (Montagu et al., 2011).

maternal mortality ratio of 438 per 100,000<sup>2</sup> wherein about 6,000 women die each year,<sup>3</sup> among the highest maternal mortality ratios in the world.

For most women in Amuru sub-county and elsewhere in Uganda, pregnancy and childbirth are normal events that they will go through several times during their lives, as on average 6.8 children are born to each rural woman during her lifetime (Uganda Demographic and Health Survey, 2011). At the same time, these births are also shaped by a complex set of practices, policies, and discourses governing maternity care. These exist at local, national, and international levels. The current study examined childbirth and maternity care in Amuru sub-county, northern Uganda, a region recovering after a protracted conflict.

In this study, I addressed the following question: *How is maternity care and childbirth socially organized in the context of Amuru sub-county, a rural area recovering from conflict in northern Uganda?* The focus on social organization was deliberately broad, in order to recognize that numerous overlapping settings and factors might influence maternity care and childbirth practices. For example, family settings, community settings, and health care settings can feature in the organization of maternity care and birth, while factors including access to resources, geographic location, and cultural practices each are likely to exert their influence. The geographic and social context in which I grounded the aforementioned research question was deliberately specific in recognizing and responding to calls for locale specific research in global maternal health.

The goal of the current study was to describe the local birthing and maternity care context, beginning with the experience and standpoint of birthing women (for this study, mothers with a child under age two) using institutional ethnography (IE) approaches (detailed in Chapter

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<sup>2</sup>In *Uganda Demographic and Health Survey, 2011*. There is some debate around the rate as it is difficult to measure.

<sup>3</sup>(Sebina-Zziwa, Nyamugisira, & Larok, 2013.)

Two). I mapped the social coordination of maternity care and birth in Amuru sub-county, starting with the accounts of birthing women and augmenting the field of inquiry via interviews with health workers and health administrators and analyses of locale-specific texts, discourses, and policy documents related to maternity care.

The interviews included open-ended questions such as “What does 'maternal health' mean to you?” “What do you do to prepare for childbirth?” and “What is important to you at the time of giving birth?” Through these interviews, I learned about the people and factors shaping birth experiences and maternity health care from the perspectives of birthing women in Amuru sub-county. The second stage of the study was comprised of interviews and focus groups with health workers and administrators. In this stage, the concerns and experiences of birthing women were brought forward and further investigated.

## **Overview of the Dissertation**

This dissertation is comprised of seven chapters. As well as providing an overview of the research problem and question, this introductory chapter offers a brief literature review and provides a rationale for the study. The literature review introduces the Millennium Development Goals (MDGs) as they relate to maternity care, and focuses on the call for context-specific research on maternity care and birth, the role and status of skilled birth attendants (SBAs) and traditional birth attendants (TBAs), cultural factors in childbirth and maternity care practices, and the effect of a post-conflict setting on maternal health.

Chapter Two focuses on methodology and methods and provides an account of the study's fieldwork. I introduce institutional ethnography (IE), a critical mode of sociological inquiry on which this study relies and detail the data collection (interviews and focus groups)

with childbearing women and a second stage of data collection undertaken with health workers. Chapter Two outlines the ethical considerations that shaped the study.

Chapter Three provides an overview of the social and political context of Amuru sub-county, with reference to events shaping life in northern Uganda more generally. This chapter draws on literature that informed the inclusion of post-conflict in my research question, along with additional relevant literature on post-conflict that I have turned to in order to further the analysis of key issues, as well data based on observations, interviews, and focus groups that are original to this study. The chapter outlines the Lord's Resistance Army (LRA) conflict, describes the local economy of agriculture, and brings forward current social concerns such as land issues and epidemics. While my research deals with the everyday, it is not an everyday with which most readers will be familiar. Anticipating this, I have provided in Chapter Three a detailed description and analysis to guide readers to what follows in the dissertation.

Chapters Four through Six draw together findings and discussion. In Chapter Four, I use two lenses – women's daily environments of care and health providers' perspectives – to examine key factors shaping everyday aspects of maternity care and birth. These include work, nutrition, transportation, and the role of various health workers. These areas of analysis were identified through the study as important to the social organization of maternity care and childbirth.

In the context of concern over the prevention of HIV influencing the overall approach to maternity care and birth in Amuru sub-county, Chapter Five focuses on HIV testing practices during pregnancy. In particular, the chapter examines couples' HIV testing during ANC with a focus on gender and power. I identify how a compulsory approach to couples' HIV testing has adverse ramifications for women's access to maternity care.

Chapter Six is a detailed examination of an NGO project delivering mama kits (bags containing baby supplies) to childbearing women. I examine the nexus of local and global health

policies and practices, as well as discourses of vulnerability and responsibility. I make the case that by using the kits as an incentive to attending antenatal care (ANC) and delivery care, and through the operationalization of scarcity, these resources became part of how access to care and barriers to care were socially constituted. Chapter Six also includes a discussion of remote location as it relates where delivery occurred and who assisted at birth, which was relevant to analysis because of how distribution of mama kits was implemented.

Chapter Seven concludes this work. In this final chapter, I review key insights and put forward recommendations. I also identify study limitations, and describe areas for potential further inquiry.

## **Literature Review**

In order to further situate the study, this literature review presents an overview of the role of the Millennium Development Goals (MDGs) as they relate to this area of inquiry and presents a call by advocates for context-specific research into maternal health and maternity care. It goes on to review literature on the role and status of skilled birth attendants (SBAs) and traditional birth attendants (TBAs), social and cultural factors in childbirth and maternity care practices, the effect of conflict/post-conflict on maternal health and maternity health care, and HIV prevalence in this area.

### **Background on the Millennium Development Goals (MDGs)**

The Millennium Development Goals (MDGs) are eight goals for international development adopted by world leaders at the United Nations in the year 2000. The goals set targets in each of eight focus areas to be achieved by 2015. Millennium Development Goal 5 (MDG 5) is “to improve maternal health” and has two targets, 5.A, “to reduce by three quarters the maternal mortality ratio,” and 5.B, “achieve universal access to reproductive health.” Target

5.B of the goal is a more recent (2005) addition and has been less prioritized than 5.A (Yamin & Boulanger, 2013). Progress on target 5.A, to reduce by three quarters maternal mortality, is measured by two indicators: the maternal mortality ratio itself and “the proportion of deliveries attended by skilled health personnel” (WHO).

The MDGs have been criticized as “imprecise and ineffective” (Attarran, 2005, p. 0955) or as a “global wish list” (Saith, 2006, p. 1168). In particular, progress on MDG 5 has been criticized as difficult to measure because of lack of reliable data. For example, Attarran (2005) asserts “it is exactly in the poorest countries where the maternal mortality problem is severest that the data about deaths and births are least satisfactory” (p. 0958). Currently, it can also be said with certainty that MDG 5 will not be met: a 2013 report identifies Uganda’s progress on Goal 5 as stagnant, and indicates that Uganda “is unlikely to meet the targeted reduction in maternal mortality by 2015” (The Republic of Uganda, 2013, p. 24). Internationally, MDG 5 has made the least progress and is the least adequately funded of the eight goals (Women Deliver, 2009). Despite these critiques and failures, I refer to MDG 5 as the clearest articulation of an international goal on maternal health and approach to maternity care provision and as an important influence on how maternal health and maternity health care is approached in target countries such as Uganda.

#### The call for context-specific study of maternity care and childbirth

While global health bodies including the World Health Organization (WHO) have advocated for broad goals on maternal health, many authors have also pointed to a need for more context-specific research into maternity care and birth in low-income countries in the global South<sup>4</sup> (Kyomuhendo, 2003; MacKian, 2008; Say & Raine, 2007; Spangler, 2011). Say and

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<sup>4</sup> I occasionally use the terms “global South” and “global North” in order to point to those features this study’s

Raine (2007) chronicle the need for global maternity care research – particularly research that focuses on the use of skilled care – to be more attentive to local contexts. Their review of inequalities in the use of maternal health care in developing countries makes the case that subtle and complex individual level factors, such as perceptions regarding formal care and preference for the social support of traditional care, shape the use of maternal health care. Therefore, they argue, interventions at the level of health services will have limited impact unless local perceptions regarding birth and care are understood and considered in making such interventions. While reducing maternal mortality through promoting the increased use of skilled attendants at birth has been identified as a goal across global contexts, Say and Raine (2007) suggest that locale specific understandings are necessary to make progress towards MDG 5.

In a discussion of inequality and social exclusion as they affect childbirth in Tanzania, Spangler (2011) made the case that “to be effective, services must explicitly meet the needs of societies’ most marginalized—they must ensure equitable access in unique contexts” (p. 493). Extrapolating from Spangler’s assertion, women in post-conflict rural Amuru have particular needs that must be met for health care access to be equitable. The call for context-specific research in maternity care is echoed in other areas of the literature that focus on SBAs and TBAs, cultural aspects of maternity care, and conflict.

#### Skilled birth attendants (SBAs) and traditional birth attendants (TBAs)

One important context of maternity health care in Uganda is the widespread use of traditional birth attendants (TBAs). These village-based lay practitioners attend about 60% of

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setting share with other settings in sub-Saharan Africa and low-income countries in other continents, and to contrast the setting not only to Canada, but to other countries with similar economic profiles. Unlike the term “developing countries,” “global South” does not indicate that these countries need to catch up to “developed countries.” While the term global South is preferable to “developing countries,” it is not ideal. In using it, I do not intend to disregard the tremendous in-country disparities of health, income, or status within global North countries such as Canada, or to suggest that countries within the global South are more similar than different.

births (Keri, Kaye & Sybille, 2010; Kyomuhendo, 2003). Scholars and non-governmental organizations (NGOs) use the term “traditional birth attendant” (TBA) across national contexts to describe women who provide health care but are not formally credentialed. However, the practices, roles, and skills of TBAs vary within and between national contexts. A Ugandan definition of a TBA is:

[ . . . ] a person recognized by her community as able to assist women in childbirth. These practitioners are the ‘*mothers of the village*’ because they assist in reproductive health care, like family planning, birthing, prevention of sexually transmitted HIV/AIDS counseling, promotion of immunization and breastfeeding. (Kyomugisha, 2008, p. 11)

However, this broad and positive definition of TBAs can be seen as out of step with efforts to limit the role of TBAs in favour of skilled birth attendants (SBAs).

The trend within Uganda and elsewhere of relying on TBAs for labour support is widely viewed as problematic because it seen as antithetical to the maternal health development goal of skilled attendance at birth, which has been identified as the primary means of reducing maternal mortality (Achadi, Pitchforth & Hussein, 2013; Say & Raine, 2007; Wirth, 2008). This is exemplified by the prominence of “Proportion of births being attended by skilled health personnel” as one of only two indicators for measuring progress on MDG 5.A. (Maternal mortality is the other indicator.) Globally, a widespread focus on training TBAs as a means to reduce the incidence of maternal mortality began in the 1970s, but skepticism about this approach emerged in the subsequent decades (Van Lerberghe & De Brouwere, 2000). The World Health Organization (WHO), for example, promoted training of TBAs between the 1970s and 1990s (Harrison, 2011; Sibley et al., 2007). Van Lerberghe and De Brouwere (2000) explain the move away from TBA training as follows:

The resistance or inability to change of TBAs, their lack of credibility in the eyes of the health professionals, the *de facto* impossibility to organise effective and affordable supervision, all have discredited training of TBAs. Whatever its other merits, it is now considered an ineffective strategy to reduce maternal mortality.

Harrison (2011) argues that the training of TBAs “is a distraction in that it seeks to manage extreme poverty instead of working to eliminate it” (para. 5). Shifts in the priorities of international health bodies significantly impact care, but the outcome of these priority shifts are poorly understood in the Amuru context.

The role played by TBAs is complex and contradictory. While a high proportion of births in Uganda are attended by TBAs (Keri, Kaye, & Sibylle, 2010; Kyomuhendo, 2003) international and Ugandan health agencies emphasize the role of skilled birth attendants (SBAs) in preventing maternal mortality and other negative perinatal outcomes. This focus means that programs to train or otherwise support TBAs have been de-emphasized or halted. Within Uganda, a “ban” on TBAs as sole attendants at birth has been discussed, and even announced, but not legislated. Further, discussions of health and responsibility in Ugandan media have promoted the idea that women’s “shunning” of formal care options contributes to maternal mortality.<sup>5</sup>

Instead of training TBAs, measures to promote skilled attendance at birth have been identified as the primary means of reducing maternal mortality (Say & Raine, 2007; Wirth, 2008). Skilled birth attendants (SBAs) are defined as those with formal medical training (Campbell & Graham, 2006; Say & Raine, 2007). How formal training is defined, however, can vary. Say and Raine (2007) identify any medically trained attendant as an SBA in their survey, while Campbell and Graham (2006) use the more narrow definition of “midwives and doctors” (p. 1292). Harvey et al. (2004) assert that while the WHO “defines an SBA as someone ‘trained to proficiency in the skills necessary to manage normal deliveries and diagnose, manage or refer obstetric complications,’ at the same time, ‘WHO’s estimates [on attendance by a SBA] implicitly

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<sup>5</sup> For example: “Pregnant women shun hospitals.” (*New Vision*, 2004); “Kaberaiido mothers shun hospitals.” (*New Vision* 2010); “Why K’jong women still shun the labour ward.” (*New Vision*, 2006); “Pallisa mothers shun antenatal care.” (*The Monitor*, 2011). Kyomugisha (2008) quotes an MP as stating: “despite the government’s efforts to bring health services nearer to the people, some women still die with maternity complications because they don’t use the health centre services. ...30% of women die every year because they have shunned the use of modern medical facilities and prefer to use the traditional methods, which put their lives at a great risk ” (p. 20).

assume that anyone categorized as health personnel qualifies as a skilled attendant” (p. 204). The lack of consensus on what comprises formal training for SBAs suggests that the role and training of health workers need to be identified in context-specific studies of maternity care. While TBAs have skills that are recognized by their communities, their lack of formal education excludes them from the category of “skilled birth attendants”. This is stated explicitly in the Republic of Uganda’s (2008) “Roadmap for Reduction of Maternal & Neonatal Mortality and Morbidity”: “TBAs are not considered skilled attendants at birth, even if trained” (p. 48).

The concept of “skilled *attendance*” has been introduced in order to emphasize that, in addition to the presence of those with midwifery skills, an “enabling environment” is required to support safe birth (WHO, United Nations Population Fund [UNFPA]). Such an environment provides the resources required to deliver care, including “facilities, supplies, transport and professionals to provide emergency obstetric care when it is needed” (UNFPA). It has been demonstrated that skilled attendance facilitates safe birth, but at the same time there is general acknowledgement that skilled attendance is difficult to provide or access in many contexts, including low-resource, rural areas such as Amuru sub-county.

While international bodies governing approaches to global health, such as the WHO and the UNFPA, have shifted away from the training of TBAs in order to focus on skilled attendance, some authors have made the case for the continued importance of TBAs in improving maternal health outcomes (Jokhio, Winter, & Cheng, 2005; Ray & Salihu, 2004). Advocacy for TBAs’ continued role is based on factors such as cultural preference and the ability of TBAs to work in hard-to-reach communities (Ana, 2011; Jokhio, Winter, & Cheng, 2005). For example, Kyomugisha (2008) makes the case for a “regulatory policy framework” to govern the work of traditional health practitioners, including TBAs, in Uganda (p. 41). Ana (2011) makes the case for TBAs’ continued involvement on the basis of their ubiquity and accessibility in contrast to the

insufficient numbers of trained midwives, arguing that the benefits of TBA involvement have been proven. The controversy around TBAs' role is important to how childbirth is organized in the communities where they practice, including Amuru sub-county.

Although the use of TBAs by birthing women in Uganda has received considerable scrutiny, the issues contributing to the prevalence of birth at home with TBAs are not fully understood. As Ssenooba et al.'s (2003) "Maternal Health Review" in Uganda conceded:

The overall status of women, social expectations to deliver at home, and demands on women's time have all been identified as factors leading to home delivery and use of TBAs rather than trained medical birth attendants for delivery assistance. However, there are clearly also technical access barriers (such as geographical distance from facilities or cost) which may prevent utilisation of services, and issues with the quality of care available in facilities. It is important to disentangle the web of access barriers to identify the way these various factors are interrelated. TBAs may be socially more appropriate for some women, but they may also be particularly preferred when there is a perception of low quality in public health centres. Similarly, transportation barriers exist, but other factors may increase the delays in seeking care, thereby making early planning to offset transportation barriers more difficult. (p. 29)

This excerpt elucidates the complexity of factors influencing women's practices regarding care during birth. It further suggests that "barriers to access" and "cultural preference" cannot be understood or addressed as separate factors shaping care. Instead, they are interrelated in context-specific ways such that learning from birthing women is key to understanding the interplay between technical barriers that limit access and social factors shaping preferences. The questions raised by Ssenooba et al.'s (2003) maternal health review signal the possibility that a narrow focus on provider preference and barriers to skilled attendance may obscure attention to other everyday material contexts affecting care. The current study includes data from childbearing women's accounts of care and its impediments, and incorporates a broad definition of health worker in order to be able to describe the role of both skilled attendants and lay health workers.

## Social and cultural aspects of maternity care and childbirth

A focus on local contexts of care and birth means attention to social factors. The literature I review here foregrounds social and cultural factors shaping care and birth in Uganda. MacKian (2007) writes: “Although the current policy climate aims to encourage women to utilise formal health provision, they are often the least able to negotiate access effectively” (p. 112). However, she suggests that a supportive community level environment may be key to negotiating care. Citing Parkhurst et al. (2006), MacKian (2007) argues that in communities where there is a clustering of health facility users, this clustering may indicate a particularly welcoming or otherwise facilitative “therapeutic landscape”. These clusters of users, she posits, point to the need to better understand how “women’s participation might be encouraged beyond the more obvious routes of providing services and attempting to ‘educate’ them to change their ways” (p. 112). This suggests that context-specific research about women's experiences, beliefs, and values regarding birth and various forms of maternity care is valuable as a means of understanding how the use of formal health care is governed by local factors. These insights draw attention to dominant discourses as a relevant site of analysis for researchers concerned with women's health and health care in Uganda.

Kyomuhendo (2003) examines social and cultural factors shaping childbirth practices at a local level in a rural western Uganda village, characterizing the national context of maternity health care as one in which improvements have been made to policy but not to practice. While it was once justifiable, she argues, to blame maternal mortality and morbidity on poverty and instability, this is no longer the case. She writes, “Today there is a favourable and enabling policy environment, including good policies on gender equity, universal primary education, reproductive health and decentralisation of health services” (2003, p. 17). In considering this

assessment, it is important to recognize that, unlike the western region of Kyomuhendo's focus, which has been politically stable for some time, northern Uganda faces ongoing instability in the aftermath of decades of conflict. The policy environment to which Kyomuhendo refers is primarily at the national level and is therefore broadly applicable. However, the differences between her study setting and Amuru raise the question of whether her statements regarding the diminished relevance of poverty and instability to maternity health care are applicable in remote areas where conflict has been relatively recent. Kyomuhendo's positive assessment of policy trends echoes MacKian's evaluation, as does the finding that an improved policy environment is not reflected in other areas affecting health.

Specifically, Kyomuhendo (2003) suggests that the favourable policy environment has not been met by an increase in the number of women seeking formal care or by reduced rates of maternal mortality. She attributes this to a "lack of resources at all levels, from facilities and staff to drugs and blood" (p. 17). However, she takes cultural beliefs regarding pregnancy as a central focus:

The clinical causes of maternal deaths, the characteristics of women who die and the causes inherent to the health care system are well known in Uganda and elsewhere. Less is known about the cultural beliefs that may contribute to women's deaths. Many authors believe that maternal mortality in Africa has been influenced by socio-cultural beliefs, including gender and power relations, and differences in roles and status between the sexes. (p. 17)

Kyomuhendo identifies a dearth of literature on the socio-cultural aspects of maternity care in Uganda and a need for attention to socio-cultural factors influencing birthing experience and maternity care. However, as maternal mortality frames the concern with socio-cultural aspects, the work links "cultural beliefs" and "death" in a way that seems to lay blame with women and culture for health concerns that are also shaped by socio-political factors including structural violence.

In Kyomuhendo's (2003) study, two major factors stand out as shaping health during pregnancy and birth: the first is a belief that birth is “a thorny road,” inherently difficult, dangerous, and a woman's burden to bear; the second is birthing women's negative accounts of nurse-midwives as bossy, rude, and hurried. Some women felt that hospital staff “ignored the value and meaning they attached to their birthing experiences” (pp. 21-22). Health workers often viewed birthing women as ignorant or as having overly high expectations, oblivious to health workers’ time and resource constraints. Health workers were also wary of the kneeling position that many women preferred, worrying that they could be blamed for negative outcomes resulting from such practices. Kyomuhendo (2003) concludes that education is needed at the community level so that women can better understand all aspects of reproductive health, including that surviving pregnancy should be an attainable norm.

Kyomuhendo (2009) suggests that among Banyoro women in Uganda, birthing unassisted is highly regarded as a demonstration of women’s strength and power (p. 231). She writes that “One who experiences no problems and needs no assistance is held in much esteem, having walked bravely through the hazardous path and emerged unscathed” (p. 231). This perspective, she argues, contributes to the limited uptake of skilled attendance. However, as Kyomuhendo (2009) notes, “there are diverse and distinct cultures” within Uganda, and such observations are not broadly applicable. She also suggests that the role of husbands in controlling financial decisions as well as other barriers to formal care contribute to the prevalence of birthing without a skilled attendant. Similar themes are discussed by Knudsen (2003) with regards to women in Kiboga, central Uganda. She points to “lack of financial independence, lack of power, and a sense of self-worth closely tied to fertility” (p. 253) as well as health system and infrastructure factors as undermining to women’s health. In Kyomuhendo’s (2004) study of near-miss experiences, this balance between cultural and health system factors is summarized as follows:

It emerged that severe maternal illness is not necessarily a result of direct (biomedical) causes *per se* but may stem from other factors deeply rooted in culture and gender relationships. These factors notwithstanding, women are hampered by deficiencies in the formal health care system including *inter alia* inexperienced health workers, especially at lower level units, poor referral systems and the lack of a well-functioning transport system, limited space in the wards or operating theatre, and inability to access the busy health staff (p. 1).

Kyomuhendo's studies suggest that scholars of maternal health and maternity health care can strike a balance between understanding cultural factors including gender, and understanding health system and clinical factors.

Kapakyenga, Östergren, Turyakira and Petterson (2012) assessed the influence of birth preparedness and decision making on location of birth and assistance by SBAs among women in south-western Uganda. They found that among participants who made a decision about where to give birth in consultation with others, the use of SBAs was higher. Regular antenatal care attendance also promoted the use of SBAs. In contrast, residing in a rural setting, or making the decision regarding place of delivery alone, was associated with reduced use of SBAs.

Kabakyenga, Östergren, Turyakira and Petterson's (2012) study took place in a different geographic and social setting than the present study, but engaged with factors such as rurality that are of shared relevance.

The studies reviewed here suggest that cultural beliefs and practices at the local level shape childbirth and maternity care, and, most notably, if and how women seek formal care. As Kyomuhendo (2003) has noted, "In Uganda, the literature on the socio-cultural aspects of maternity care is scant" (p. 19). This is particularly true with regards to Acholiland. Due to differences in study setting, it is not clear whether cultural beliefs and practices in Amuru sub-county relate to care-seeking in similar ways to those discussed above.

## The post-conflict setting

Amuru sub-county is in the process of recovery and rebuilding after the recent end to armed conflict in Uganda's northern region through a ceasefire agreement signed in 2006 between the Lord's Resistance Army (LRA) and Government of Uganda forces (Dolan, 2009). This decades-long conflict is described in Chapter Three. Since the end to armed conflict, or indeed during those years, there has been little study of maternity health care and childbirth among the Acholi people. However, what is known makes clear the need for further research focusing on maternity health care and childbirth experience with an understanding of the post-conflict setting in this region. Given the dearth of literature specific to maternity care and health care in Uganda, in this review I also refer to relevant literature situated elsewhere in sub-Saharan Africa.

The impact of the past conflict on the health of childbearing women and on practices surrounding childbirth has not been extensively documented. However, war and displacement have impacted most aspects of civilian life in northern Uganda. These impacts are examined in Chapter Three, in which I discuss the social context of Amuru sub-county, including the post-conflict context, in relation to women's health. Maternal mortality is significantly higher in sub-Saharan African countries that have recently experienced conflict than in those that have not; O'Hare and Southall (2007) cite the adjusted maternal mortality ratio as 1,000/100,000 in countries with recent conflict, compared to 690/100,000 in countries without recent conflict (p. 565). In broad terms, we know that "a complex humanitarian emergency imposed on an already weak health system compounds the risk of maternal death" (Austin et al., 2008, p. 914); however, the specific points of weakness affecting childbirth and maternity care in the context of Amuru sub-county post-conflict are poorly understood.

While the current study seeks to fill a gap by examining the coordination of birth in the post-conflict context in northern Uganda, research has been conducted in relation to other aspects of maternal health in the region. This includes a study of husbands' participation in antenatal care (ANC) in peri-urban Gulu, which neighbours Amuru district. Findings revealed distance (of more than 5 kilometres) was one factor inhibiting husbands' attendance at antenatal care (viewed as significant for its influence on women's likelihood of seeking skilled attendance) (Tweheyo, Konde-Lule, Tumwesigye, & Sekandi, 2010). Orach's (2000) study, published before the ceasefire, estimates maternal mortality in the Gulu area (encompassing, at the time, Amuru district) to be higher than the national average, at 662 deaths per 100,000 births in comparison to an estimated national average of 500 per 100,000. Orach (2000) concludes that the training of TBAs was needed.

The health consequences of conflict, displacement, and post-conflict are intertwined with the social and political consequences. Social justice and health care access are interwoven: "Receiving health care, not receiving health care, and how health care is offered all affect physical health and at the same time carry messages about citizenship" (Sinding, 2010, p. 1657). Finnström articulates how such messages may work in his book about the meaning of the conflict in everyday life in northern Uganda, *Living With Bad Surroundings: War, History, and Everyday Moments in Northern Uganda* (2008). I examine this interrelationship between conditions related to well-being and social justice in Chapter Three. Dolan (2009) argues that the "minimal assistance" doctrine of NGOs during the war went hand in hand with implicit criticism, as people were given messages about how to improve their health, without the resources to assist them. He argues that the war, including the internal displacement camps, constituted *Social Torture* (2009). These recurring violations occurring under the guise of protection are also pursued in Branch's (2011) book, *Displacing Human Rights: War and Intervention in Northern Uganda*, which

focuses primarily on the role of humanitarian intervention. While these books do not focus directly on maternal health, they address the ways in which the contexts of conflict and displacement have shaped narratives about health more broadly. The work of these authors and the literature on the post-conflict context as it relates to health is discussed in further detail in Chapter Three.

#### HIV prevalence and social factors impacting HIV rates in Amuru

The upheaval caused by the recent conflict and displacement in Amuru sub-county and surrounding areas has contributed to high rates of HIV in Amuru, including among pregnant women. Researchers found rates of HIV among pregnant women attending ANC at Lacor Hospital, near Gulu, to be 11.3% in 2003 (Fabiani et al., 2006). This rate is described as stabilized but unusually high. The study was based on a national HIV surveillance project, which set out to understand HIV prevalence and factors associated with infection by examining data from antenatal care. Lacor Hospital, Gulu, where the study was based, is the full-service hospital of the non-profit which also operates Lacor Health Centre III, Amuru (and two other level III health centres in the area). It is near Gulu, the closest town to Amuru and the major town of the north. Among the broader population, HIV rates in the north have been measured at almost double those in the rest of the country (Westerhaus, Finnegan, Zabulon, & Mukherjee, 2007). Fabiani et al. (2006) observe that “high prevalence can probably be attributed to the effects of the civil strife that has affected the area since 1986, namely the social and economic crises, food shortages, population displacement and reduced access to health care and prevention services” (p. 4). Examining HIV prevalence among young people in the post-conflict transition period in Gulu district, Patel et al. (2014) found prevalence at 12.8 among study participants. Non-consensual sexual debut was strongly associated with HIV infection, pointing to a need for interventions

that address sexual violence. The context of HIV affects approaches to care as it pertains to pregnant women, their intimate partners, and their care providers. Couples' testing – the testing of pregnant women and their male partners during ANC – is one aspect of how HIV shapes approaches to antenatal and delivery care. The process of HIV testing plays a disciplinary role in structuring access to care and has potential to affect women's intimate relationships; these are discussed in greater detail in Chapter Five.

### Summary of literature review

Findings drawn from the literature confirm the need for context-specific studies of maternity care including the role and status of SBAs and TBAs, social and cultural factors in childbirth and maternity care practices, and the effect of conflict/post-conflict on maternity health care and birth. The approach to SBAs and TBAs is an important but controversial aspect of maternity care and birth. The literature review reveals divergent policy contexts in Uganda and that the role currently played by TBAs in Amuru and elsewhere in northern Uganda was poorly understood. Further study was required to understand the role played by TBAs in Amuru and how this related to the overall organization of maternity care and birth. Overall, the studies reviewed here indicate that approaches to care can be highly localized, that policies have not translated to better health care or outcomes, and that there is value in understanding dominant discourses about health as they affect approaches to care. The literature on post-conflict indicated that health consequences of conflict and displacement are interdependent with social and political consequences. There was also a paucity of literature on maternity care and birth in northern Uganda related to the post-conflict setting. Taken together, the literature reviewed here suggests that research addressing maternity care and birth in northern Uganda Acholi communities is much needed. The current study addressing how women's birthing experiences

are arranged in this local context in the aftermath of twenty years of armed conflict and internal displacement offers integral insights to the social organization of maternity care and birth in this region.

## Chapter Two: Methodology and Methods

### Introduction

Undertaking the research for the current project was an exciting and sometimes daunting process of discovery: from my family's home base at a rural health centre's staff housing, I traveled by foot, boda-boda (motorcycle taxi), or van to learn from Amuru community members under mango trees, in thatched huts, and in community halls. In this chapter, I describe the methodology guiding the research and detail my research activities. I begin by describing institutional ethnography (IE), explaining how it fits with and leverages my research goals. I go on to identify specific features of IE, including approaches to institutions, work, texts, and discourse, and how each is relevant to this study. I outline formal ethics procedures and social justice concerns relating to the study. I then provide an overview of my research design and methods, which included interviews, focus groups, field notes, and reflexive journaling.

From February through August 2012, I lived at Lacor Health Centre III,<sup>6</sup> Amuru in a small rural community. Located at the site of a former Internal Displacement (IDP) Camp, the health centre was a hub for Amuru sub-county. It was run by Gulu's Lacor Hospital, a Catholic hospital under the joint operation of Italian and Canadian NGOs. My family and I stayed in staff housing, with the medical staff of the health centre and their families as our neighbours. For the opportunity to imbed myself in this rural community, and for the friendship and support I encountered there, I am tremendously grateful. My seven months' immersion in this Acholi community shaped my perspectives on this research significantly.

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<sup>6</sup> Health services are identified by levels corresponding to local political entities. A health centre I, the VHT, corresponds to the village level. A health centre II is the lowest level of health centre to have a physical facility, and corresponded to a parish level. A health centre III, like Lacor HCIII where I lived, corresponds to a sub-county level, and is required to have a senior clinical officer and a lab. A health centre IV also has a doctor and an operating theater, and corresponds to the district level.

## Study Overview

This study sought to map the social coordination of childbirth and maternity care in Amuru sub-county drawing on methods based in IE. My research question asked: *How is maternity care and childbirth socially organized in the context of Amuru sub-county, a rural area recovering from conflict in northern Uganda?* Health sociologist Christina Sinding (2010) identifies that “IE studies begin . . . by drawing forward the activities, knowledge, and concerns of a group of people related to their involvement with a particular institutional complex” (p. 1657). Accordingly, I used IE to draw forward the activities, knowledge, and concerns of childbearing women in relation to the institutional complex organizing maternity care and childbirth. My research question focused on how childbirth experiences are constituted within social contexts. Therefore, my methodological approach focused attention on how social institutions and discourses shape birth experiences in local contexts. Attention to childbirth and maternity care in this setting was important not only because of the poor outcomes I introduce in Chapter One and discuss throughout the dissertation, but also because appropriate care and support in this period is intrinsically important to women’s lives, health, and wellbeing. My point of entry was the concerns of childbearing women; my research scope moved up and out from there. This orientation, in tandem with my extensive fieldwork period while based at a former internal displacement camp in this rural, post-conflict setting, were unique features of this project. A social justice orientation and long fieldwork period anchored the current study in the context-specific social and discursive constitution of maternity care and childbirth.

## **Institutional Ethnography (IE)**

### Positioning myself as researcher

I first became interested in the needs of mothers and children in post-conflict settings when working in Thailand at a home for children in 2004. Most of the hundred children who lived there had fled conflict and displacement in neighbouring Burma. I struggled to accept the injustices these children had faced, and in particular, could not reconcile my anger over one child, a popular boy of eight who had AIDS. Despite my growing understanding of the economic and social impacts of the conflict, my anger was directed towards his mother, who sold sex near the border and whose rare visits her son proudly anticipated. I knew that I needed to push past this visceral emotion to a clearer analysis of the conditions that had led to his illness, abandonment, and eventually to his death. Through the stories shared by youth and the human rights activists who were our neighbours, I learned about the impacts on families of surviving violence, poverty, displacement, and statelessness. When I worked on a gender-based violence research project in South Africa, at the Center for the Study of Violence and Reconciliation, I was struck by how similar certain challenges were to those of displaced Burmese people, despite the different historical and cultural settings. Later, when I became a mother myself, I grew interested in the value of social and medical support during pregnancy and the transition to motherhood, and in inequities in how this support is distributed. I observed such inequities in my own east Vancouver neighbourhood, where First Nations mothers and new immigrant mothers did not share the waiting room at the new and exemplary midwifery clinic where I received care. I started to learn about barriers to access to care for refugee women, rural women, and others in British Columbia. When some of these interests coalesced through my PhD studies and I considered undertaking research with a focus on Uganda, my partner was keenly supportive. His

own parents, of Indian ancestry, had left Uganda after generations in East Africa, as part of the mass expulsion of Asians from Uganda in the early 1970s. He had visited the country, and looked forward to the opportunity to return and to share it with our son. Throughout my doctoral research, my previous engagement with women and children in the context of conflict and reconciliation, as well as my experiences with birth and parenting, has shaped my perspective.

### Background and goals

Institutional ethnography (IE) is an approach to social research developed by Canadian sociologist Dorothy Smith. What distinguishes this approach is that IE studies focus analyses on the processes of social organization by learning about people's everyday actions and experiences and how they are coordinated via institutional processes. Smith's insights leading to the development of IE were grounded in the Canadian women's movement, as she worked to bridge the gap between women's lived social realities as mothers and sociological or institutional paradigms of motherhood (Griffith & Smith, 1987; Smith, 1987; Smith, 1997). Since these first inquiries, IE scholars have contributed to other movements for social change. As health sociologist Eric Mykhalovskiy (2002) suggests, IE's focus on “how people's daily lives and troubles are organized socially and institutionally” (p. 20) is conducive to the creation of knowledge supporting equity, representation, and/or inclusion, especially in the setting of political struggles. As such, an IE approach to methodology is epistemologically consistent with a conceptual approach guided by social justice.

Adequate support during pregnancy is a social justice concern. As Hankivsky, Grace, Hunting, Ferlatte, Clark, Fridking, Rudrum and Laviolette (2012) write:

Theories of social justice frequently challenge inequities at their source and require the interrogation of complex social and power relations [. . .] A social justice approach to health equity has the potential to transform social structures, which is essential in addressing the root causes of inequities. (p. 38)

My understanding of social justice is influenced by Sen's (1999) capabilities approach, which centers individuals' ability to engage in practical freedoms as central to people's well being alongside the material goods that are the focus of distributive justice. Nussbaum (2000, 2003) has extended the capabilities approach, focusing on gendered dimensions and advocating for a clearly defined approach to capabilities. To this end Nussbaum created a list of central capabilities, including, relevant to this study, life, bodily health, bodily integrity, and the political and material control of one's environment, among others (Nussbaum, 2000). Like Sen and Nussbaum, Young is interested in gender and more broadly social difference, but is more explicitly critical of the individual focus of much human rights discourse, and suggests a turn towards relationships and social groups as central to justice (2008).

While many qualitative researchers have undertaken studies in critical health research drawing on IE methodologies, such an approach has seldom been applied in research set in the global South.<sup>7</sup> For this reason, I have bolstered my IE approach with other methodological and theoretical insights relevant to research in the global South, including those described in the sections titled "Social Justice Concerns in Ethical Research Practices" and "Field notes and reflexive journaling".

## Institutions

"Institutions" within IE are more broadly defined than elsewhere in social science research. An important contribution of IE is its insight into how institutional influences are pervasive beyond the "walls" or formal bounds of self-described institutions (such as a hospital) (Mykhalovskiy & McCoy, 2002). "Institution" within IE refers "to a complex of ruling

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I am, however, aware of studies such as Jakubec's (2004) work on mental health in west Africa, referred to in Campbell and Gregor (2008), and Grace's (2012) transnational work on HIV legislation which is concerned with African examples.

relations—the multiple activities of individuals, organizations, professional associations, agencies and the discourses they produce and circulate—that are organized around a particular function such as healthcare or education (Smith, 1987)” (Mykhalovskiy & McCoy, 2002, p. 19). Smith (1987) states that, “In contrast to such concepts as bureaucracy, ‘institution’ does not identify a determinate form of social organization, but rather the intersection and coordination of more than one mode of the ruling apparatus” (p. 160). It is these activities and discourses I considered as I worked to understand the social organization of maternity care and birth. The broadening of the institutional context of birth and maternity care beyond health care institutions per se avoids a shortcoming Kumar (2013) identifies with a focus on health access as a technical solution to maternal health problems in the global South. She writes: “constructing maternal mortality as a problem engendered by lacking access to healthcare facilitates conceptualizing social problems as having technological solutions; thus the structural causes of the problem are effectively erased” (p. 25). The IE approach to institutions avoids shifting analysis from social dimensions to technological dimensions of a problematic, in this case the social organization of maternity care and birth.

### Participants as experts

In an IE approach, research participants are not considered to be the objects of study. Rather, participants act as expert informants on their own experiences as they intersect with the wider social phenomenon that is being researched. For example, McCoy's (2006) “Keeping the Institution within View” describes how, in such an approach, presenting people's assessments of health care delivery can be a form of advocacy. McCoy states that:

What an institutional ethnographic approach contributes to that advocacy project is an institutional focus that keeps attention oriented toward the organization of health service delivery (what is being evaluated) and prevents it from stalling at a typology of evaluative criteria (studying the patients). (p. 117)

Objectifying or creating a typology is something for social justice researchers to avoid, as Mohanty (1988) has discussed, and centering the expertise of participants is one way to avoid objectifying practices in research. Della Failles (2011) summarizes Mohanty's view that so-called "Third World Women" "are represented in 'terms of their object status', being a 'homogeneous 'powerless' group', more often than not victimized (Mohanty 1984: 338)" (p. 226). The "third world woman" becomes a fictional object that tells more about Western women than about particular settings in the global South (della Failles, 2011, p. 226). Approaching participants as experts rather than as the objects of study decenters the researcher's role as expert, and is consistent with social justice research practice.

Because some scholarship on maternity care tends to objectify, such as by looking to personal or cultural deficits to explain a lack of uptake in formal health care, recognizing the expertise of childbearing women and the legitimacy of their knowledge of how care is organized is a particularly important intervention within this field of inquiry. Writing on representations of women's experiences of childbirth in the global South, Kumar (2013) makes the point that:

researchers could engage in colonial representation in at least two ways: First, by focusing on proximal determinants of health, such as access to healthcare, without giving due consideration to distal factors such as poverty and economic exploitation on a global and/or national scale. Second, by constituting women in resource-poor contexts as a 'coherent group with identical interests and desires, regardless of class, ethnic or racial location' (Mohanty, 1988, 64), thereby overlooking intersecting axes of difference that may impact women's health in equally problematic ways. (p. 22)

In learning from childbearing women about maternity care and childbirth, my goal was to understand their knowledge and experience as they interacted with and constituted a part of the local social organization of maternity care and childbirth.

The IE practices of viewing participants as experts is consistent with other qualitative research approaches committed social justice goals, as is suggested by Fine's (2006) question:

If researchers consider expertise to be lodged primarily with other PhDs who have been socialized in the language and logic of our theories and methods, to what extent does social research align itself primarily with dominant discourses, ignoring the expertise of those who suffer most? (p. 13)

In the current research, it was more useful to set out to understand the social organization of maternity care and birth than to stop at understanding local women's experiences of care and birth, because a better knowledge of the existing social organization could be a platform for action such as advocacy and policy recommendations. Moreover, valuing the local and experience-based knowledge of research participants without locating participants as the objects of study was particularly pertinent in a setting in which people were vulnerable because of certain specific factors, including their lack of political power, their absolute poverty and lack of access to resources, and their lack of inclusion in decision making.

## Work

Institutional ethnography has contributed a broader definition of "work" to sociological studies as a way to understand the organization and significance of people's ordinary activities. The work this definition describes is "intentional: it is done in some actual place under definite conditions and with definite resources, and it takes time" (Smith, 2005, p. 154). Mykhalovskiy and McCoy (2002) provide an example of this approach through their use of the concept 'health work' to help understand the work that people living with HIV/AIDS undertake in managing their health. They used 'health work' to mean "the wide range of practices that people engage in around their health, without defining in advance what that work might or should involve" (p. 24). Further, they understood such work to take place within the larger institutional complex of healthcare. Following Mykhalovskiy and McCoy's (2002) study, various other studies of health care in developed countries have interpreted the activities patients undertake in adhering to treatment routines, or seeking medical care more generally, as "work" (Lowndes, 2012; Sevigny,

2012). However, the concepts of work and health work are particularly apt in a setting such as rural northern Uganda where access to the basic amenities for coordinating health care – transportation, communication technology, and money – is so scarce.

By paying attention to what work participants did in relation to maternity care and birth, I learned of work that took place in relation to health care provision, such as planning for transportation, and work that took place in relation to family and community, such as smearing the hut (resurfacing the floor). Further, I learned that certain approaches to HIV testing and to NGO programming introduced work for childbearing women that might have been unanticipated by policy makers. (This is discussed in Chapters Five and Six.) Understanding the particularities of the work participants undertook as part of self-care or seeking health care contributed to an expanded or refocused understanding of the social organization of maternity care and birth.

## Texts

In addition to work, texts are key to IE methodology. Within IE, texts are broadly defined as written or graphic materials that can be reproduced and are used in coordinating translocal activities. That is, texts produced in one place are influential in coordinating activities and knowledge in a different place. Texts are important as a bridge between local contexts and broader, or extra-local, contexts:

The magical character of replicable texts from the point of view of institutional ethnographic interest is that they are read, seen, heard, watched in particular local and observable settings while at the same time hooking up an individual's consciousness into relations that are translocal. (Smith, 2006, p. 66)

In order to understand this coordination between local and extra-local contexts, institutional ethnographers pay attention to when texts are consulted or invoked. At the outset, guided by Smith's writing about IE and by other IE studies, I anticipated that texts of interest might include

a law or policy that was referred to, a document that was to be presented at a certain time, or a form that was to be completed.

### *Texts and the low-literacy setting*

An additional consideration with regard to texts was how the contexts of low literacy and low media consumption influenced the circulation and operationalizing of texts. Within IE, the importance of texts is often situated in historical contexts that, while broad, are particular to the industrialized global North, in contrast to a rural setting in the global South. Smith situates her discussion of texts in European history and North American politics, and concludes her study of how texts facilitate ruling relations with the statement: “Advanced contemporary industrialized societies are pervasively organized by textually mediated forms of ruling” (2002, p. 212).

Campbell and Gregor (2012) refer to how *literate* people put texts into action in everyday life (p. 32) while Smith labels texts as “those most commonplace objects of our contemporary world, so much present that we take their ubiquity entirely for granted” (2006, p. 26). Grace (2013) writes that “in late (post) modernity institutional knowledge is text-mediated” (p. 38). These examples show that the cultural shifts making texts so central in organizing knowledge and activities have not occurred universally, but do not theorize the role of texts in societies that are not characterized by industrialization or the ubiquity of media.

In Amuru sub-county, low-saturation of media (including internet access, print media, and even radio) is part of what makes it a very different place from the global North where the majority of IE studies have been situated. The forms texts take are different, and the prevalence of illiteracy contributes to this difference. I found that some of the bureaucratic texts functioned in ways similar, on the surface, to the forms that govern health care work Canada, such as the requirement to present a card or a letter at certain times. Less similar was the role of “text-

mediated discourses that frame issues, establish terms and concepts” (DeVault & McCoy, 2006). These were drawn on by health care providers and administrators and thus played a role in how health care was organized. However, among childbearing women, the discourses framing childbirth and maternity care were mediated very locally, and the role of texts was at times indirect and difficult to trace. For example, MDG 5 or maternal mortality was not part of their discourse, and neither were ideas such as “barriers to access”. However, participants did know that attending a health centre for antenatal and delivery care was encouraged for their health and the health of their baby, and they did speak about “barriers” without using such terminology.

## Discourse

Throughout my analysis, I discuss discourses as they are relevant to the social organization of maternity care and birth in Amuru sub-county. Discourses are overarching narratives that have the power to shape social realities. At the same time, people are active in reproducing discourses, and can also modify or disrupt them. Drawing on historian of ideas Michel Foucault, Smith (2005) writes that: “The functions of ‘knowledge, judgement, and will’ have become built into a specialized complex of objectified forms of organization and consciousness that organize and coordinate people’s everyday lives” (p. 18). Discourses operate at various levels of specificity and influence, with some becoming part of a larger ideology. Smith (2005) explains, “ideological discourses are generalized and generalizing discourses operating at a metalevel to control other discourses” (p. 224). For example, I argue that through texts including MDG 5, “maternal mortality” not only refers to the everyday/everynight reality of women dying in childbirth, but, in the context of sub-Saharan Africa, is also an ideological discourse that influences what can be said and done in relation to maternity care and birth. In an IE approach, discourse is always understood in relation to social actors and activities as well as to language.

Finally, a further area of text and talk highlighted by Smith and particularly relevant in research related to health care is institutional language, or institutional discourse. This consists of talk in which the actual steps or people involved in a task disappear into professional jargon or short forms. Campbell and Gregor's (2008) discussion of data collection provides an example: “when someone says, 'I processed that application,' or 'I manage the household finances,' the actualities of work are missing” (p. 72). In my own conversations with research participants, I found that the concept of institutional language was particularly relevant when interviewing the health care workers, who might refer to “filling in a partograph,” for example. However, a kind of short form also came up in the interviews with childbearing women, who would refer to ‘mudding’ their hut or buying ‘small-small things’. For my research assistant (RA), who was translating, this was the language of shared work knowledge, and I had to follow up to ensure I clearly understood the activities this work actually involved and its significance – what were these small-small things, and what did women have to do in order to be able to buy them? Particularly for researchers who are familiar with professional jargon, it is an important skill to tease out the actual processes that are behind these short forms in order to understand the processes of social organization. In this respect, being a cultural and geographic “outsider” (Gair, 2012) was helpful as was my lay status: people expected to have to explain things to me.

### **Social Justice Concerns in Ethical Research Practices**

IE is consistent with a social justice approach to research, but to adequately consider relational ethics for this project, it was necessary to draw on other methodological approaches that explicitly resist the colonizing potential of research. Smith “rejects the dominance of theory” in sociological inquiry (Smith, 2005, p. 49); this rejection means that IE “findings are not already prejudged by a conceptual framework that regulates how data will be interpreted” (Smith, 2005,

p. 50). Hussey (2012) contextualizes the rejection of reliance on theory as a form of methodological bracketing. He explains:

The researcher makes the ontological shift to reject speculative explanations. This involves a move away from general and generalizing theoretical explanations to a particular, embodied, situated, “sensuous world of people’s actual practices and activities” (1990: 633). This technique of bracketing ideological procedures implores the researcher to focus analysis on explicating temporal- spatial-situational actualities (1990:637–638)” (p. 9).

With these critiques of reliance on theory in mind, I have used social justice as an important touchstone. I have looked to non-colonizing methodologies in order to avoid colonizing research practices. While my findings, consistent with IE, report on the actualities of work and experience, I am aware that these activities took place in a broader social context. This context has been shaped by past conflicts, inequities, and colonialism which have continued to constrain and delineate what can happen with regard to maternity care and childbirth and also impact the research context and research relationships.

Various scholars have examined the connections between the practices of academic research and on-going colonialism (Browne, Smye & Varcoe, 2005; Mohanty, 1988; Smith, 2008). Others have tried to identify and develop research that can be decolonizing. For example, Linda T. Smith (2008) makes the case that qualitative research is a valuable tool for indigenous communities, for its power to “situate, place, and contextualize,” to “create spaces for decolonizing,” and to “understand little and big changes that affect our lives” (p. 136). Browne, Smye, and Varcoe (2005) write that:

A postcolonial interpretation locates health and social conditions in the domain of the historical and structural disadvantages that shape them. From the selection and framing of research questions, to decisions on the dissemination and presentation of findings, vigilance is required, in order to decrease the potential for research processes to undermine our broader transformative goals”. (p. 31)

Such insights into research approaches advance a potentially transformative agenda in addressing power dynamics between academic researchers and communities struggling with poverty and poor resources.

As well looking to social justice and non-colonizing research practices to help ensure ethical research, I draw on intersectionality, an approach that examines how multiple social and structural factors overlap and constitute systematic power relationships based on oppression and privilege. Intersectionality “requires a consideration of the complex relationship between mutually constituting factors of social location and structural disadvantage so as to more accurately map and conceptualize determinants of equity and inequity in and beyond health” (Hankivsky et al., 2012, p. 18). As Weber writes, within intersectionality:

Inequalities are conceived as social constructions situated in social contexts and structures beyond the individual – in societies, institutions, communities, and families – and are characterized as power, not simply resource, difference between dominant and subordinate groups. (2006, p. 24).

An intersectional approach is consistent with a social justice approach to research, and is highly relevant to discussions of gender and power in the current study.

Before arriving in Amuru, I had reflected and written about relationships and ethical considerations that might arise in this research context. I knew that I would be an 'outsider', as a white Canadian researcher who would not be communicating in Luo (Acholi), the language spoken in Amuru district and throughout northern Uganda, but in English, a colonial language in this context, though also a national language and widely spoken. Throughout the conflict and post-conflict period, the involvement of non-governmental organizations (NGOs) and their Western staff had had both positive and negative impacts on local communities. I wondered whether the international NGO community would be viewed as having colluded with the government to create the internal displacement camps to which many had been forcibly displaced

(as Branch [2011] and Dolan [2013] describe), and whether there would be a degree of cynicism or distrust in response to my role as a researcher from overseas.

I worked to avoid conducting research in a way that was potentially colonizing, stigmatizing, or otherwise harmful to research participants or the community. Relationships are central to ethical research, and I was attentive to the nature of my relationships with research participants and assistants. In order to avoid a condescending and exclusive approach to research ethics, Eikeland (2006) suggests we need to replace a worry over how researchers 'treat' participants with the question: "How should we *relate to each other*?" (p. 42, my italics). In the period leading up to formal data connection, I worked to develop relationships within the Amuru community. This included staff and neighbours of Lacor Health Centre III. These relationships and my understanding of the community were facilitated by my decision to be based in Amuru, rather than in nearby Gulu town, where many international NGOs and researchers were based. While Gulu would have offered some conveniences of an urban setting, such as (somewhat) more reliable power and phone reception, or the availability of restaurants and western food, being based in Amuru contributed to my research. It not only gave me access to unfolding events and a greater understanding of local conditions, as discussed in "Field notes and reflexive journaling," but also signaled my commitment to the sub-county and facilitated the development of meaningful relationships with people in the sub-county. Via colleagues, I was also introduced to other stakeholders working in health care or government in Amuru and Gulu. In many cases, they shared their insights about the issues at play in local maternity care delivery, and had recommendations on how to best work with rural research participants. I had the privilege of working with a committed and knowledgeable RA, Acero (pseudonym) who was an experienced RA and a trained social worker. She helped create comfort and rapport with participants, translated questions and responses, and offered me interpretations from her own perspective and

her knowledge of Acholi culture. Before beginning data collection, she trained with me to learn more about IE and qualitative research methods. She supported my efforts to ensure that participants' privacy and informed consent were prioritized, and answered my questions on language and cultural norms. Her thoughtful participation contributed to this study.

Through careful research practices I was able to avoid a colonizing approach to research. However, reflective research practices cannot make inequity safe or comfortable. I experienced the tremendous distance between the economic (and sometimes social) capital of most Westerners, including myself, and that of almost anyone living in Amuru, in a conflict-torn village in sub-Saharan Africa. For example, my RA's salary reflected the internationalized economy of research and NGO work and was higher than many could earn, but her work was temporary. We travelled with her baby, but she struggled to find safe and inexpensive care for her older child. Our lives and concerns were shaped by structural inequalities that an ethical approach to research could only mitigate, but not redress.

On one occasion, the material inequities were particularly evident; when a young woman who had not been invited to participate in the study asked to be included and said, "I'll follow you to London" (where someone who looks like me might be presumed to have originated). I was concerned that I would come across someone in my interviews who needed help of a kind I wasn't 'supposed' to provide. I was relieved when the mother of a baby who looked small and weak had already sought care, and had medication, but still worry about one woman who told me that she prayed to God to avoid a twelfth pregnancy that she'd been told would likely be fatal. In these instances, I felt that my efforts to be non-colonizing in my research were a small gesture in the face of the everyday impacts of colonialism and other forms of structural violence in people's lives.

## **Ethics Approval**

In Canada, the current study was approved by the University of British Columbia's Behavioural Research Ethics Board. Within Uganda, I sought ethics approval at three levels: Lacor Hospital's ethics review board, the Uganda Council of Science and Technology, and the President's Office. These were not concurrent proposals (each stage of ethics submission had to be approved before application could be made to the next), and I began the process of Ugandan ethical approval in country in order to enable a face-to-face meeting with the Lacor ethics committee. Due to the three non-concurrent stages of ethics approval required within Uganda, in addition to my university's ethics protocols, there was a considerable period during which I was "in the field" but unable to conduct research with participants. This period was nevertheless productive and important to the study, as I describe below in the field notes and reflexive journaling section. I arrived in Uganda in February 2012, and began conducting interviews in June 2012, by which time I had received ethics approval from all institutes.

## **Methods**

### **Data collection**

In this section, I describe the activities I undertook as part of this study of maternity care and childbirth in Amuru sub-county. Data collection strategies included interviews and focus groups in two stages as well as observation and reflexive field notes. During stage one, I held interviews and focus groups with childbearing women, with Acero, my RA, providing translation. In stage two, we spoke with health workers. Stage two discussions were framed by what I had learned from the childbearing women and through fieldwork and observation.

### *Stage one: Interviews and focus groups with childbearing women*

The first stage of my formal research consisted of 35 semi-structured interviews and two focus groups with five participants in each group with childbearing women. These were aged eighteen and older who had at least one child under two years old and were willing to discuss their approaches to and experiences of recent pregnancy, maternity care, and birth. Age eighteen is roughly the time at which marrying and giving birth is accepted within Acholi communities, while those giving birth younger might be regarded as taking part in an “early marriage” (Baines & Rosenoff Gauvin, 2014, p. 17). Research with younger mothers would also have had ethical and practical dimensions beyond the scope of this study. Having a child under the age of two meant that the experience of pregnancy, maternity care, and birth was relatively recent, to assist in recall, and that the care and births women were discussing took place in a similar time frame to each other. In speaking to women who met these requirements, I began my study from the standpoint of childbearing women.

In my research prospectus and ethics submission, I had indicated that I would interview between 20 and 35 women. While by the twentieth interview I was encountering repetition of certain themes, each woman’s experience was unique and contributed to the richness of the data and therefore I continued to recruit participants. Further, I knew from the literature, from my early interviews, and from fieldwork, that geographic location was likely to be important to my analysis, and therefore wanted to have a similar number of interviews in each village. Six interviews were undertaken in five of the six villages; in the sixth, five interviews were held. In this village, nearby the health centre, where five interviews were held, I also held a focus group. The second focus group was held at one of the most remote villages. I therefore conducted 35 interviews and spoke with 10 focus group participants in order to attend to the importance of

diversity of locale. Thirty-five was the high end of my anticipated range for interviews. Despite the additional expense in time, transportation costs, translation and transcription caused by a larger number of participants, the participation of each of these childbearing women contributed greatly to the richness of the data, description, and interpretation in this study.

Childbearing women participants were purposively recruited from six of the twelve major villages within Amuru sub-county. I selected the villages after I had been living at Lacor Health Centre III for some time, with input from the clinical officer in-charge, the district health officer (DHO), and a leader with the village health team (VHT). In selecting sites, I wanted to have some range in geographic proximity to care, an important feature of access. Reading, conversations, and observation suggested that distance from health facility would shape various aspects of planning for childbirth. Building some diversity or range of experience into recruitment is consistent with IE fieldwork, as researchers may “seek informants who can report on varied circumstances and situations,” (DeVault & McCoy, 2006, p. 32). Institutional ethnographers may also “conceive of this kind of selection in terms of diversity of experience rather than categorically” (DeVault & McCoy, 2006, p. 32). In the parishes that make up Amuru sub-county, I learned, there were twelve villages and four health centres; conducting interviews in six villages, two with close proximity to health centres facilitated the goal of having a broad and diverse group of participants within the geographic scope I had identified. I found, however, that those close to another health centre actually tended to travel to Lacor Health Centre III. The prevalence of women with poor geographic access to a health facility in my study is consistent with the circumstances of women in rural northern Uganda.

The study included participants of various ages (excluding the youngest mothers) (see Appendix 2), and other diversities. While most residents belonged to similar socio-economic groups, for some participants, particularly the wives of leaders, financial concerns were less

prominent; other women worried over basics such as daily meals. Most participants were Acholi, but a few (two among the childbearing women) indicated they were members of neighbouring ethnic groups who had moved to be with their husbands.<sup>8</sup>

Many local residents, including the health centre's director, my RA, and Western and Acholi acquaintances who had undertaken research in the villages, advised me that it was essential to introduce myself, my RA, and the project to local leaders. Based on this advice, recruitment took place face-to-face in the villages. We sought the approval of local leadership and ensured that leaders understood the goal of our visit to their village, how long we would be there, and with whom we would be talking. Recognizing local leadership is important to non-colonizing research practices (Smith, 1999). The local leadership was represented by either a Local Council I or a Rwot Kweri. Local Council leaders are formal representatives of the government at the local level, while Rwodi Kweri (plural form) are male traditional leaders selected by their community on the basis of skill in agriculture. These two forms of leadership exist side-by-side (they are not part of the same hierarchy of leadership, but both are recognized by the community). As Porter (2012) describes:

In theory, there is no relation between the roles of the LC I and the rwot kweri as they are different systems entirely. One is a civil servant, the other is a cultural leader. But in practice their roles are determined according to the community's faith in their leadership and the community's particular needs. (p. 88)

In each village, I discussed the research and its goals with a local leader, showed my letters of approval, and asked permission to be in the village and conduct the interviews or focus groups. At the end of our time in the village, or at a time convenient to the leader, we would sit down to discuss any issues facing that village, and any concerns the leader had regarding maternity care.

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<sup>8</sup> Participants tended not to distinguish between formal marriages and commonlaw partnerships, calling involved male partners "husbands". I have referred to participants' male partners as husbands throughout, in accordance with this practice.

Within each village, Acero and I were introduced to potential participants. Generally, the local leader introduced one woman who fit our criteria (over eighteen with a child under two) who then facilitated further recruitment through her network. In the context of small rural villages where literacy was rare and transportation and communication were both costly and hard to access, this made better sense than scheduling a meeting in advance. We sat down together in a location selected by the participant: this was sometimes in their hut, sometimes in a shaded outdoor area, and sometimes inside a community space such as a church. While the leader often brought out chairs or a bench, we generally sat on a mat on the ground or floor together with the participant, so that we were all on the same level. I usually wore a knee-length skirt and a simple top without accessories, and carried a kitenge (African print) cloth for shade or to cover my legs. These strategies were designed to facilitate an appropriate interview location and a comfortable setting for participants. Ensuring that interviews took place near the participants' own homes in a comfortable setting, and taking steps to diminish any perception of myself as an authority, was one means of avoiding colonizing research practices in the field, and also contributed to credibility and rigour (Schensul & LeCompte, 2013). Before each interview, we spent some time explaining the research and its goals, reviewing and signing consent forms, and fielding any questions about the study. We explained what the voice recorders were and offered a playback demonstration, an effort to put participants at ease with the technology. Participants brought their smaller children to sit with them for the interviews. Acero also brought her young son along for fieldwork, which meant that there was often not one, but two babies in each interview. His presence helped establish that the visiting researchers were also mothers. We paused for small interruptions so participants could help their children as needed. I introduced myself as a mother as well as researcher, explained where I was from, and that I was not a nurse or health worker (in case any part of our interaction was misunderstood as a health visit). My own son did not

accompany us when leaving the village, but when he was curious about a focus group held with health workers at the health centre, I let him sit with us for a short while.

During interviews, I asked open-ended questions including “What does 'maternal health' mean to you?” and “What do you do to prepare for childbirth?”.<sup>9</sup> Such questions provided an opportunity for the participants to produce narratives that explained their experience of birth and care, including the activities and work they undertook in planning or facilitating their own care, and for them to give detailed examples of the strengths and challenges in local support for childbirth. Acero provided translation, and helped suggest follow-up questions. My intention was for the interviews to focus primarily on the birth of the youngest child, under two years of age at the time of the interviews. While this remained the primary focus, when women were pregnant at the time of the interviews, or had had several children in close succession, a broader focus on their experiences was introduced. This happened when participants were keen to share information about their current or recent pregnancies or to compare one recent experience with another. These narratives were relevant to my research question. This flexible approach to interview content is consistent with IE approaches to interviewing, in which interviews are “an open-ended inquiry” (DeVault & McCoy, 2006, p. 23).

In addition to interviews, I conducted two focus groups in this first stage, also with women who had children under two years old. There were five participants in each group. I spoke in total with 45 childbearing women in this research stage. As with the interviews, before the focus groups we gave an overview of the study, explained and obtained signatures on consent forms, demonstrated the voice recorders, and discussed anonymity. We asked that participants treat the discussion as confidential, but acknowledged that we could only ensure that we, the researchers, would do so. Employing focus groups with childbearing women as a final stage to research

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<sup>9</sup> My interview guide is included as an appendix.

among that group was fruitful in that it provided a directed discussion on themes I had identified as key via reflection on the interviews. Wilkinson (2005) identifies focus groups as a method that shifts the balance of power towards participants (p. 282) due in part to the fact that such groups are often situated in a social context in which participants are comfortable. It was clear that focus group participants were relaxed and enjoyed the opportunity to discuss these matters together. While the interview setting was appropriate for women's private experiences, fears, and concerns, the focus groups sometimes tended towards a more general discussion of the issues, with support for those women who shared personal stories. Focus groups took place at one village neighbouring Lacor Health Centre III and considered to be 'very walkable,' and at a second village quite distant from Lacor Health Centre III (and any functioning health centre). My guiding questions for these focus groups were developed based on responses to the initial interviews.

#### *Stage two: Interviews and focus groups with health care workers*

During the second stage of formal data collection, I conducted a small number of focus groups and interviews with 22 health workers involved in maternity care, such as village health team (VHT) members, traditional birth attendants (TBAs),<sup>10</sup> and health care centre medical staff (nurses and midwives). I included this research stage based on the IE practice of looking 'up and out' from one's initial site of inquiry into institutional practices that shape that initial site. DeVault and McCoy (2006) describe this second stage as an opportunity for the researcher to "begin examining those institutional practices that he or she has discovered to be shaping the experience but that are not wholly known to the original informants" (p. 21). They note that, "often, this shift carries the investigation into organizational and professional work sites" (p. 21).

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<sup>10</sup> Since recently, practicing TBAs are required to be VHT members. Women make up a minority of the VHT; among them, many are TBAs.

I anticipated that in this context, the process would include looking to the experiences, knowledge, and practice of health care workers. While the formal element of recording talk with childbearing women and then with health workers were sequential, since I was living at the health centre I was learning from health workers all the time. These informal conversations and trips we took together became part of my knowledge of how care was organized.

The goal of these subsequent focus groups and interviews with health workers was to explore the link between mothers' insights into how support for childbirth is coordinated locally, and the work processes of those involved in providing health support for birthing women. While I asked general questions so health workers could describe the care they provide and any challenges they meet in providing it, the primary focus of these interviews was determined by the contents of the initial interviews with birthing women. For example, some women had reported giving birth at the health centre but unattended by health centre staff, so I asked health workers about whether this sometimes happened and if so, what might lead to such circumstances.

In discussing care for pregnant and birthing women, I used a broad and encompassing definition of care providers, rather than focusing either solely on formal healthcare supports or informal care supports. This was because both employees of the formal health system and participants at the village level (such as TBAs and members of the VHT) were likely to play a significant role, because their roles might overlap, and because, at the outset of research, it was unknown whether childbearing women in Amuru made a clear distinction between formal and informal sources of maternal care and labour support. As it transpired, birthing women did tend to refer to a large group of varied health workers as “daktari,” a Swahili<sup>11</sup> word meaning doctor.

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<sup>11</sup> While the mother tongue of the Acholi is Acholi (Luo), widely spoken throughout northern Uganda, English and Swahili are both official languages. Swahili is widely understood in east Africa, and people sometimes use Swahili loan-words when speaking other languages.

Following is an overview of who I interviewed, which is also captured in Figure 1, a chart of participants in both study stages.

<b>Stage One: Childbearing women</b>	
Interviews with childbearing women	35
Focus groups with childbearing women	2 (5)
<b>Total number of participants in stage 1</b>	<b>45</b>
<b>Stage Two: Health workers</b>	
Focus groups with TBAs	2 (5)
Focus group with VHT members	1 (5)
Interview with midwives	1, 2 participants
Interviews with nursing staff	2
Interview with clinical officer in-charge	1
Interview with public health officer	1
Interview with district health officers	1
<b>Total number of participants in stage 2</b>	<b>22</b>
<b>Total number of study participants</b>	<b>67</b>

**Figure 1: Overview of study participants in both research stages**

Since the VHT had a relatively large local membership (including many TBAs), I chose to work with focus groups instead of one-on-one interviews. I spoke with one focus group of five general members of the VHT and two focus groups of five TBAs (who were also VHT members). These focus groups were held in Acholi, with VHT members introducing some commentary in English. At the level of the formal health system, there were fewer providers in each category. I interviewed two nurses; the clinical officer in-charge, who had both a clinical and an administrative role; the public health educator (a health centre employee); the district health officer (DHO), an employee of the government who oversaw health care in the district; and two midwives in a shared interview. Due to understaffing and a busy harvest season, it was difficult for the two midwives to schedule an interview time; they requested permission from their manager to be interviewed while at work, and a joint interview was the most feasible way to meet with them both. These interviews with formal health care providers were held in English,

as was the preference of participants. In several cases, these recorded, semi-structured interviews were in addition to informal conversations or interviews held earlier in my fieldwork period. In total, there were 22 research participants in this second stage for a total of 67 in the study overall.

I identified that I would talk to people in groups of the same type, and that the size of the group would be partly determined by the availability and number of practitioners in each provider group, but would not exceed five. Wilkinson (1998) suggests that six to eight participants is a typical range, while Freeman (2006) suggests that six to twelve is optimal because “this number of participants is small enough for everyone to contribute, yet large enough to share diverse opinions across the whole group rather than fragmenting into smaller parallel discussions” (p. 492). The relatively small group size of five participants (at both research stages) was selected to create an intimate and comfortable setting, and to make room for the presence of an RA and her translation. The size was effective in that all group members participated, contradicting, building on, or corroborating others’ insights as they saw fit.

To recognize participants' time and contribution, a small gift was provided to the women who participated in the interviews: a bar of soap and a bag of iodized salt. In deciding on what I should offer, I took care to ensure that the amount was not so large as to be potentially coercive, as would be the case if the value of the gift was considered too large to pass up, but large enough to acknowledge the time and expertise shared by the research participant. Further, these items were selected as having a health value and being locally used and available. The soap was of a type used for either laundry or hand washing/bathing, while iodized salt prevents iodine deficiency disorder and is particularly important during childhood and childbearing. I sought advice from other researchers and local leaders as to what would be a fair gift for participants. The value of this gift was about two thousand five hundred Ugandan shillings (approximately one dollar). In interviews/focus groups with the junior and informal health workers, I brought the

soap and salt as I felt it would be well received and appreciated. With more senior health workers and administrators, I did not offer this gift, as I felt it would be awkward and perhaps suggest a lack of professional symmetry; I simply offered a cold drink to have during our talk.

### *Translation*

Question guides were translated and then checked by Acero; we discussed the Acholi phrasing when adding new questions or probes. Acero and a second translator provided translation of interviews and focus groups that included Luo (Acholi). In case of ambiguity, a Luo-English dictionary was consulted. I checked each translator's work by having the other person translate random portions and cross-checking these against each other. There were few if any discrepancies. I also checked each translation against my field notes, which included notes taken after each interview based on the oral translation provided therein. When an interview was solely in English, I transcribed it myself, double-checking any loan words from Luo or Swahili with Acero.

### *Field notes and reflexive journaling*

As part of my fieldwork while I was in Amuru, I kept a journal that was a combination of field notes and reflexive writing. I used the field notes to track my observations or people's comments related to maternity care and birth, or other areas of social life as they appeared relevant to maternity care and birth. I also included reflexive journaling focused on initial analyses and on my own role and relationships as researcher. For example, I wrote about being called Mama Sachaa and about a rumour that circulated that I was breastfeeding my son, then four or five. I wondered about this, and finally realized it pertained to the prevalence of breastfeeding as a means of child spacing and the fact that he was so old for a single child. As Smith (2014) writes, "There is constant leakage from the multivoiced society in which we do our

work into our sociological work” (p. 234). Reflexivity is a means of understanding how our analyses are shaped by circulating discourses. A guiding principal during fieldwork was that “data are everywhere”; the journal was a place where I had free reign to consider observations without having to make a decision about whether they were ultimately significant parts of my data or analysis. This was also where I worked out initial analyses, which I then discussed with my Acero or others. These detailed field notes helped to form an audit trail, as I could see when certain analyses began to emerge. For example, in two entries at the end of May, I was critical of responsabilization practices around public health messaging generally, and on malaria in particular. I wrote “some of the health messaging that people wear on their backs [i.e., on t-shirts], like “eradicate neglected disease” – well, who are they talking to? The poor people in these villages are not the ones who can eradicate them.” This insight that certain practices shift responsibility towards individuals and away from social structures informed my analysis of the social organization of maternity care and childbirth.

Further, observation increasingly became an important part of my methodology while I was waiting for final ethics permission to start the formal stage of data collection. The period in which I was awaiting approval was productive though at times, frustrating. During this period, I was glad to be living at the Health Centre in Amuru rather than in Gulu town, despite Amuru's remoteness and its various inconveniences (as I experienced them), such as lack of hot water and a fridge. There were benefits to not launching immediately into the formal stage of data collection. I could familiarize myself with Amuru sub-county, both geographically and sociologically. I developed relationships with health centre staff and neighbours. I also had long talks with various ambulance drivers who gave me a ride to Gulu town when transporting patients, telling me their stories as we bumped along the dirt road at high speed. Living in staff housing, I was able to witness a five-and-a-half day work week transform into a seven day work

week due to an outreach trip, chat with the midwives while they sat outside their rooms of an evening cutting up plastic sheeting for deliveries, and, when I heard the distinctive roar of the ambulance late at night I could get the story the next morning. The labour ward was the closest to the staff housing, so I had a keen sense of what was going on.

In addition to these activities in Amuru, I also spent time in Kampala, meeting with academics working in the area of maternal health and conducting a grey-literature review at the Makerere University library. In Gulu, I met with NGO workers and academics and found maps of the area. I became interested in local issues beyond maternity care and birth. In contrast to the long days of interviews during which I was focused on hearing from participants and often returned home emotionally and physically drained by stories and travel, I had time to listen to people's hopes to-start a small business, frustrations over lack of local opportunities, and accounts of local politics. The waiting period provided an opportunity for my family and me to acclimatize, which was particularly important since the move to Amuru was a very new experience for my son. He celebrated his fifth birthday there, and proved himself adept at language learning and making friends, but less than enthusiastic about life without some of our taken-for-granted luxuries. My partner, who was working with the village health team (VHT) on a bicycle project, shared stories, contacts, and encouragement. Mannay and Morgan (2014) make the case that while there is a temptation for researchers to "rush into the field armed with audio recorder and camera," (p. 4) there is an often overlooked value in "the waiting field," which they describe as "'spaces previous to,' 'spaces of interruption/disruption' and 'spaces of reflection'" (p. 7). Ultimately my research benefitted from this period of fieldwork while the ethics approval in Uganda was finalized.

### *Following analytic threads and working with texts*

I identified relevant texts over the course of my research, fieldwork, and writing. These texts included the ANC card (discussed in Chapter Six), the Local Council I letter (Chapter Five) and the text (though it was never physically present) of the Millennium Development Goals (MDGs) 5 (improved maternal health) and 6 (the reduction of HIV/AIDS). These played a role in shaping how maternity care was facilitated or curtailed. Knowledge of how and when various texts are invoked or consulted facilitates understanding of how women's birthing practices are linked into larger institutional systems such as the health care system.

During the data collection stage, part of my process was to follow analytic threads. For example, it was clear early on that the antenatal care (ANC) cards issued to each pregnant woman were important to coordinating care. Women sometimes referred to attending ANC as “catching the card,” and focused their descriptions of attending ANC more on acquiring the card than on the care they received. I incorporated this knowledge into my data collection by asking follow-up questions (to childbearing women), incorporating questions about the ANC into my focus groups with childbearing women and questions for health workers, and by collecting an ANC card as a sample. Through these means, I worked towards understanding how the ANC cards are activated as a text, in order to be able to see the role they play in coordinating care. Relying on emerging analysis to shape ongoing data collection is consistent with IE practices (Campbell & Gregor, 2002, p. 60; DeVault & McCoy, 2006, p. 21; Smith & Smith, 1998, p. 311).

Other less formal means of data collection included joining staff on outreach trips and other observation of health work. I accompanied a team of health workers to an isolated village on the Nile, where they provided vitamins and deworming tablets and conducted antenatal check-ups. I observed the midwives and other staff setting up their antenatal station and chatting with groups

of patients. Although the midwives invited me to make myself at home in the labour suite, I felt that would be disrespectful or intrusive, and did not observe any births. I would have been interested to observe delivery staff at work, but it was not necessary to my research goals. My extended period of fieldwork allowed for serendipitous opportunities, such as observing outreach to all areas of the sub-county or sitting in on an NGO visiting program delivering nutrition education to mothers who had been identified as vulnerable. These aspects of fieldwork extended the lens of the other more formal data collection methods of IE.

### Data analysis

My process of data analysis was iterative: each stage of research, from planning, to data collection, to writing, presented opportunities for me to reflect on what I was learning and on how it fit in with my overall research question. This occurred as I constantly adjusted my understanding of the social organization of maternity care and childbirth throughout the fieldwork stage, as well as when I set out to purposively work through my overall analysis at particular research stages. An example of the smaller scale was the issue of whether TBAs were banned from assisting at home deliveries. Documentary evidence was both scarce and contradictory, so in amassing various pieces of textual evidence/sources and talking with different people, my understanding of the ‘ban’ shifted. While I ultimately came to understand that the status of TBA delivery was, indeed, inconclusive and contradictory, through the process of investigation I learned more about what this meant in specific times and places. I also approached data analysis iteratively at key phases. For example, after the first few days of interviews, I reflected on what I had learned and how my interview guide might change to reflect new ‘leads’ or insights. I added questions to better understand issues that seemed to be important but were not anticipated or solicited in my initial interview guide (such as the role of the mama

kit, discussed in Chapter Six). I discussed with my RA how to bring forward non-material concerns, while also reflecting that given the setting, the material concerns that were repeatedly identified as part of preparation and as ‘important’ to the participant often did play a larger role than non-material concerns that I had anticipated would be identified. For example, I came to see that a concern over who was present at the time of birth, important in my own cultural setting, were overshadowed by a more basic concern, as one participant told me, that someone should be present. Mykhalovskiy (2002) describes this as “checking [one’s] understanding as it develops” (cited in DeVault & McCoy, 2006, p. 757). Analysis, then, took place alongside data collection, which allowed me to maximize the contribution of participants and other experts in the field.

After completing the research and arriving home, I read all the data from the interviews, focus groups, and field notes. At this stage I read with an open mind and put aside a focus on themes I had identified in the field, in order to be open to new interpretations. Subsequently, I mindmapped themes and insights on paper and read again. I then began the process of coding and organizing the data using a qualitative data analysis software, HyperResearch. I began with the codes I had initially identified, and refined these to reflect the nuances in the data. Rather than using coding to guide my analysis, I used it to organize the data so that the themes and quotations I had highlighted as important were easily accessible for the purposes of writing. I coded the childbearing women’s responses, health workers’ and administrators’ responses, and my field notes separately. When writing about a particular theme, I looked at each of these pieces. While writing I was also doing analysis, as I see writing itself as a process of inquiry (Campbell and Gregor, 2002, p. 93; Richardson, 1994). Discussing representation and social responsibility, Fine, Weis and Brown (2000) offer a set of reflexive questions for researchers at the writing stage. These include asking whether individual stories are connected to the historic, economic, and structural realities in which they are situated, whether the representations include the

mundane aspects of experiences, and whether the data could be appropriated for political purposes. I have been attentive to such considerations as I write. For example, I included Chapter Three, “Local Contexts: Conflict, Displacement, Return, and Ongoing Social Distress,” because it became clear that these contexts were too large and complex to be located in the introduction, and because the analysis, were necessary to situating the findings, was necessarily based in the study’s fieldwork. As Schensul and LeCompte (2013) note, clearly identifying social contexts pertinent to the research “enhances the possibility of comparisons and replicability” for other researchers (p. 343).

The current study is context-specific and analysis of data is rooted in my knowledge of this particular community. However, it is relevant to other related settings and inquiries with shared features. I have embedded the discussion of findings within rich description and participants’ accounts; other researchers will be able to extrapolate the extent to which these findings resonate with their own research settings (Polit & Beck, 2010; Schensul & LeCompte 2013; Tracy, 2010). Similarly, researchers will know whether analytical lenses employed in subsequent chapters – such as responsabilization, scarcity, or structural violence – are applicable to their own area of inquiry.

## **Rigour**

Establishing methodological rigour is a way to demonstrate research quality or credibility. Some authors draw on concepts originating in quantitative paradigms such as reliability and validity to determine rigour (Meadows, 2001; Morse, Barrett, Mayat, Olson, & Spiers, 2008), while others make the case that an alternative approach to rigour valuing features such as “attentiveness, empathy, carefulness, sensitivity, respect, honesty, reflection, conscientiousness, engagement, awareness, openness, and context” (Davies & Dodd, 2002, p. 288) is required for

qualitative research. Within IE, rigour and quality have been approached somewhat differently, as implicit within the research and analysis processes undertaken. Therefore, writing on IE tends to detail these processes without discrete guidelines or norms regarding rigour.

For those who overtly state how rigour is established within their IE studies, making processes clear and transparent is key. For example, Proding, Shaw, Rudman and Stamm (2014) state that “Rigor in institutional ethnography is established through the transparent translation of its conceptual framework into the research design and analytical description” (p. 499). This is undertaken by providing analytical description that is “transparent and comprehensible” (p. 499). These authors draw on DeVault and McCoy’s (2006) assertion that in IE, rigour comes from corrigibility, as researchers iteratively strive to complete as full a picture as possible of the “map of social relations” (p. 33) developed via their research. Where inconsistencies or lacunae exist, researchers undertake their work of creating a more full account (DeVault & McCoy, 2006, p. 33). This is why IE studies often have second stages, as exemplified by the turn to health workers and administrators in the current study. Campbell (2006) makes the case that explicitly linking analyses to what her participants say about their experience contributes to the trustworthiness of her account (p. 107).

Within the current study, I have employed rich description and participant quotations to contribute to the trustworthiness of my analysis. As Tracy writes: “high quality qualitative research is marked by a rich complexity of abundance – in contrast to quantitative research that is more likely appreciated for its precision” (2010, 841). Reflexive practices, described later in this chapter, also contribute to the quality, trustworthiness, and responsible undertaking of the study (Varcoe, Brown, Callam, Buchanan, & Newman, 2011). Schensul and LeCompte (2013) acknowledge that for ethnographers, all data are filtered through the “perceptual apparatus” (p. 325) of the researcher such that the researcher herself is a research instrument, making

ethnography a poor fit with objectivist standards for research quality but not compromising credibility or rigour in ethnographic research argues that the discursive context of speech and positionality are crucial to meaning, such that truth can no longer be understood as straightforwardly a matter of the correspondence “between a proposition and an extra-discursive reality” (p. 14). Specific strategies with regard to engaging participants, translation and transcription, and international fieldwork are described within this chapter in ways that point to their rigour. Careful attention to ethics of research has also contributed to the trustworthiness and rigour of the current study.

### **A Note on Style**

When I writing about particular participants, I use pseudonyms. I use verbatim quotations from participants. Bracketed ellipses indicate excised speech, generally my own nominal interjections, and square brackets indicate an editorial change made to ensure clarity or anonymity. These quotations are framed within my own interpretive statements. Rather than assuming that these instances of data can ‘speak for themselves,’ (Olliffe, 2003), I have employed this strategy to foreground my own position within the research. Instead of espousing objectivity, I acknowledge my own co-construction of the data. Understanding the researcher as having a position in relation to the research is key to IE (Campbell, 2002).

I have offered thick description, including details about the setting and participants’ lives. By contextualizing the setting where the data were collected, I orient the reader to the research setting. Data are framed through my interpretations as well as quotations from relevant literature. Findings are presented alongside discussion about their meanings. Following Smith (2005), I use the term “findings”. This approach is consistent with that of institutional ethnographers including Smith (2005), Mykhalovskiy & McCoy (2002); and Campbell & Gregor (2002) as well as

mainstream qualitative researchers including Sandelowski & Barasso (2003) and Lincoln, Lynham, & Guba (2011).

## **Conclusion**

In this chapter, I have discussed the methodological principles that guided me in designing and executing this program of research. I have described ethical considerations from both an institutional and a community perspective, and outlined the various forms of data collection that I undertook. The overarching goal of this research has been to understand the social organization of maternity care and childbirth in Amuru sub-county, northern Uganda. This overview of the methodological considerations and methods of data collection demonstrates my thinking as I approached this area of inquiry. In the following chapter, I describe the impact of the past conflict and ongoing social distress on the overall setting as well as on health care and maternal health. In the Chapters Four through Six, I focus on this study's findings, fleshing out the social and institutional contexts in which maternity care and birth take place, and discussing findings on the interplay between power, gender, and HIV testing during antenatal care and the role of the basic goods provided by NGOs to mothers.

## **Chapter Three: Local Contexts: Conflict, Displacement, Return, and Ongoing Social Distress**

### **Introduction**

This chapter situates the study within the broader local contexts of Amuru sub-county, northern Uganda. It draws on literature, observation, and participant accounts. My rationale for undertaking the research was twofold: first, research was necessary in order to gain a greater locale-specific understanding of the social organization of maternity care and birth and as such contribute to women's health. Second, an institutional ethnography in this complex and unique setting would be innovative and key to advancing nuanced understandings. My previous experience working on women's health issues in Africa, as well as academic and family connections to Uganda, facilitated planning to do research there. There is a paucity of research pertaining to childbirth and maternity care in northern Uganda, likely due to inaccessibility during the war years. Previous research indicates that maternal health outcomes were poor and that birth took place in complex social and healthcare settings. While large-scale initiatives, such as the Millennium Development Goals (MDGs), seek to reduce maternal mortality throughout the region, I undertook a study that started at a local scale and sought to understand the particular and complex social organization of childbirth and maternity care. Maternity care and childbirth are important areas of inquiry and intervention throughout sub-Saharan Africa, a region in which maternal mortality is the highest in the world; this research began from the standpoint of birthing women in this particular Acholi community in northern Uganda.

The social, political, and economic conditions that shape people's lives more broadly, also shape maternity care and birth. I completed fieldwork in 2012; the conflict had ended in 2006, and the majority of displaced people had returned home to begin rebuilding their lives, their homes, and their farmlands. The post-conflict period has been a time of flux; people have

been returning home and interventions from government and NGOs have been the local infrastructure as it related to healthcare. Long years of war and displacement have impacted every aspect of life for surviving Acholi people, including health, health care, and childbirth. This chapter provides an overview of the long and brutal conflict and outlines its ongoing social and economic impacts as they shape life in Amuru sub-county broadly and as they directly affect birthing women and access to care. In describing the conflict, I draw on the work of researchers who emphasize its political and social causes and consequences. I discuss abduction and forced displacement, outlining their ongoing significance for all aspects of life, including health broadly and reproductive health specifically. In the final section, I discuss the social distress caused by outbreaks and threatened outbreaks of disease and by land disputes in the post-conflict period, arguing that these are sites of an ongoing struggle for inclusion and justice. In striving to provide a detailed contextual account, I am setting the stage for the findings provided in Chapters Four, Five, and Six. Offering a rich description of key characteristics of the post-conflict setting will make for a deeper understanding of these findings.

### **Overview of the Conflict in Northern Uganda, 1986 – 2006**

Described as a ‘dirty war’ for its targeting of civilians and use of terror and as means of warfare (Finnström, 2008), the conflict between the Lord’s Resistance Army (LRA) in northern Uganda and the government of Uganda spanned over two decades, from 1986 until 2006 (and still continues outside Uganda’s borders). The war between the LRA, a group of rebels led by Joseph Kony, and the government’s Uganda People’s Defense Force (UPDF), was characterized by the abduction of children, mass forced displacement, and the indiscriminate killing of civilians (Branch, 2011; Dolan, 2013; Finnström, 2008). As Spittal et al. (2008) write, “The war has resulted in countless deaths, child abductions, widespread violation of human rights, the

destruction of the social and economic fabric of society and the displacement of more than half the population” (p. 11). These violations have left the economic and social dimensions of Acholi life deeply damaged, with adverse consequences for women’s health.

In writing about the conflict I rely on secondary sources, in particular the work of Sverker Finnström (2008), Adam Branch (2011), and Chris Dolan (2013), three researchers situated in northern Uganda at various points during the conflict, each of whom is critical of simplistic explanations for the war and the usual sites of blame or innocence. I provide an overview of the political forces contributing to the conflict and its major events. As Finnström (2008) writes in his book about the conflict and everyday life, *Living with Bad Surroundings: War, History, and Everyday Moments in Northern Uganda*, “There is no one version that is fully agreed on by all parties involved” (p. 8). My goal is not to describe a definitive version, but to identify the key events of the conflict and to make the case that the recently ended war remains an important element of the social context in northern Uganda, including the social setting of maternity care and birth in Amuru sub-county.

The LRA conflict took place in Acholiland, formally the Acholi sub-region of northern Uganda. This region is 99% Acholi by ethnicity (Finnström, 2008). Based on a 2002 census, Finnström describes the Acholi as making up 5% of the Ugandan population (33).<sup>12</sup> The population is primarily rural; before the war, 90% of residents made their living through subsistence agriculture (Finnström, 2008). Acholi people are predominantly Christian; Finnström (2008) cites a 1991 census finding that 70% of people in Acholiand identify as Catholic, 25% as Protestant, and only 0.5% as Muslim, and suggests since that time Pentecostalism has also gained a following (p. 246).<sup>13</sup> Since the internal displacement (IDP) camps were disbanded, most

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<sup>12</sup> A scheduled 2012 census was not undertaken, due to lack of funds.

<sup>13</sup> A 2002 census did not record religious affiliation.

residents had returned to their rural homes and by 2012 were once again farming and keeping livestock, though to a more limited extent than prior to the conflict. Amuru district was created in 2005 and was formerly part of Gulu district. This area is northeast of Murchison Falls National Park and south of the border with South Sudan (see figure 2, “Map of Uganda”). My study focused on a sub-county within the district, also called Amuru; I was based in staff housing at Lacor Health Centre III, Amuru, which was located at a disbanded IDP camp, where some crumbling camp infrastructure, such as signage and tap-stands, remained.

Dolan’s (2013) *Social Torture: The Case of Northern Uganda, 1986-2006* notes the difficulty of identifying the start of the conflict (p. 39). To identify its roots, most commentators look to the colonial period. Uganda became a British Protectorate in 1894 and gained independence in 1962. British administrators relied on a “divide-and-rule strategy” (Dolan, 2013, p. 41), which included the consolidation of oppositional ethnic identities. During this period, the Bagandan people residing in the south were accorded economic and political power as farmers and civil servants, while the Acholi were recruited into the military and into manual labour. Dolan explains that “no one group or sub-region enjoyed both military and economic power simultaneously, and discourses of ethnic difference were established which live on to this day” (2013, p. 42). While the distribution of power in the colonial period and since has contributed to armed conflict, the view of this conflict as stemming primarily from a priori ethnic tensions or that the Acholi are “warlike” is historically inaccurate and prejudiced, as Branch, Finnström, and others have argued.

Upon independence, the role of Acholi people on the national scene shifted in relation to the various post-colonial national governments. Under the brutal regime of Idi Amin (1971-1979), Acholi people were the targets of mass killings, ostensibly as reprisal for their association with the prior president, Milton Obote. When Obote came to power again (Obote II, 1980 -

1986), many Acholi were once more prominent in the armed forces. In January 1986, Yoweri Museveni took power by defeating the Acholi-dominated Uganda National Liberation Army (NLA) with his National Resistance Army (NRA) in a violent insurgency (Finnström, 2008). The year 1986 also marked the start of the rebel movement. Museveni remains president as of 2014.

In March of 1986, Museveni's NRA had "reached and taken Gulu town," the major town of the north (Dolan, 2013, p. 43). Resistance to its violent occupation, and its practice of stealing cattle, came from the Ugandan People's Democratic Army (UPDA), made up of soldiers of the former regime. Opposition also came from Alice Auma, known as Alice Lakwena, and her Holy Spirit Movement (HSM). A spirit medium and healer, Lakwena became a military leader to recruits who shared her goal of overthrowing Museveni's National Resistance Movement government and forming an inclusive and non-violent government. The HSM was a short-lived military force; the group was overpowered at Jinja by the NRA on an attempted incursion to the capital, Kampala, in October 1987. A peace accord was signed with the UPDA in 1988, but rebel movements opposing the government persisted. The HSM continued under Alice's father, Severino Lukwoya, while Lakwena herself fled to Kenya. Joseph Kony became leader of northern rebels, calling his group the Lord's Resistance Army (LRA) and basing his claim to leadership on spiritual authority. Kony, as Branch (2011) points out "was generally confronted with a deficit of volunteers, a population unwilling to support continued violence, and a number of different opponents" (p. 68). Initial NRA responses were harsh: homes and granaries were destroyed by fire, and many people were killed (Dolan, 2013).

While the conflict pitted Kony's army against Museveni's, civilians were the main victims, with assailants and perpetrators originating on both sides. Various features of the war,

including the abduction of children into the LRA, the arming of civilians by the UPDF, and the constant threat of being branded as either a rebel or a supporter of the government, blurred the distinction between civilians and combatants (Finnström, 2008, p. 89). Attacks on civilians occurred in LRA reprisals for lack of support and in turn contributed to that lack of support. The LRA's large-scale abduction, maiming, and attacking of civilians has led to the view that they operate without a coherent political or military agenda, but Finnström (2008) and others have ascertained that the group did make political demands.

In the early 1990s, the LRA (often referred to simply as 'the rebels') increasingly targeted Acholi civilians, resenting their lack of support and their perceived collaboration with the government forces (Dolan, 2013, p. 45). In 1994, peace talks were held but failed. Each side blamed the other, with Museveni's demand that LRA forces come out of the bush and surrender within a week remembered as particularly damaging (Branch, p. 74, Dolan, 2013, p. 46; Finnström, 2008, p. 89). A series of massacres and mass abductions in 1995 and 1996 heightened the terror. Many people, especially children, began a practice of "night commuting," walking to safer areas (including Lacor Hospital) to sleep communally and returning to their homes, schools, or gardens by day (Dolan, 2013, p. 46). This survival strategy led to family breakdown as well as the breakdown of protective social structures (Falk, Lenz & Okuma, 2004). In late 1996, the government created the first internal displacement (IDP) camps, which it identified as "protected villages". Some residents willingly left their homes where they feared attacks or abductions, but removal to the camps became increasingly forcible over time. In 2002, the UPDF's "Operation Iron Fist" escalated fighting against the LRA and also expanded forced displacement. The "protection" the government promised did not materialize; the presence of UPDF forces was minimal in the camps, and they seldom fought back against LRA attacks.

Abductions and attacks continued in the camps. The majority of the population of Acholiland, some 1.8 million people, was displaced into these camps (McElroy et al., 2010).

While the conflict has often been understood as local and ethnic, major powers have also been involved. The LRA was bolstered from the early 1990s by support from Sudan, and in return assisted in Khartoum's fight against south Sudanese rebels (Finnström, 2008, p. 84). Other global features of the war included extensive international humanitarian aid in the IDP camps, the United States' listing of the LRA as a terrorist group in 2001, and the International Criminal Court's identification of Kony and other LRA commanders as wanted war criminals in 2005. Branch (2011) makes a detailed case that international humanitarian aid facilitated the government's strategy of forcible displacement and was otherwise harmful to the Acholi people. Finnström argues that "the war is indeed a global war even if it is fought on local grounds" (2008, p. 9). International military assistance to both sides, and humanitarian assistance to civilians, complicated the conflict but did little to resolve it.

A cessation of hostilities agreement between the LRA and the government was signed and renewed in 2006 at the Juba Peace Talks (Dolan, 2013; Government of Uganda, 2006). However, Kony himself refused to sign the final agreement in 2008, leaving lingering doubt as to whether peace in Acholiland would be lasting. Therefore, dating the end to armed conflict in Acholiland to the time of the Juba Peace Talks is only possible retrospectively. At the time of this writing (2014), Kony is still at large, leading a smaller army in hostilities in countries neighbouring Uganda.

### **Ongoing Social and Economic Impacts of the War**

The aforementioned political and military events brought great social and economic devastation to Acholi people. These impacts were highly gendered, and changed family

dynamics, work responsibilities, and approaches to health care for women. In this section, I offer more detail about these social and economic repercussions, focusing on two events experienced by many Acholi people: abduction and internment. Dolan (2013) refers to the period of the conflict as an overall reversal of fortunes for the Acholi people, who experienced the destruction of their livelihoods alongside witnessing the atrocities of war (p. 40). Abduction and displacement were two features of the conflict that make a return to normalcy in the aftermath of violence difficult. They have lasting harms that impact maternity care and birth, in terms of individual needs and social supports.

#### Abduction, health and community membership

Over 60,000 children and youth were abducted over the course of the war (Baines, 2011; Westerhaus, 2007). Fewer girls than boys were abducted (Annan, Blattman, Mazurana, & Carlson, 2011); among the abducted children, between 15% and 30% were girls (Austin, 2008; Corbin, 2008; Pham, Vinck, & Stover, 2012). Here, I focus on the experience of girl abductees, in order to provide a more narrow entry point into a complex social reality and because of the direct connection between abduction and women's lives and reproductive health. However, it is important to recognize that boys and men experienced wide-ranging violence that impaired their physical, mental, and social wellbeing, and that this harm in turn contributed to the social and material context in which women seek care.

The girls and women who were abducted and forced to travel, live, and fight with the LRA faced specific and ongoing impacts to their health, including their sexual and reproductive health. While the development of consensual relationships among abductees was not permitted, girls were "given" to, or forced to "marry," commanders. Baines (2014) has argued that "against the backdrop of deprivation and coercion in which it took place" forced marriage and

motherhood also “became an important strategy of survival as well as a means to achieve a position of authority” (p. 414). In addition to the trauma of abduction and forced marriage, forced sex left girls and women susceptible to pregnancy (Omona & Adua, 2013) and infections including gonorrhea, syphilis, and HIV. As Westerhaus and colleagues (2007) write:

child abductions create increased vulnerability to HIV infection among the young. During the war, more than 66, 000 children have been abducted to fight as soldiers or serve as sex slaves. Males abducted into the LRA are coerced through physical violence to use rape as a weapon of war, and many of the girls are forced into sexual slavery as ‘wives’ to LRA commanders, with some eventually contracting HIV. (para. 3)

Given the circumstance and the ages of the young women, pregnancies were both unwelcome and dangerous. Mazurana, McKay, Carlson and Kasper (2002) state that “In Uganda, girls who were abducted by the LRA are reported to have suffered serious complications and infections after birth and developed gynecological problems that sometimes caused permanent disability” (p. 114). Women’s experiences of forced marriage and other sexual violence have an ongoing impact on their wellbeing and their reproductive health.

The challenge for mothers in captivity is described by Evelyn Amony (2012), who was forced to marry LRA leader Joseph Kony, spending four years in custody and bearing four children to him:

We were constantly on the move, running and hiding from the UPDF, crossing rivers and walking miles, often with injuries. After giving birth, it became more difficult for me to keep up with my unit [ . . . ] I had to carry one child on my back and other children in my arms, all while carrying luggage on my head. I watched several of my friends die as a result of bombs being dropped during combat by the UPDF soldiers. (Amony & Shaya, 2012, para. 3)

For abducted women, giving birth was one in a sequence of traumatic events.

In addition to the health consequences of their abduction, the returnees and their children have faced social consequences after living among the rebels. Amony, who has gone on to lead a Women’s Advocacy Network, describes the challenge thusly: “Women, in particular, have a difficult time adjusting to life after returning from captivity because of the social stigma from

their communities and families, which also extends towards their children” (para. 12). She elaborates that this stigmatization can include the rejection of women and children, who are often blamed for what they have done and who may not be seen as innocent victims. Community members may fear that the formerly abducted will be possessed by “cen,” polluting spirits that can disrupt the social world (Allen, 2007). Such stigma and ostracism means that women have less access to the family support, both social and economic, that women rely on to have a healthy pregnancy and to seek care. Annan and Brier (2009) find that for abducted girls, one of the prominent risks of return is family violence, particularly intimate partner violence.

As a result of stigmatization, those returning from abduction sometimes form new household arrangements after kin have rejected them (Austin et al., 2008). International NGOs have contributed to this stigmatization by misreporting on the sexual experiences of girl abductees; initial reports suggested that girls were forced into “promiscuous” sex with multiple commanders, whereas it was more often the case that they were forced into serial-monogamous or polygynous marriages (Spittal, Muyinda, Oyat, & Patel, 2008). This misunderstanding, and the harms it led to for women attempting to reintegrate into their communities, suggests the importance of understanding the specific consequences of the post-conflict context by drawing directly on the expertise of childbearing women.

#### The internally displaced persons (IDP) camps

While the camps were initially euphemistically referred to as protective villages, the forcible displacement of the majority of Acholi civilians was a military strategy intended to cut off the supply of food and soldiers to the rebels (who raided and abducted, and were sometimes voluntarily supported by civilians). The IDP camps were a location of structural violence, a term describing social arrangements based in inequity which impair people’s abilities to meet their

most basic needs to the extent that they cause lasting harm or slow death (Farmer, 2010; Galtung, 1969). The concept ‘structural violence’ is often used by those writing on northern Uganda (e.g. Annan & Brier, 2010; Branch, 2013; Finnström, 2008; Westerhaus, Finnegan, Zabulon & Mukherjee, 2007). People in the camps experienced diminished independence and extremes of poverty. Accommodation was flimsy and crowded. Poor conditions led to disease: in 2005, each week witnessed the deaths of over 1,000 people (Finnström, 2008). The major causes were hunger and illnesses such as Ebola and meningitis (Finnström, 2008).

In an overview of NGO health interventions in the IDP camps, Dolan (2013) argues that:

the doctrine of minimal assistance (. . .) went hand in hand with implicit criticism. People with no access to resources were told they were having sexual relations too young, not feeding their children a balanced diet, not planning their families well and having too many children they could not feed properly as a result. (p. 143)

This indictment of interventions is in Dolan’s chapter “Protection as Violation” in *Social Torture*. The criticism of sexuality and childbearing practices prevailed alongside conditions that limited women’s autonomy with regards to both sex and family planning. For example, Austin et al. (2012) write that, “in IDP camps in northern Uganda [. . .] unmet need [for family planning] was found to be 58%, compared to the national average of 40.6%” (p. 14). As Dolan indicates, a health responsabilization message, which is based on ideals of patient choice and individual empowerment (Foley, 2008; Ruhl, 1999), was particularly pernicious in a context wherein people had limited control over the daily conditions in which they lived.

A UNICEF study of gender-based violence in Pabo IDP camp, nearby to Amuru, found that girls and women were “easily forced into marriage with men who [were] not of their choice, lured into sex for survival in the camp and above all lacking the power to negotiate for safe sex” (Suffering in Silence, 2005, p. 26). These and other forms of sexual violence impact women’s reproductive health over the course of their lives.

Gender-based and sexual violence impacted women and girls in the IDP camps. As

Westerhaus et al. (2005) describe:

Women who tend crops and collect firewood on the perimeters of the camps are frequently attacked and raped by both Ugandan soldiers and members of the LRA. Additionally, women are frequently driven to transactional sex (i.e. providing sexual services for money) in order to provide for their children and attain the means to provide educational opportunities for their children. (p. 1184)

Women and girls in IDP camps experienced sexual violence with similar potential to impact their health and wellbeing as the violence recounted in the above discussion of abducted girls. For example, Patel et al. (2014b) found that “all young people in northern Ugandan have been similarly affected by HIV infection during war and displacement” (p. 1), making the case that the narrow targeting of those who were abducted is counterproductive. Okello and Hovil (2007) described that within the camps, “Community mechanisms that would have protected girls [were] seriously limited in a context of eroded cultural and societal checks and balances” (p. 441). This contributed to the high incidence of sexual violence.

During lulls in fighting some people commuted daily to their gardens to grow food, but many were often unable to tend their gardens. People in the camps relied on humanitarian assistance for food, and feared rebel violence. They often stayed hidden in the days after a relief distribution, anticipating rebel raids (Finnström, 2008). The rebels, at times, tried to force people back home, exhorting them to leave and then burning the closely packed huts in the camp. Some people survived in the camps for over a decade in conditions that led Dolan to theorize that the camps were part of a strategy of social torture that characterized the conflict as a whole. Despite hardship and violence, as Finnström (2008) argues, people were able to carve out limited space for personal agency in the camps. Life went on, but its daily patterns necessarily changed.

The process of return has been “complex, arduous and protracted” for those who were displaced (McElroy, 2012, p. 19). For those without a claim to land, including families headed

by children or single women, there was no return option; they remained in the camps. Those returning home managed a life in two places at once. They worked to build homes, latrines and bathing shelters and to clear, plough and plant land so that there would be a harvest. McElroy (2012) examines consequences for children's health resulting from how resettlement took place. Many problems she identifies, including poverty, food insecurity, and lack of access to resources such as health care and education, affect the whole community. The challenges of return were ongoing and continued to affect people's lives as they worked to rebuild their communities.

### **Ongoing Social Distress: Land Conflicts and Disease Epidemics**

Beyond understanding this area as still being in recovery from conflict, it is important to recognize that regional disparities and divisions continue to cause distress today. My fieldwork took place in the year of the controversial KONY 2012 social media campaign by the organization Invisible Children (IC). This campaign called for 2012 to be the year in which international forces collaborated to capture LRA leader Joseph Kony. The campaign was criticized for its potential to hinder peace in the region by its call to arms, and for the organization's remove from the local context, its failure to recognize local forms of justice, and other factors. For example, scholars who blogged on the campaign included Erin Baines (2012), who titled her piece "Ugandans 2012" and made the case that retribution was the wrong approach; Beth Stewart (2012), who wrote that targeting Kony would also mean targeting (abducted) children; and Akena Francis Adyanga (2012), who focused on problems of representation and characterized the campaign as exploitative. In the wake of this campaign, a neighbour (and health worker) remarked to me, "Joseph Kony could walk down Juba road today and nobody would see him". Finnegan's (2013) critique of the IC campaign cites a reporter who, after covering the area for two years, finds that during rebuilding, "disease and land conflicts are

the biggest problems— not Kony” (p. 31). The focus on capturing Kony indicates a disjuncture between IC’s assessment of the problem facing northern Uganda and local people’s assessment; the latter tended to point to disease, land conflicts, and lack of infrastructure.

While social media was drawing the West’s attention to Kony, the immediate impact of disease epidemics and land grabs was more pressing to local residents than bringing down a villain. Local people celebrated an end to armed conflict to be sure, but for many, the threat of disease and ongoing uncertainty or displacement due to land issues meant that life could not return to normal. In this section, I also discuss agriculture as an ongoing way of life and describe how poverty, accompanied by lack of access to resources, was a prominent feature of life for many in the area. In post-conflict northern Uganda, distressing and quotidian aspects of life exist side by side and contemporaneously.

#### The outbreak of disease

Along with other common illnesses, people in northern Uganda had to worry about the return of Ebola hemorrhagic fever and nodding disease, an illness of unknown etiology that recently emerged in northern Uganda, causing debilitating illness and death among children. A major outbreak of Ebola swept through Gulu district in late 2000 through early 2001 (Finnström, 2008). Towards the end of my fieldwork period, in August 2012, an outbreak of Ebola elsewhere in Uganda was a source of fear, as people remembered those who had suffered or were lost in the previous outbreak. Among them was Dr. Matthew Lukwiya, the supervising doctor at Lacor Hospital, who died while caring for patients in 2000.

Anger over injustices in the country’s north is evident when people speculate about the possible cause of nodding disease. Several thousand children in northern Uganda are suffering from this progressive and fatal illness, which is characterized by a nodding seizure that often

manifests when food is presented (Lacey, 2003; Mitchell et al., 2013). Mitchell et al. (2013)

noted that community members connected this new disease to the war:

“Despite the medical theories regarding potential causal agents in the etiology of nodding syndrome, the communities of Kitgum, Lamwo, and Pader strongly associate the temporal relationship of the war with the onset of nodding syndrome in their children. The LWF field officer assigned to address the impact of nodding syndrome in northern Uganda explains that, ‘Conclusively, people [in northern Uganda communities] say that this is a result of the war. Before the camps, there was no nodding syndrome.’” (p. 23).

Mitchell et al. (2013) cite beliefs among Acholi people that food aid or black fly were the cause of this devastating illness, while some Acholi members of parliament suggested a link to “atomic weapons”, or poison food aid (staff reporter, Acholi Times, 2012). In a 2012 speech on Peacebuilding in Gulu, Branch asked the following rhetorical question: “Perhaps bullets aren’t being fired, but is Nodding Disease any less deadly?” summing up the anger over the perceived connection between war and the illness.

Finnström (2008) suggests that the literal truth of various disease-related rumours that circulated during the war is less important than the moral truth expressed by believing in or repeating such rumours. (An example he cites of such a rumour was that the oil provided in the internal displacement camps caused impotence.) Finnström also identifies rumours as an attempt to gain control over difficult surroundings. Like Finnström, Branch suggests that rumours about aid and health (such as that poisoned sorghum was responsible for a cholera outbreak) were significant as resistance to the larger context of forced displacement. In terms of disease and health care, the “bad surroundings” that gave Finnström his title persist, inherent both in these unpredictable and untreatable diseases and in the paucity of health care services.

In a piece examining the benefits and pitfalls of truth and reconciliation processes, poet and scholar Juliane Okot Bitek (2012) shows that nodding disease, the violence of war, and the violence of poverty are inseparable, suggesting too that the spiritual impacts and physical impacts

of the conflict are inherent in each other (p. 394). In her poem, cen, or evil spirits, manifest around unburied remains, land mines, abject labour, and nodding disease. Each of these is a feature of the post-conflict context, alongside high incidence of HIV infection. The clinical officer, Jonas, when I asked him about the approximate rates at Lacor Health Centre III, Amuru, described the HIV rate among pregnant couples as follows: “everyday you test people, if you test thirty you will find at least three, three here [who are HIV positive].” This was close to findings in a Gulu-based study of prevalence among pregnant women attending ANC at 11.3% in 2003 (Fabiani et al. 2006).

In addition to fear of disease, access to basic health care was an ongoing struggle during my fieldwork period. The provision of health care, or the failure to provide health care, can have an important symbolic as well as pragmatic value, in that it can be interpreted to symbolize the ill or good will of the government towards the north, and the inclusion or exclusion of northern Uganda by the government. As Sinding (2010) has noted, as well as affecting health, the way health care is provided or withheld provides messages about citizenship (p. 1657). Shortages of staff, medication, and facilities exist throughout Uganda, but were particularly prominent in the north, where the building of infrastructure post-war has been slow. The failure to meet government standards for health centre distribution means that for most people, access to basic health care is challenging and constitutes part of ongoing social distress post-conflict. The difficulty of access to health care particularly affected pregnant women, who were expected to attend a health centre for four antenatal appointments and for delivery, despite lack of health centre coverage and other access barriers (discussed in detail in Chapter Four). The health consequences of conflict, displacement, and post-conflict cannot be separated from the social and political consequences.

## Agriculture

While the post-conflict context was important in Amuru and throughout Acholiland, it was not the sole or primary characteristic of place there. The chief local economic activity was subsistence agriculture; it has returned, not unchanged, but enough to dominate social and economic life. While money and paid work were hard to come by, work itself was not. The majority of adults and older children worked hard at growing food for their families and for sale in local markets. They worked in their fields and gardens, plowing, planting, and harvesting with hand tools. Once food was harvested, much of it needed to be dried and pounded before consumption. Many Acholi lived, once they had dispersed from the camps, in small and often remote household settings. This tie to the land contributed to the difficulties of transportation (which I discuss in depth in Chapter Four), since even as improvements were made to main roads, many people still lived in unfrequented areas. The wartime theft of cattle and destruction of mango trees, and the need to reclaim fields, paths, and waterways that had overgrown in the years of displacement, had limited the scope of agriculture. While the war interrupted economic life, the work of farming was something people could return to, a well-known rhythm giving shape to the calendar year and sustenance for life.

As Oosterom (2011) describes it, women have been responsible for a large portion of this rebuilding work. She argues that this increased workload has persisted since the time of the camps, when gender roles shifted such that women shouldered many more responsibilities:

Women indicated it is they who bring up and ‘teach’ the children, and do the bulk of the household work, as well as most cultivation. Even though men can be seen working in the gardens, digging in groups or with the ox-plough, it is, according to the women, done less than before the camp.” (p. 404)

As I discuss in Chapter Four, for many women, having to undertake heavy work was a challenge to ensuring a healthy pregnancy. This challenge could be shaped by male partners’ willingness

or unwillingness to share the workload during pregnancy. Increased alcohol use among men, described as a problem in the camps and in the post-conflict period (Annan & Brier, 2009; Oosterom, 2011), had affected their willingness or ability to be supportive during pregnancy. More discussion of this is taken up in Chapter Five.

### Land disputes

Land disputes also greatly complicated the work required by returnees who relied on farming for food and generation of income. These disputes have occurred both between local families, and between residents and outside interests such as government initiatives or corporate sugarcane farmers. Finnström writes that “to lose their land is perhaps what Acholi people fear most, and in the judicial vacuum that has accompanied the war, displaced people can do little to legally protect their interests” (p. 179). Because land tenure in this area has not generally been identified through legal title or deeds, but through less formal processes such as passing gardens down through generations, disagreements over land disputes could be difficult to resolve, and have led to violence.

Individual or family disputes between individuals over who owns or has the right to farmland have arisen because of the long years spent in IDP camps, away from the fields. Although many still visited their gardens, some gardens were too far or too dangerous and thus lay fallow. Disputes among individuals or families have been a complication of resettlement, as some people returned to their place only to be pushed out (observation and personal communications; IRIN, 2012).

On a larger scale, land issues have arisen because of government and corporate takeovers of traditional Acholi lands. In Apaa, located on a contested boundary between Amuru district and Adjumani district in the West Nile area, there has been a dispute over whether land was part

of a wildlife reserve, as the Uganda Wildlife Authority claims, or was the customary land of its residents. This dispute has led to forced evictions, violence between neighbouring villages, and decreased food production capacity (Refugee Law Project, 2012). During a police eviction from this land, one man was killed (Webb, 2012). The potential for land to be appropriated for this wildlife reserve was a concern in Tedi, one of the six villages where I interviewed childbearing women (personal communication, LC I, Tedi). In addition to this dispute over wildlife reserve boundaries, corporate interests were taking over “unused land” for large-scale agriculture and production; in Amuru, the Madhvani group was involved in disputed land for its sugar cane production (Barnabas, 2013; personal communication, residents and leaders). This led to situations in which corporate representatives said the land was populated only by squirrels, while local women protested by stripping down, a form of protest and shaming (Lawino, 2012).

Barnabas (2013) sums up the disputes as follows:

The dynamics of land conflicts in Northern Uganda is linked to the historical legacy of the Lord’s Resistance Army (LRA) rebellion and the consequential displacement, return and resettlement and population settlement, weak land administration and governance, politics and investment, mineral wealth and curses, creation of new districts and individual greed to mention but a few. (p. 018)

Farming (along with other land-based economic activities such as beekeeping or collecting wood for charcoal) made up both a livelihood and a life for the majority of people in this area; disputes over land have had a significant impact on individuals and communities.

As Branch (2011) writes:

Acholiland perhaps is being reconstructed, but various forms of violence and exclusion continue within Acholi society, particularly around contestations over land and political authority, and continue to characterize the relation between the Acholi and the national government – the very conditions that gave rise to the rebellions and then sustained them for over twenty years. (p. 10)

Just as the decades of conflict and displacement have shaped the overall social landscape in which maternity care and birth take place, so too have disputes over land tenure and the outbreaks

of diseases. This is true in the individual cases where land disputes or illness affected the families of childbearing women and particularly in how such features of ongoing social distress impacted the broader social wellbeing of people in this area. The impact of land disputes varied from village to village, and contributed to the rationale to include several villages in the current study.

#### Poverty and lack of infrastructure

Widespread poverty and an accompanying lack of infrastructure affected people's day-to-day lives. Poverty and lack of infrastructure have been shaped by the past conflict, but were far from unique to this region or setting. While some aspects of community life, such as gardening and house building, followed generations-old practices, this way of life had also been overlaid with a capitalist economy and its demands. From education to 'airtime' for mobile phones, there was a need for money that, for most people, was not met by the income generated by selling food surpluses or other small-scale income generation activities. A lack of infrastructure further compounded the effects of poverty. Poor roads contributed to the difficulty, cost, and danger of transportation, a paucity of operational health facilities made health services less accessible and more costly in time and money, and the list went on. Maternity care and birth, alongside other aspects of life, were affected by a lack of money and infrastructure.

#### Impacts on study participants

The six villages included in the current study were Turdakatuba, Pagak, Oberabic, Rec Kicere, Lujoro, and Tedi. While all the villages were rural, Turdakatuba and Pagak were the least remote; people living there could walk or take a short boda-boda ride to Amuru Health Centre III, the trading centre (shopping area) surrounding it, and the monthly market held there. Lujoro and Tedi were the most remote by these criteria; they were the furthest from Amuru

Health Centre III and from Gulu, the nearest major town and the site of the nearest hospital.

While still some distance from Amuru Health Centre III, Rec Kicere and Oberabic were located relatively close to the district capital (Otwee) and the small trading centre there; they were closer to health centres located at Rec Kicere and Otwee than to Amuru Health Centre III, but these nearer health centres were not able to support antenatal and delivery care.

In each village, I asked Acero to share her impressions, and recorded notes about distinguishing features such as the presence or absence of livestock, beehives, and household gardens, whether school-aged children were at home or in school, and path/road conditions. Local leaders shared their concerns regarding issues facing their community, in relation to pregnancy and birth and more generally. They brought up concerns such as land seizure and lack of school facilities (Tedi), HIV (Rec Kicere), and alcohol abuse and relationship breakdown (Turdakatuba). Leaders understood these broader social concerns as important to women's health.

Participant's experiences during the conflict comprised part of our discussion as they told me about their approaches to pregnancy, care, and birth. The conflict shaped some participants' experiences in physical, spiritual, social, and material ways. Taken together, these stories demonstrate that the conflict and the post conflict setting both influenced how women approached maternity care and birth.

Physical repercussions of the conflict were exemplified by injuries that affected reproductive wellbeing. One participant, Faith, worried during pregnancy because of an injury she had received as a child, during her abduction by the LRA. She had been shot in the side of her abdomen, an injury to which she attributed to a previous miscarriage. As well as being painful due to this injury, pregnancy was a distressing time as she worried that she might have another miscarriage. Another woman from the same village, Mildred, had burns to her ribcage and upper thigh incurred during the conflict. They made pregnancy uncomfortable for her, but

she was able to safely deliver healthy children. Their neighbour Betty asked if she could speak about her husband. He had been beaten with a machete across his back and neck, and had since been advised by doctors not to work or ride a bicycle. However, with ten children to raise, some of whom were born to a deceased relative, both Betty and her husband found it impossible to take the rest health care workers advised.

The spiritual impacts of war speak to ongoing psycho-social trauma caused by loss and witnessing or experiencing violence. Penny said that during two of her pregnancies, an evil spirit (cen) would come to her in quiet moments, and tell her “[Penny], you are going to die in childbirth”. She attributed this to the many who had been killed nearby and whose remains were allowed to go unburied for some time. After being prayed for by born-again Christians, she told us, she was free of spirits in a subsequent pregnancy. A focus group participant, Florence, seemed to suggest that, for her, the spiritual impact of war was a loss of mental health which she had since recovered. She said that after seeing a ghost of a man who looked like her brother-in-law (who was still living) several times, she found herself going from shop to shop begging for candy, without realizing what she was doing. In the same focus group, participants shared stories of spirits that would strangle a pregnant woman during birth; the remedy was to have a witch doctor provide a cleansing. The participants attributed the deaths of one woman in labour and one child to such a strangling spirit. The inherent uncertainties and worries of pregnancy were underscored by spiritual impacts such as these.

Material impacts include the land disputes and poverty described in this chapter. Several people mentioned land disputes, with Anita particularly impacted because her husband was imprisoned due to such a dispute, and was not present to support her during pregnancy. At first, I found it contradictory that she said he was jailed for a land dispute, and then said he had been poaching; I felt perhaps her first explanation was an attempt to save face. Only as I learned more

about land disputes did I realize that policing what would have formerly been hunting as poaching was a way of pushing people off of disputed land. Land disputes and related evictions and imprisonment are an example of ongoing social distress after the end to the LRA conflict. Focus group participants in Lujoro referred to the loss of “wealth that walks on its legs,” particularly cattle and goats, as a significant impact that the conflict had on people’s ability to be healthy. The impacts of the post-conflict setting and ongoing social distress varied greatly between individual study participants, but taken collectively their experiences indicate that these contexts are important to the social coordination of maternity care and birth.

## **Conclusion**

O’Hare and Southall’s (2007) comparison between the maternal mortality ratio in sub-Saharan African countries which have or have not experienced recent armed conflict found that:

The median adjusted maternal mortality in countries with recent conflict was 1000/100,000 births, while for countries without recent conflict it was 690/100,000 births. The median reported maternal mortality ratio is also significantly higher in countries with recent conflict. There is a skilled attendant at significantly fewer deliveries if there has been recent conflict. (p. 565)

This echoes Austin et al.’s (2008) assertion that complex humanitarian emergencies impact maternal mortality. In this chapter, I have outlined some of the structural, social, and individual harms arising from the conflict, and made the case that these are highly relevant to how maternity care and birth are socially organized in Amuru sub-county, northern Uganda.

Bisaillon (2012) has identified that a feature of IE research is to “learn about the material features of the economic, historical, political, and social contexts in which people’s lives occur. Within these are clues about the social and ruling relations organizing people’s social experience” (p. 609). This study is situated in a social context in which a return to “normal” (to agriculture, to living with family, to relying on long-established social supports) exists in tandem with social

distress resulting from the traumas of the conflict as well as from ongoing sites of struggle for rights and citizenship, including health and land tenure. This social context affects how maternity care and birth are organized. The setting I have outlined here informs my analysis in the upcoming chapters. It impacts health care provision and the effect of lack of resources, discussed in Chapter Four; it impacts the interplay between power, gender, and HIV testing during antenatal care, discussed in Chapter Five; and it impacts the role of the basic goods that NGOs provide to mothers, discussed in Chapter Six.

# Map of Uganda

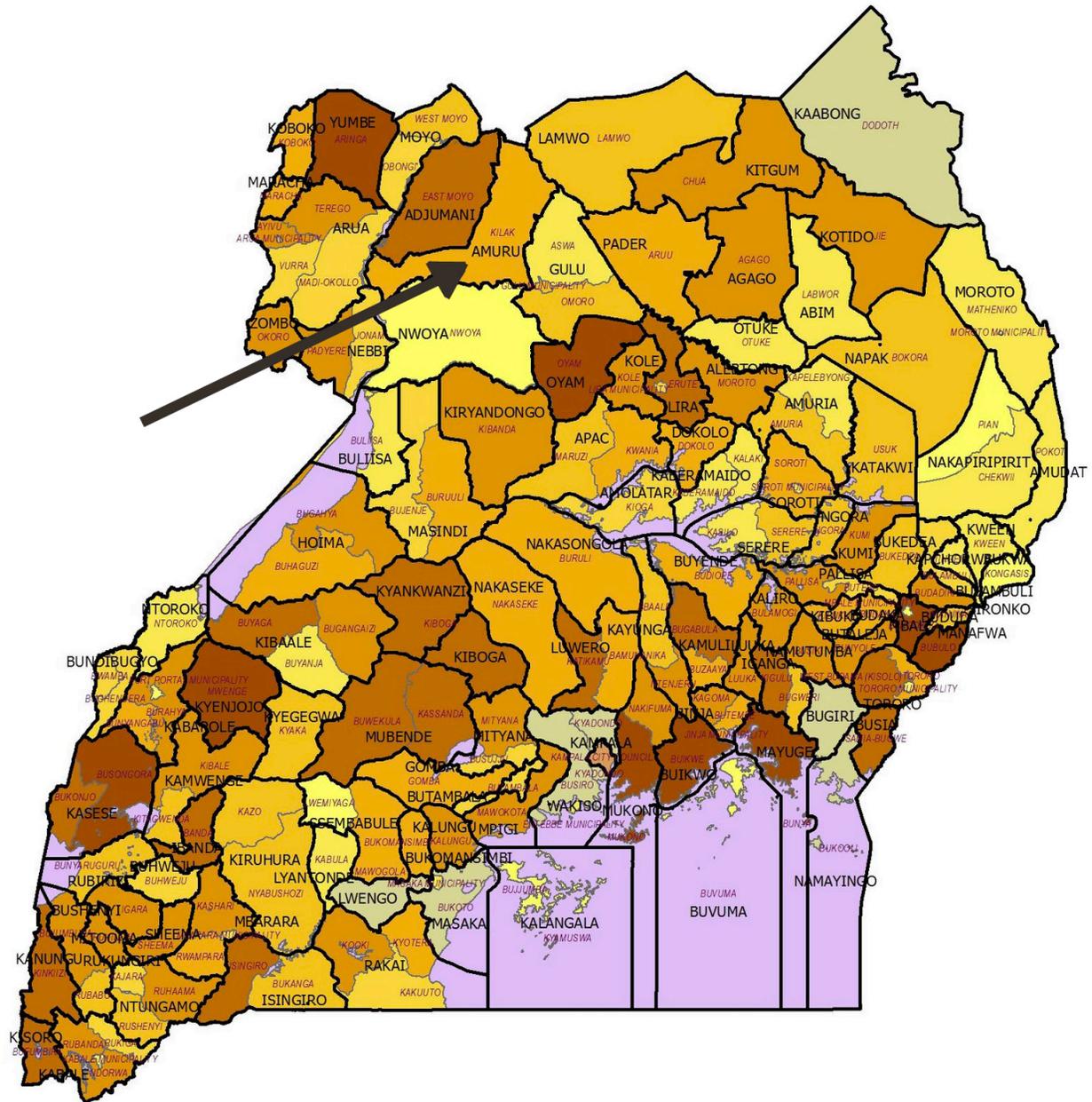


Figure 2: Map of Uganda showing districts (2010)

## **Chapter Four: The Social Organization of Maternity Care: An Overview of ANC, Delivery Care, and Prominent Factors Shaping Care**

### **Introduction**

In this chapter, I provide an overview of how antenatal care (ANC) and care during childbirth were organized in Amuru sub-county. I also describe prominent contextual factors shaping approaches to care including transportation, nutrition and work. My purpose is to depict factors coordinating the social context of maternity care.

In the first section, I focus on care provision. This includes a description of focused or goal-oriented ANC; approaches to HIV testing during ANC; and an overview of an NGO project for new mothers. I introduce the multiple stakeholders who were involved in maternity care provision, identifying the various care providers and health workers and describing their roles in maternity care. Collectively, these factors provide a context for the data analysis and research findings discussed in Chapters Five and Six.

In the second section, I focus on key features of women's everyday life, examining how local contexts related to transportation, nutrition, and work acted to structure maternity care and women's experiences of childbirth. For participants, transportation to ANC and delivery care was expensive and presented a logistical challenge. Eating well and avoiding heavy work were aspects of self-care that participants understood to be important. However, for many, such advice from health workers was difficult to implement. While the challenges of transportation, nutrition, and work were part of ordinary life in post-conflict Amuru, such challenges were socially constituted and were therefore modifiable. For example, several health centres in the sub-county were not fully operational; had they been, participants would not have had so far to travel. In this section, I also explicate how transportation, nutrition, and work were shaped by larger social and

economic factors – including poverty and poor infrastructure – such that maternity care and childbirth were affected.

### **Focused or Goal-Oriented Antenatal Care (ANC)**

Throughout Uganda, antenatal care (ANC) is labeled as “focused” or “goal-oriented” and is intended to achieve specific outcomes in a small number of visits (a minimum of four). The

World Health Organization (WHO) has adopted focused ANC:

Based on the evidence from a multicenter randomized controlled trial (Villar et al. 1998), the World Health Organization (WHO) recommends the implementation of a focused ANC platform that consists of four ANC visits and a well-defined set of activities proven to be beneficial for maternal and neonatal health (WHO 2001). (Conrad et al., 2012, p. 301)

The focused or goal-oriented approach is a departure from a risk-based approach to ANC, as Lincetto et al. (2006) describe:

In recent years, there has been a shift in thinking from the high-risk approach to focused ANC. The high-risk approach is intended to classify pregnant women as ‘low risk’ or ‘high-risk’ based on predetermined criteria and involved many ANC visits. (p. 53)

It is argued that a weakness of a risk-based approach is that many women designated high-risk do not develop complications, while others identified as low-risk do develop complications (Lincetto et al., 2006). Attending a large number of appointments is not feasible for many pregnant women in the global South for whom transportation challenges and other costs associated with ANC pose barriers; a focused approach addresses this challenge (Lincetto et al.). Goal-oriented or focused ANC is intended to reduce the high cost to health care systems and individuals associated with a risk-based approach consisting of more visits. Further, a focused approach responds to critiques of the efficacy of risk-based approach, identified above. Uganda’s 2010 clinical guidelines identify the goals of ANC as:

Prevention and treatment of any complications; Emergency preparedness; Birth planning; Satisfying any unmet nutritional, social, emotional and physical needs of the pregnant woman; Provision of patient education, including successful care and nutrition of the newborn; Identification of high-risk pregnancy; Encouragement of (male) partner involvement in antenatal care.

These goals are to be met over the course of four ANC appointments. Florence, a participant in the current study's Lujoro focus group, described ANC as follows:

When I entered the hospital [health centre], the health worker welcomed me. I was examined and found that the person inside my stomach was fine. I was given medicine and told to continue with the checkups and the good health. If I felt any pain then I should move with my card [i.e. take the ANC card to the health centre] and get medicine for that part that is paining. So I continued to protect that pregnancy, and completed the checkups up to the time of delivery.

She focused on the role of ANC in ensuring the health of the baby and in protecting the pregnancy. Her description indicated her understanding of a participatory role in managing her health and health care during pregnancy.

Another important feature of ANC as it was provided in Amuru was the ANC card mentioned above. Issued to women at their first ANC appointment, this card recorded women's health information as pertinent to pregnancy, including their age, the number and outcome of previous pregnancies, and their HIV status. Women were required to keep their card and to show it at health centre visits, including at the time of delivery. Participants sometimes saw ANC attendance and the ANC card as a key to making health centre delivery possible, as I establish below. Throughout Uganda, HIV testing for pregnant women and their partners (couples' testing) was also offered in the first antenatal visit. In Chapter Five, I provide an analysis of how the processes of HIV testing during ANC affected care.

## The Message to Attend ANC

Participants were familiar with a public health message exhorting them to attend ANC. Among the women with whom I spoke, all had attended at least one appointment. Health care workers conveyed the importance of attending ANC during their outreach visits to villages, the primary purpose of which was immunization and mobile ANC. This message was also disseminated through signs near the health centre, as pictured below (Figure 3, “Sign on visiting the health centre when pregnant”); at group health talks at the health centre held while patients were waiting for care;<sup>14</sup> through the work of the village health team (VHT) and among them the traditional birth attendants (TBAs);<sup>15</sup> and through radio announcements.



**Figure 3: Sign on visiting the health centre. The English translation is: "Women: It is important to come to the hospital/health centre when you are pregnant". The supporting agencies are represented in English and Japanese with their logos.**

<sup>14</sup> Health talks or health education referred to information shared by health workers with groups of people, who were gathered waiting for health care in the reception area of the health centre, or who had gathered at a central place near their home to receive outreach. Lacor Health Centre III Amuru employed a public health educator, who was responsible for such programming. However, other health workers also gave such talks on topics including hygiene and other public health issues.

<sup>15</sup> Practicing TBAs were required to register as VHT members.

Each of these forms of messaging had its respective drawbacks: for example, some women indicated that they never listened to the radio, or that outreach had not reached their village. However, participants demonstrated knowledge of the need to attend ANC. This was consistent with national trends: in Uganda, 94% of rural women attended ANC for at least one visit in 2011 (Uganda Bureau of Statistics, 2011). While this high percentage indicates that ANC is a known service, lower rates of women attending a full complement of ANC (four appointments) indicate ongoing challenges. In addition to health messaging, the practice of giving a mama kit at the time of delivery was seen by both childbearing women and health workers as a way to reinforce the message to use formal health services. The role of the mama kits in coordinating access to antenatal and delivery care is further examined in Chapter Six.

While childbearing women knew that ANC attendance was highly encouraged, the reason for going (i.e., optimal health) was not always understood in the same way by childbearing women participants as by health workers. Participants often referred to attending ANC as “catching the card,” emphasizing receiving the card as an important aspect of ANC participation. The ANC card acted as a kind of ticket or key that facilitated access to health services. For example, Anita, a twenty-year-old mother of two, described ANC attendance as like “a key because when you reach the hospital like this then you hand in your [ANC] card and they see how many times this person has tested, what problems have been got”. ANC and the ANC card, then, acted as a means to coordinating care at the time of labour. While women recognized the health benefits of ANC, there were also indications that women attended ANC because they felt they must. Faith, who had been abducted and shot in the abdomen during the LRA/UNPDF conflict, and worried about miscarriage, described ANC attendance as akin to a “law”.

So they [VHT or outreach health workers] say when you are pregnant it is like a law: you have to go to the hospital for ANC, so that you understand how your health is. If they find

that you have sickness they guide you on how you should live, so that they help the child you are carrying in your womb.

Attending ANC was viewed as complying with a law or obtaining a key, as well as supporting a healthy pregnancy and delivery.

### **The Provision of Mama Kits**

In Amuru, an NGO project distributed ‘mama kits,’ a bag containing baby basics: a bar of soap, a washing basin, towels, jelly (baby cream), and sheets, towels, or cloths (for tying the baby to the mother’s back, for warmth, for drying, and to absorb blood). The kits offset “substantial costs to women of approximately US \$5” (Mbonye et al., 2013, p. 5). They also contained items to be used by health centre staff, including tetracycline eye ointment (to prevent or treat neonatal eye infections). The mama kits were given to women by health centre staff at the time of birth in the health centre and were a project of the Red Cross, a non-governmental organization (NGOs). However, the VHT administered enrolment for the kits, while staff at health centres coordinated distribution. Women who wished to receive a kit were required to register with, and receive a registration card from, their local VHT member. Registration for the mama kits took place via outreach in pregnant women’s home villages, or on a given day at the health centre. In practice, registration and distribution of the kits was a complex process involving multiple stakeholders and impacting how women approached care. Distribution of the mama kits was not universal; not every mother received a kit after giving birth. In the context of poverty, the past conflict, and parallel ongoing NGO involvement and NGO withdrawal, material resources acted to shape childbearing women’s experiences and practices. In Chapter Six, I further identify how the mama kits project was a site that concentrates the operation of power and affects access to care.

## **Formal Health Care Providers**

### **Clinical officers**

Within Amuru sub-county, there were no doctors participating in care to pregnant and birthing women. Amuru district had only one Health Centre IV (HCIV), which was required to have a doctor; it was located in Atiak, a town north of Amuru sub-county near the border with South Sudan. The most senior health care worker required at any Health Centre III was a clinical officer. As described by Wilson et al. (2011), “clinical officers have a separate training from medical doctors, but their roles include many medical and surgical tasks usually carried out by doctors” (para. 3). Throughout sub-Saharan Africa, particularly in rural areas, clinical officers fill the gap left by the shortage of doctors. The clinical officer at Lacor Health Centre III Amuru, Jonas, split his role between administrative and clinical work. The midwives and nursing staff members who provided care to pregnant and birthing women reported to him. While the clinical officer was trained in delivery care and would attend a birth if other staff members were unavailable, he did not work scheduled shifts in the labour ward or antenatal clinic.

### **Midwives**

At the time of my fieldwork, Lacor Health Centre III, Amuru employed two midwives. Other health centres in the sub-county employed a single midwife, or no midwife. A health centre in Oberabic serving a large parish (Acwera) had, in mid-2012, hired its first midwife. In Uganda, midwives are formally trained over the course of three years’ post-secondary education and are registered with a Midwifery Council. Their work centers on antenatal, delivery, and post-partum care. At Lacor Health Centre III Amuru, midwives also participated in outreach trips and provided mobile ANC services. In contrast to midwives, nurses had a broader range of responsibilities including work in other wards.

Nursing staff: Enrolled comprehensive nurses, registered nurses, nursing assistants, and nurse aides

In addition to midwives, there was a range of nursing staff members who played a role in care to pregnant and birthing women. The qualifications of nursing staff varied significantly. Enrolled comprehensive nurses (ECNs) are comprehensive nurses with additional midwifery training. ECNs hold a certificate and are enrolled with the Nurse's Council. Registered nurses (RNs) hold diplomas in general nursing. In contrast to these formally trained and accredited nurses, nursing assistants and particularly nurse aides at Lacor Health Centre III, Amuru, had a more basic training. Nursing assistants had between three months and one year of classroom training, focusing on basic patient care. Nurse aides had no classroom training; they were trained on the job. Their duties included cleaning as well as patient care. At Lacor Health Centre III, nursing aides were hired from local communities (interview with Jonas; Matsiko & Kiwanuka, 2003). Some nurse aides were selected to undertake further training to become nursing assistants. Lacor Health Centre III employed one ECN, one RN, several nursing assistants, and several nurse aides at the time of this fieldwork. While only an ECN has equivalent skills and training to a midwife (interview with Jonas), all levels of nurses, including nurse aides who were lay people, attended deliveries. Due to minimal staffing, scheduling for double coverage of health workers on the delivery ward was not always possible. Staff members often worked alone, particularly at night. Women who gave birth at the health centre, then, received care from practitioners with a wide range of skill-levels and formal training. Occasionally, women gave birth at the health centre unattended (interview data from phase one and phase two).

## The setting for formal health care provision

Most care was provided at the health centre, a series of wards and offices joined by open air corridors and located in a gated compound at the site of a former IDP camp. Health centre staff also made periodic outreach trips to remote areas of the sub-county, and provided antenatal care. I observed some ANC examinations that took place roadside in the ambulance (Land Cruiser). However, when I asked childbearing women in remote villages about outreach, in the context of their difficulty reaching the health centre for ANC, I learned there were barriers to relying on outreach for ANC. At an antenatal visit, women would be given a date by which to come for their next appointment. They would be fined if they missed that date (interview with Jacky). Outreach trips occurred relatively infrequently, meaning that women could not rely on outreach to provide the required amount of antenatal care.

Some participants, including Sara and Amelia from Rec Kicere, Penny from Oberabic, and Rose from Turdakatuba, mentioned that they gave birth unattended by a care provider at the health centre. When I followed up with health workers and administrators, they attributed this partly to the fact that, at night, patients sometimes bypassed the room where they should have checked in, and went directly to the staff housing area above the health centre proper, thus delaying access to care. I witnessed this happen in the case of a motorcycle accident at night; seeing the health centre mostly dark and lights on at our home, the victim's friend came to our door to ask for help. Based on the accounts of those who had given birth unattended as well as Jonas's description, understaffing was also a factor in contributing to unattended births.

## **Informal Health Care Providers**

### Traditional birth attendants (TBAs)

The World Health Organization (WHO) defines a TBA as “a person who assists the

mother during childbirth, and who initially acquired her skills by delivering babies herself or through an apprenticeship to other TBAs” (WHO 1992 cited in Sibley et al., 2009, p. 5). This definition is consistent with the women who practiced as TBAs in Amuru. I learned about their roles and practice from childbearing women and from other health providers and administrators, as well as from TBAs themselves during focus groups. The TBAs, all women in their 50s and 60s, told me they had learned through *experience*, by *necessity*, and by *taking courage*. In previous generations, they explained, all older women would have been expected to be able to assist at a birth.<sup>16</sup>

To explain the process of becoming a TBA, one participant, Dorota, simply told me: “Me, I first saw it from big people (elders) and felt it is all courage. And then I felt that I should also have that courage and help pregnant women”. Amaya told the story of the first birth at which she had assisted. This took place before she had given birth to any child of her own, suggesting she was still a girl. She said:

One time I found a woman knelt down, next to a house, so I went and knelt near her, and when the child came, I waited and received the baby. There were two babies. I waited and received the second one too, and also then I removed the placenta. I went to the big people (elders) and said that the woman who knelt there had delivered twins. So that courage, I have had it forever now.

The TBAs I spoke with had all participated in organized training (funded by NGOs and often delivered via health centres) at various points over the past three decades. However, in each case, often by telling a story, they identified local and informal experience as how they had become TBAs.

While the term “traditional birth attendants” is often deployed in contrast to skilled birth attendants (SBAs) (defined as those with formal training), this can be misleading. The contrast is

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<sup>16</sup> With life expectancy at 54 in Uganda (Index Mundi), these women are elders in their communities.

misleading because TBAs certainly have birth skills, often including skills useful in a difficult labour such as a breech birth or multiple delivery, and also because not all of those providing formal care in health centres entirely fit the official definition of SBAs. For example, those who worked as nurse aides were often, like TBAs, lay people. They had been hired from within the community without formal qualifications and trained on the job to perform health work, including attending births. This is often overlooked in the dichotomy between “traditional” and “skilled” health workers. While the term “village midwife” is occasionally used in the Uganda context, the term “traditional birth attendant” is more prevalent.

The childbearing women who participated in the first stage of the current study primarily looked to TBAs for labour support, rather than for a broader role of support and care throughout pregnancy. The labour support that women sought from TBAs was often as a backup to or substitute for clinical support in a health facility. For Jacky, a lack of transportation and cellphone network access made going to the health centre impossible. In contrast, Pauline delivered her child in the health centre, but told me: “If it [labour] had been abrupt, I would have delivered at home with the help of a TBA I would have called”. Margaret reflected on her TBA-assisted home birth saying: “it was distance and the problem of transport. Otherwise, I would have delivered at the hospital [health centre] like my fellow women”. Her view, that health centre birth was a norm among her peers at this time, was prevalent, but in fact, of 45 participants in this stage (35 interviews and 10 focus group participants), 10 had given birth outside of a health centre or hospital.

TBAs play an important yet contentious role in maternity care in Uganda. In sub-Saharan Africa, approximately 58% of women delivered their first child outside of a health facility (Rogo, 2006). Many of these births are attended by a TBA. In Uganda, Kyomuhendo’s (2003) study in a rural area of western Uganda also found that 58% of women gave birth outside a health facility.

Yet TBAs have a precarious status. Due to shifts in approaches and informal policy pronouncements, identifying the current Ugandan policy approach to TBAs is challenging. While major Ugandan newspapers *The Monitor* and *The New Vision*, as well as the British paper, *The Guardian* reported a 2009 ban on TBAs,<sup>17</sup> at the outset of my fieldwork I could not identify policy documents to indicate that such a ban had taken place. Over the course of my fieldwork, I learned that the situation governing TBAs was, in fact, unclear. There had never been an official written policy banning TBAs, but there had been a number of speeches or documents referring to a ban. Recently, it was reported that the Ministry of Health was resolved to ban TBAs by 2015 as an HIV reduction strategy (Mafaranga, 2013). The government's strong anti-TBA stance, coupled with lack of any concrete guidelines, challenged administrators working in communities where TBAs practice.

Writing before the time of this presidential statement against TBAs, Kyomugisha (2008) states: "Caught between tolerating the need for their service and seeing it as illegal, the government [of Uganda] occasionally openly discourages it" (p. 21). The Uganda Ministry of Health (UMOH), for example, had circulated an edict to NGOs, asking them to stop training TBAs.<sup>18</sup> In our interview, the clinical officer in-charge at the health centre explained the situation as follows:

Actually, what transpired in the past that they, the TBAs, should not conduct deliveries, it was not a policy; it was not a law, neither was it a bylaw, but it was a statement, just, from the president that came out after [a] woman died in labour in eastern Uganda. So the president said "this was done, she died in the hand of a TBA, so with immediately effect, all TBAs must not conduct deliveries". So this was just a statement, there was no

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<sup>17</sup> See for example, The Guardian's articles "Traditional birth attendants show no sign of abandoning their work in Katine" and "Should Uganda ban traditional birth attendants?" (2010). The New Vision, the state-run newspaper, "Revisiting the policy on traditional birth attendants", or in the Monitor, a leading independent, "Why traditional birth attendants will keep thriving" (2013).

<sup>18</sup> The Guardian. "Should Uganda ban traditional birth attendants?" Blog post in a series on development in Katine, Uganda. March 30 2010.

documentation. That was why it became very difficult to implement such a statement, to start working.

The lack of a clear policy governing the role of TBAs in health care provision made it difficult, and at times confusing, for local health care administrators and indeed TBAs themselves, to know how to proceed. In light of the continued need for their services, TBAs with whom I spoke suggested they needed some support for safety at deliveries. This included the following supplies: rubber boots (for protection from snakes), gloves (for hygiene), and flashlights (for travel and as a light source for delivery care). In addition, TBAs identified their need to be trained how to ascertain a woman's HIV status from the ANC card (since they couldn't read). This is an example of how illiteracy influenced the role of texts in coordinating care translocally. The intention of recording HIV test results on a card that women carried was to allow care providers at a later date and in a different location to check these results. However, the ANC card text could not coordinate knowledge of women's HIV status in this way for TBAs, since they could not read and had not been trained to identify how the results were recorded. The barriers to accessing formal delivery care identified in the second half of this chapter and in Chapters Five and Six contribute to the ongoing birth work provide by TBAs despite the confused and negative policy environment and the lack of support for their work.

#### The village health team (VHT)

The village health team (VHT) members were another group of lay people who did health work with pregnant women. The VHT program is a UMOH initiative introduced in 2001 utilizing unpaid, volunteer, community health workers. Members of the VHT, who receive some training, are considered to be a Health Centre I, the lowest level of health centre. That is, while they do not work out of a physical health facility, they are the first point of contact between individuals and the health care system (Uganda MoH, 2010, p. 9). Their role is to provide a

bridge to formal health care. They are also health educators and mobilizers, acting to inform their community of upcoming outreach visits and ensure that people are present on such days.

In describing the VHT's role, the UMOH draws on a discourse of responsabilization (Foley, 2008; Rossiter, 2012; Ruhl, 1999). This discourse leverages statistics on disease prevention to place responsibility for poor health or disease outbreaks on individual or community behaviours. This decentralization practice shifts responsibility for poor health outcomes away from the inadequate and poorly funded formal health system, and towards individuals and communities. The rationale for the VHT makes claims about empowerment and taking responsibility: "Community participation and empowerment is a strategy that enables communities to take responsibility for their own health and wellbeing and to participate actively in the management of their local health services" (UMOH, 2010, p.7). This focus shifts the blame for health problems to individuals and communities, rather than health systems of other public sectors: "In Uganda, over 75% of the diseases are preventable if only people changed and adopted appropriate and well known behaviors geared towards better health" (UMOH, 2005) (p.7). The VHT program is intended to be a means of facilitating access to health care while at the same time reducing demands on the formal health care system by improving health within communities. Participants primarily mentioned the VHT in relation to registration for the mama kits (discussed in detail in Chapter Six), but also mentioned them as a source of information.

### **Transportation, Nutrition, and Work**

#### Transportation

Transportation connected the communities where pregnant women lived to the health centres where antenatal and birthing care was provided and therefore facilitated access to maternity health care. However, access to transportation was difficult, and, at times,

insurmountable. The challenge of accessing transportation affects the location of birth and therefore the type of attendant present. Other studies investigating barriers to access to maternity care in Uganda have identified the logistical and financial difficulties of transportation (Kyomuhendo, 2003; Knudsen, 2003; Parkhurst, Rahman, & Ssenooba, 2006). In this section, I outline how remoteness, poverty, and post-conflict shaped how maternity care was accessed. I make the case that transportation was not one problem but was a multi-dimensional problem. An ongoing reliance on TBAs at the time of birth was connected to the difficulty of transportation from remote communities or at night.

A central road linked Amuru, where Lacor Health Centre III was located, to Otwee, the district headquarters, and other trading centres. To the southeast, this road connected to the Juba road, a major north-south route on which Lacor Hospital is located. The roads themselves were narrow, poorly surfaced, and unmaintained. They could quickly become impassable during the rainy season. Private car or truck ownership was rare: short distances were covered by foot, bicycle, or boda-boda while longer trips could be taken by shared van-taxi or boda-boda. Emergency ambulance transportation was facilitated via health centres, which would call for an ambulance (often a converted Toyota Land Cruiser) to transport patients who needed medical assistance beyond the health centre's scope. At government run facilities, however, lack of a vehicle or money for fuel hindered emergency transport. Lacor Health Centre III had ambulance service via Lacor Hospital. Management was able to improve emergency transportation in response to an incident in which a nighttime ambulance delay led to a 'near-miss' for a labouring woman; both she and her baby survived, but she had to have a hysterectomy. After that incident, an improvement was made to the procedure for contacting night ambulance drivers. Night drivers were required to be present at Lacor Hospital during their on-call shifts, so that when one

of the rural health centres operated by Lacor called for an ambulance, there would be a driver available (personal communication, Jonas).

A motorcycle taxi, or boda-boda, was not an ideal mode of transportation for a laboring woman, and indeed advanced labour could sometimes make it impossible. The more pervasive challenge, however, was not being able to get a boda-boda. For some, the cost was prohibitive. Since costs rose in relation to distance travelled, remote women were more greatly affected. People often contacted drivers by walking to an intersection where boda drivers were known to wait; women might also gather in advance the phone numbers of drivers who they knew. Drivers' unavailability after dark and reluctance to travel at night reduced transportation accessibility for labouring women. Poor road conditions made travel at night unsafe; drivers also feared "bad people" and were more susceptible to crime if travelling at night. Further, during heavy rain, travel was difficult and uncomfortable, and might be hard to arrange.

One participant, Elizabeth, when asked which people were most important to a pregnant woman, said the boda-boda driver. When my research assistant laughed in reflecting this answer back to her, she said perhaps her husband was most important. However, her initial mention of a boda-boda driver was revealing. Without a boda-boda driver, a woman might not be able to deliver at the health centre. She would labour at home, supported by whoever was available.

The remote location of many households contributed to transportation difficulties. As farmers, people in Amuru often situated their homes in proximity to their land, rather than in proximity to roads or trading centres. The narrow paths that households were located on were not accessible by car or truck, and even motorcycle access could be difficult when paths were bushy or wet. While the distance to the road was likely to be regarded as walkable, walking any distance can be difficult when heavily pregnant or in labour, and, once one is at the road, transportation was not always available (for reasons described above). If transportation to the

health centre was often a challenge, transportation to a full-service hospital was out of reach, as the trip was too long and too costly for most people to manage independently. Even in the closest villages, people talked about transportation to the health centre as an issue, but distance appeared to contribute to whether women would attend ANC or deliver in a health centre.

The connection between transportation challenges and birthing at home was articulated by Jacky, who lived in the remote village, Tedi:

I started to feel labour pain in the evening when the sun was down, and it was hard to get a boda (motorcycle taxi). So one has to call a boda from Amuru to take you to the hospital, but also the phone network here is very poor, so they had to look for the network – one has to go and stand on an anthill [to get any cellphone reception]. So by the time they called the boda to reach here I had already delivered because the labor started so urgently. I had to deliver with the help of the trained TBA who was around here.

For Jacky, relying on a TBA for labour support was circumstantial, rather than part of a birth plan, preference, or deliberate choice.

Some women travelled to ANC appointments by bicycle, either doubled by their partner or riding the bike themselves. Women were advised not to ride a bike themselves when their pregnancies were advanced, after about 6 months. It was not typical for every household to have a bike; couples sometimes borrowed from a sibling or neighbour. It was observed and reported by participants that bike ownership was gendered such that when a household owned a bike it generally belonged to a man.

Transportation problems in Amuru sub-county were multifaceted and, as such, require interventions that factor in these multiple elements. Transportation interventions that isolate one transportation barrier can only address that one element. For example, programs that distribute boda-boda vouchers (described in Pariyo et al., 2011) focus on cost, but not other transportation barriers. Increasing the number of operational health centres would mitigate the need for access to transportation: in Amuru sub-county, if each health centre designated a II or III was

operational to prescribed norms, most women could walk to antenatal care, saving them the work, expense, and risk of arranging transport. Participants suggested various approaches to improving transportation to health care. Suggestions included: pooling savings to purchase fuel for ambulances, organizing emergency community funds for women without the means to pay for a boda, and providing a shuttle service from any health centres that could not provide appropriate care to the nearest health centre with adequate maternity care services.

#### *Lack of capacity to provide care at sub-county health centres*

Otwee Health Centre III, a government-run facility, was an example of a health centre that was not functioning to its designated capacity. Due to its problems with service delivery, participants who lived near there would bypass it in order to reach more reliable care at Lacor Health Centre III; no participants reported having given birth to their most recent child there. The DHO, Peter, lived in the neighbouring district, Gulu, but had his office near Otwee health centre. He described an encounter he had with a group of local women who, frustrated over the (total) absence of beds in the maternity ward, had formed a group to barricade the road out of the district head quarters, demanding to speak to him before he left for his home in Gulu that day. They made their case for beds in the maternity ward; however, Peter explained that he had prioritized trained staff over beds, being unable to provide both. He asked them, rhetorically, whether if they stayed at home there would be a bed, and emphasized that skilled staff members were the most important intervention the health centre could make in delivery care.

The Women of Uganda Network reported that in May 2013, five health workers at Otwee Health Centre were arrested; they were detained and charged with “neglect of duty and absenteeism from work place without permission at expense of tax payers’ life”. A volunteer working with a social accountability group had been the one to raise the alert, working through

authorities to contact the police. This information pertains to my study because it helps establish the context of inoperational health centres and the distress this causes. Bisailon (2012) identifies that a feature of IE research is to “investigate that which informants experience as problematic, troubling, and contradictory” (p. 609). The instances of activism described here bolster the evidence in interviews and focus groups indicating that lack of capacity to provide health care to specified level was a priority issue for participants and other people in Amuru. The clear demands of local activists indicate that patients saw themselves as able to shape how formal care was organized, and not as passive recipients of whatever care was provided. Further, the activist demands support my finding that when women stayed home to deliver, this wasn’t always a case of preference for home and the care available there, but was sometimes an indictment of, or a response to the challenge in accessing, the health care environment.

#### Nutrition and work

Participants often paired nutrition and work as aspects of self-care during pregnancy. Eating well and avoiding heavy or prolonged physical labour were known to be important to taking care of the health of mother and unborn baby; this was emphasized in health talks and during ANC, yet in some instances participants found this difficult. The focus on avoiding heavy work and seeking nutrition indicated that the local livelihood, subsistence farming, was significant in shaping approaches to care at birth. All capable family members farmed by hand with a heavy hoe, and as farming was the principle livelihood, it was challenging to avoid this work. Poverty also contributed to the difficulty of adequate rest and nutrition. Participants reported that pregnant women would sometimes work for their neighbours, typically at farm work, to save for good food and for basic supplies necessary at the time of birth; the need to

provide these supplies contributed to the difficulty of avoiding heavy work or getting adequate rest during pregnancy.

Participants paired seeking good nutrition and avoiding work because both were well-known self-care advice. Further, they were linked because the one depended on the other. Eating well depended on having a good yield, varied crops, and some money for store-bought food such as dried fish, oil, sugar, salt, and perhaps eggs or meat. For most participants, good nutrition depended on hard work. Various participants pointed this out as an irony of the self-care advice. Further, knowledge of the advice to avoid arduous work and seek good nutrition overshadowed other relevant knowledge, such as how to recognize pregnancy danger signs that indicate a need to seek care.

While some could delegate work to supportive others – husbands, older children, or co-wives – others talked about lack of help. In a focus group discussion, Leah said that some men made resting or eating more difficult for their partners:

Men are different. Some think women pretend when you tell him you are not able [to work] so he will ask you to dig equally, because the child is in the womb and not in your hand [laughter].

Such expectations contributed to the difficulty of avoiding overwork in pregnancy.

Preparations for delivery and planning for care were forms of work in themselves, in addition to agricultural or other subsistence/income generating work. Some participants turned to additional income generating work to be able to buy required supplies for delivery. This could be heavy work such as digging someone's field or, for those with the resources to arrange it, lighter work such as cooking and selling snacks. Participants identified the necessary supplies for delivering at the health centre and receiving the baby as including a plastic bed cover on which to labour (to contribute to a sterile environment), clothes and cloths for the baby, lamp paraffin for night waking, and sometimes food items. Women also mudded (or 'smeared') the floor of their

huts in preparation for the new arrival, applying a paste of dung and water to make a smooth, hard, clean surface (participants in Oberabic, Rec Kicere, Lujoro, and Tedi). This was explained as important because the new baby was like a guest, or because guests could be expected after the new baby's arrival. Further, mudding the floor was home maintenance that had to be done periodically, and there would not be time for it with a new baby. Many participants prepared simsim [sesame] for making pasted foods and millet for porridge; grinding these was labour intensive and would be difficult with a new baby. Most participants considered obtaining supplies and preparing foods or the home to be part of the work of pregnancy, although it was more difficult for some participants than for others. The difficulty of avoiding arduous work was linked to the need to purchase and prepare supplies for the pregnancy, birth, and baby's arrival.

The "lean months" that some participants described contributed to the difficulty of avoiding work and ensuring nutrition. These were the months when the last harvest had been eaten or sold and the new crop was not yet ready. Maureen, who was struggling financially, spoke of this. She listed tomatoes, eggs, and milk as foods that would contribute to good nutrition during pregnancy, but stated they were difficult to obtain. She spoke about seeing well-fed children with a sense of envy and said that, "in this month, hunger is much". In a focus group discussion, Betty said, on the topic of food, that "Nutrition is good, as they tell us [. . .] But it is not easy. [. . .]While the children are hungry, eggs cannot be eaten. It is impossible". For these women, taking supplemental nutritious foods during pregnancy competed with providing adequate nutrition to their children.

The challenge of nutrition was also linked to the post-conflict setting in that some foods took longer, or were more expensive, to re-establish. This was the case with livestock as well as crops such as avocados, for example. Finnström (2008) describes how during the war, people would grow crops that were difficult to raid, or would sell their produce quickly to an urban

middleman. He writes: “Eventually, the short-term coping strategy of selling off harvests and then buying food will make people increasingly entangled with the wider market economy and its fluctuations, or even dependent on relief distribution” (p. 36). Participants in both research stages – that is, childbearing women and health workers – noted this pattern of selling off much of a crop early. Although it was no longer a strategy to avoid raids, selling the bulk of a crop at the time of harvest impacted access to nutritious foods. Participants also looked for humanitarian-aid food support such as they had experienced in the camps. For example, Hazel recalled a nutritionally enhanced flour which included soy that was distributed around 2004, when people were returning home from IDP camps. She said, “it gives expectant mothers and the baby strength, and nowadays they don’t give”. Others recommended that the government or health centre should provide sugar or other food supports. For instance, Nightie, a focus group participant in Lujoro said that “actually when it comes to delivery, there are so many problems, because we don’t have the capacity to take care of ourselves. When you deliver sometimes we even don’t have what to eat so the hospital should try to support a little”. McElroy (2012) found that while dependence on food aid was not desirable, the vulnerability of children (her study’s focus) to nutritional deprivation was such that targeted intervention for pregnant and breastfeeding women and young children should be considered (p. 147). The context of previous humanitarian aid in the area, particularly in IDP camps and during their disbandment, appeared to have shaped childbearing women’s expectations and recommendations with regard to food support.

Ensuring nutrition and avoiding heavy work were also emphasized in my discussions with formal health care providers. While they shared the view that maintaining good nutrition and avoiding heavy work were important to self-care during pregnancy, health administrators and workers felt food insecurity or lack of nutritious food was something women could plan for and

manage, even in the poorest family (Peter, Jonas, Amy, Grace, Gloria and Dorothy). They argued that every family would have some land to plant, and noted that Amuru is a fertile and productive area. They told me that they talked to women about using food storage services and growing something similar to a kitchen garden in their compound. In contrast, many participants emphasized that having good food to eat during pregnancy and birth was very challenging. This challenge may be attributed to lost knowledge among young women who were raised in the camps, in addition to diminished agricultural productivity in the transition period. In this regard, health care providers seemed to be sharing a message of responsabilization when it came to nutrition, and did not believe that poverty was so extreme that good nutrition would be difficult.

As well as being a factor in health during pregnancy, the need to work and provide good nutrition could also lead to delays in seeking care. One participant, Hope, laughed when telling her birth story, in which a series of pressing household tasks led to a delay in seeking transportation to the health centre. She lived near the health centre, and had the money to pay for the short boda-boda ride. However, when she went into labour at a friend's home, she worried about leaving home without preparing firewood for her children. As she recounts:

Then I ran, with my boy, after he had put some beans on the fire, then I said 'you follow me'. I came home, and split firewood very fast. After I split firewood, the baby's head seemed to be down already, and [laughs] pain increased and it was much. ... I said, I will first get some potatoes. It [the pain] had subsided, so I poured water into a basin. I had bathed during the day but I said 'I will bathe only here' [indicates bathing between her legs, laughs]. I had everything packed, ready [i.e. her supplies for the birth at the health centre]. I started getting potatoes from the garden, very fast, then I went to cut [harvest] simsim [sesame] I had sowed here. I cut five handfuls, and when I had cut the simsim my labour increased so much it was impossible. I sent the children that 'you go and call this woman<sup>19</sup> to come, I am going to the hospital [health centre]'. The lady ran and came. I had bathed, I said 'I will put my clothes on', then my waters (opuyu) burst. They ran to call a motorcycle. The baby then came out! [laughs].

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<sup>19</sup> The woman was a neighbor who Hope said was not a TBA but "works almost like a TBA".

In Hope's case, delivering at the health centre was her plan, but was not her first priority. Going to the health centre would mean leaving her children, and she needed to ensure they would be able to cope. Of her older children, three had been born at home and another two at the health centre, so she was somewhat comfortable with home birth.

Pregnancy is a time of vulnerability for all women, as the biological changes to the body introduce new health risks. The struggles to maintain basic nutrition and rest during pregnancy, and the difficulty of obtaining necessary services and goods, such as transportation and birth supplies, rendered women in Amuru particularly vulnerable in the time during and around pregnancy. Such forces can be considered acts of structural violence. Medical anthropologist Paul Farmer describes structural violence as follows:

'Structural violence' is one way of describing social arrangements marked by racism and other social inequalities. In the influential view of sociologist Johan Galtung, structural violence is 'the avoidable impairment of fundamental human needs,' embedded in longstanding ubiquitous social structures, normalized by stable institutions and regular experience.' Because they seem so ordinary in our ways of understanding the world, such violent structures are almost invisible. Disparate access to resources, political power, and health care as well as unequal legal standing are just a few examples. Such arrangements to violence to society's losers; the arrangements are structural because they are embedded in the economic organization of our social world. (Farmer, 2010, p. 578)

Finnström similarly links poor access to basic transportation to structural violence, arguing that physical violence occurs "when access to transportation is very unevenly distributed, keeping large segments of a populations at the same place with mobility a monopoly of the select few" (Galtung, 1969, p. 169 cited in Finnström p. 145). As pertains to transportation for health care in Amuru, poverty, neglected rural and northern infrastructure, and poor health care infrastructure conspired to make access to transportation an issue that brought violence and impaired the capacity of women to meet their basic human needs. These seemingly mundane issues of transport, food, and work had significant impacts on the health of childbearing women in Amuru sub-county.

## **Conclusion**

In this chapter I have detailed how health care was provided in Amuru and how the everyday concerns of transportation, nutrition, and work presented challenges to pregnant women. Women's work in relation to maternity care and birth took many forms; these included attending ANC, saving money for supplies and transportation, and ensuring adequate nutrition and rest. The difficulties women faced in undertaking this work, as I have demonstrated, can be understood in terms of their limited access to power and resources as shaped by the post-conflict setting and gender dynamics. The structure of health care provision and these features of daily life were part of the landscape of maternity care and childbirth in Amuru. In the following two chapters, I focus on two distinct features coordinating maternity care: couples' HIV testing during ANC and the provision of mama kits. In examining the role of these interventions, I identify the ways in which international and other extra-local discourses, policies, and goals contribute to how maternity care and birth took place in Amuru sub-county.

## Chapter Five: HIV testing and Prevention: Factors Coordinating Maternity Care and Birth

### Introduction

The high prevalence of HIV in Uganda makes prevention and related interventions a priority, particularly in pregnancy. In this chapter, I examine measures to prevent the vertical<sup>20</sup> transmission of HIV in pregnancy and birth and the role these measures play in shaping antenatal (ANC) and delivery care. I focus on HIV testing practices during ANC as they affect pregnant women and their experiences of care. I demonstrate that the testing of pregnant women and their partners (couples' testing) during ANC was widely perceived by expectant mothers to be compulsory, and indeed was presented by health centre staff as such.<sup>21</sup> This compulsory approach could lead to negative consequences for pregnant women. These included additional work in accessing care, as well as intimate partner violence. Moreover, the mandatory approach to couples' testing could increase barriers to women's access to ANC and delivery care.<sup>22</sup>

The goal of preventing HIV transmission during pregnancy and childbirth shapes maternity care in Amuru sub-county (as elsewhere). The focus on HIV testing as a pathway to prevention has the potential to improve maternal and child health and reduce rates of HIV transmission.<sup>23</sup> My critique of current approaches to HIV testing during ANC centers on the lack of distinction between voluntary and compulsory testing and the impact of compulsory

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<sup>20</sup> Vertical transmission is the transmission from a mother to her baby during pregnancy, birth, or breastfeeding. Horizontal transmission, between birthing women and health care providers or between partners is also a site of concern and intervention, but one which I do not take up here in favour of a full analysis of HIV testing practices.

<sup>21</sup> This partially reflects recent changes to HIV testing policy from a voluntary to a routine approach (Byamugisha, 2010). However, patients should be able to opt out of routine provider-initiated testing and counseling. Mandatory testing is limited to medical-legal cases and tissue donations (Uganda Ministry of Health, 2005).

<sup>22</sup> At the time of delivery, the high rate of HIV among pregnant women and the need to prevent transmission shapes the work practices of both formally trained health workers and TBAs. In turn, these practices are part of the coordination of care for parturient women. In this chapter, however, I focus on HIV testing during ANC.

<sup>23</sup> The risk to the baby can be best understood in the context of couples' status, rather than solely the mother's status, since an HIV positive partner may transmit the virus during the course of his partner's pregnancy.

approaches on the rights and lives of women and men. This critique is situated in the context of inequitable gender and power relationships, both among couples and between health workers and the women for whom they provide care. Couples' testing took place in a context of gendered intersectional power inequities. As I discuss in this chapter, the reluctance of some male partners to test for HIV or otherwise participate in ANC exemplified these inequitable relationships. The disjuncture between global health guidelines on HIV testing and local applications impacted women's lives, their access to health care, and the dynamics within their intimate relationships. I make the case that the described practices were coercive to pregnant women, burdening women with the task of facilitating male involvement and making ANC and delivery care contingent on women's ability to recruit their husbands to participate.

### **HIV Testing During ANC: A Compulsory Approach**

In Amuru, women and their husbands were instructed to attend the first ANC appointment together in order to test for HIV and promote male understanding of and involvement in pregnancy. The purpose of testing women and their partners was to identify women who were HIV positive, or who were married to HIV positive men and were thus particularly likely to contract the virus during their pregnancy. Testing for HIV helped pregnant women and their health care providers plan for health care, including prevention of mother-to-child transmission (PMTCT) which can occur during pregnancy, birth, or through breastfeeding. Once identified, a woman's HIV status was recorded on her ANC card, where there was also a section to indicate the health of the husband. While at a national level couples' testing was identified as a routine and provider-initiated health care service that patients could opt out of, it was implemented within Amuru in such a way that it was generally understood to be compulsory.

This understanding of testing as compulsory was not isolated. Larsson et al.'s (2012) study set in Eastern Uganda found that: "The fact that HIV testing was viewed as compulsory is in line with recent concerns that the global policy change from VCT to provider-initiated HIV testing could make patients feel obliged to test (Maman and King 2008)" (p. 5). The study also identifies that:

The PMTCT policy in Uganda states that all pregnant women and their male partners should be offered HIV testing routinely during ANC. However, since very few men spontaneously accompanied their wives for ANC, health workers tried to recruit men for testing through the pregnant women. (p. 5)

Larsson et al.'s (2012) study found that absent male partners were viewed to be the responsibility of women (p. 2). The tendency to treat couples' testing as compulsory and to make women responsible for men's participation was not unique to the Amuru setting.

As I identify in the subsequent sections, mothers and health workers shared the perception of couples' testing as compulsory. Health centre practices that made partner testing appear to be compulsory (in addition to simply describing it as such) included requiring a letter from a Local Council I (LC I) to be provided by women whose husbands refused to or could not participate and generating fear that women might be denied further ANC or care at the time of delivery. Further, some local leaders punished men who refused to participate by requiring community service (usually slashing the long grass around a compound or path).<sup>24</sup> Women were the primary means through which men were recruited.

### **HIV Testing During ANC: Men's and Women's Roles**

Health talks and signs also stated that men should accompany their partners to care. As well as the one pictured here (Figure 4, "Men and ANC poster"), there was a large metal sign at

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<sup>24</sup> In each village, where possible, I talked with the local leader. We discussed issues facing their village, and I asked what they thought I should know about maternity care and birth in their setting. This information was shared in the context of such a discussion, and later corroborated by health care administrators.

the health centre turn off that read, "If you love your wife, then go together with her to the hospital when she is pregnant". It was sponsored by the Red Cross and Safe Motherhood. A poster in the out-patient ward had a photo of a man doubling a pregnant woman on a bicycle, and reads (in Acholi only): "Responsible<sup>25</sup> men go early with their wives for ANC. Test today together with your wife for HIV so that you prevent transmission of the virus to the unborn baby still in the womb". Another poster, focusing on malaria prevention, also included the message (in English and Acholi) that "It is the man's responsibility to take his pregnant partner for antenatal care". It had illustrations for those who did not read in either language. These messages called on men to be responsible, intelligent, and loving citizens through their testing practices and accompanying women to ANC. This appealed to discourses of masculinity and men's role as protector and/ or provider. However, when men did not arrive at ANC it was their pregnant partners who were called on to persuade them to attend.

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<sup>25</sup> Or could be translated as intelligent.



**Figure 4: “Men and ANC poster”.** This English translation is: "Responsible men go early with their wives for ANC. Test together with your wife for HIV so that you prevent transmission of the virus to the unborn baby still in the womb". This poster was displayed outside the outpatient ward at Lacor Health Centre III, Amuru.

The strategy of requiring women to be responsible for men’s participation in testing and ANC disregarded the reluctance men often expressed, and the difficulty women therefore had in bringing a partner. Moreover, responsabilizing women for the health care of their family members reified gendered divisions of the labour of care. Responsibilization practices are features of neoliberal health systems which shift responsibility towards individuals and away from systems (Rossiter, 2012). A voluntary approach to testing respects choice and autonomy and acknowledges that testing can be socially and personally difficult. In contrast, when couples’ testing was carried out as mandatory it became coercive in character, such that participation is a form of compliance rather than autonomous decision making. A coercive approach to

compliance with couples' HIV testing during ANC played into power dynamics that diminish power and safety for childbearing women.

### **HIV Testing During ANC: Benefits and Positive Assessments**

While male participation presented a particular challenge, couples' testing is known to have important benefits, among them an increased participation in prevention of mother-to-child transmission (PMTCT) measures among women. Medley et al. (2012) indicate that that "women who receive an HIV test with their male partners are also more likely to accept prevention of mother-to-child transmission PMTCT interventions including ARV prophylaxis" (p. 360). Larsson et al. (2012) also observe that "[t]he Ugandan PMTCT policy is based on evidence that male partner involvement is associated with women's completion of PMTCT in sub-Saharan Africa" (p. 6), but identify problems with this policy's implementation.

In addition to encouraging PMTCT completion, couples' testing alleviates some of the pressures of disclosure (Medley et al., 2012, p. 361). These pressures or negative consequences can be serious: "Women who test for HIV without their partner's knowledge or consent and turn out to be HIV positive have difficulty disclosing and face a number of potential negative reactions from their partners, including blame, and abandonment" (Medley et al., 2012). Depending on how HIV testing is carried out, it can affect pregnant women's health care and intimate relationships in negative or positive ways.

Health workers in Amuru perceived couples' testing during ANC as beneficial to women. For example, Gloria, a midwife, identified HIV testing as one of two main reasons ANC was important to her clients. (The second reason was to learn of any complications that would require a hospital trip so women could save for transport accordingly.) Gloria described the value of testing as follows: "At least they know their status. Some may go two years without testing, but

when you are pregnant, you must. At least they know their status and the advice. If they are positive, they are advised the way of life”. From the midwife’s perspective, HIV testing was beneficial to women themselves, as well as being beneficial for its role in PMTCT.

### **Compulsory HIV Testing During ANC: Where Does This Policy Approach Come From?**

The health worker participants described implementing couples’ testing during ANC as part of a national policy. The district health officer (DHO), Peter, characterized couples’ testing during ANC as such. I asked: “And so the HIV testing of husbands at ANC and the requirement for men to attend, that’s district-wide, or nation-wide?” He responded by saying:

It’s a national policy, a Ministry of Health policy they have come up with. But the challenge is how to get the men in the health facility. He is not going to come. There was a time they tried to put it as a regulation that any mother who comes with a husband is attended to first. What they discovered later on was that it was no longer the wives bringing their husband, but they were bringing any male. So we find if a mother is coming for antenatal, there is a boda-boda transporting her. . . [here I laugh] That [the motorcycle-taxi driver] would be the husband. So the whole policy lost meaning.

Rewarding women who brought their husbands to ANC was a failed attempt at regulation since women’s compliance took the form of being accompanied by *any* man, not necessarily their husband. The challenge that women faced in bringing partners created conditions in which the women who Peter described circumvented the policy. While their actions were textually mediated by the policy, this did not occur in the intended way. The difficulty of mobilizing male partner involvement, then, was a challenge for policy makers as well as health workers and birthing women.

Gloria also pointed out that HIV testing practices at the health centre were based on a national policy that, in turn, responded to the Millennium Development Goals (MDGs) to be achieved by 2015. She stated in an interview:

Pertaining to men coming to antenatal care, that one is based on the government program where by 2015 no babies will be born with HIV infection. (Sarah): Right. (Gloria): Now

in that, they are suggesting, they feel if they can make all males, it is a routine and it is a must for all males to be tested. Because I can be negative and my husband can be positive. I can get it anytime during pregnancy.

These national and local approaches, then, respond to global approaches and goals, including the MDGs. However, the process of implementing global health goals is complex, and in this case, some of the features that were discarded in implementation were the same ones that were crucial to women's rights and safety.

### **Compulsory HIV Testing During ANC: Coercion and 'An Offer You Can't Refuse'**

One major feature of global health recommendations that did not get taken up in practice in Amuru was the voluntary and coercion-free approach specified by global health organizations including the World Health Organization (WHO). Specifically, WHO and UNAIDS (The Joint United Nations Program on HIV/AIDS) guidelines for provider-initiated HIV testing state:

'Patients must receive adequate information on which to base a personal and voluntary decision whether or not to consent to the test, and be given an explicit opportunity to decline a recommendation of HIV testing and counselling without coercion' (WHO 2007: 33). (cited in Angotti, Dionne & Gaydos, 2011, p. 308).

In practice, however, this information and the opportunity to decline was not part of how testing was structured and implemented. HIV testing and counseling was treated as mandatory, and coercive measures were employed in order to implement testing.

This disjuncture between a model described as voluntary and a local implementation and perception of testing as compulsory has been identified elsewhere in sub-Saharan Africa. In Malawi, researchers examined perceptions of HIV testing during pregnancy and found that:

Although it is both international and Government of Malawi policy that women must be explicitly informed of their right to refuse testing, analysis of in-depth interviews, focus group discussions and evidence from observational field journals show that rural Malawians do not perceive HIV testing as a choice, but rather as compulsory in order to receive antenatal care. (Angotti et al., 2011, p. 307)

As in the Malawi case (Angotti et al., 2011), participants in the current study perceived couples' testing during ANC to be "an offer you can't refuse". Agnotti et al.'s (2011) study, which focused on women's testing (and not couples' testing), identified a "dissonance between global expectations and local realities of the delivery of HIV-testing interventions" (Angotti et al., 2011). Such dissonance had an impact on women's personal relationships and their approaches to antenatal and delivery care. As such, it was a constitutive force shaping the women's experiences of maternity care in the current study.

### **Gender and Intersectional Power Relationships**

The clinical officer in-charge, Jonas, identified the twofold purpose of having male partners attend the first ANC appointment. First, he emphasized, was the prevention of mother-to-child transmission of HIV (PMTCT) and planning for care according to HIV status. He went on to say: "The second part is, okay, men are being encouraged to get more close, and take more responsibility to their pregnant women". While my analysis focuses on practices surrounding the goal of PMTCT through testing, the second goal - raising men's awareness of and value for women's health during pregnancy - provides a relevant example of how health policy can have discursive effects that are both clinical and social. Health providers worked to be a part of men's shifting gender roles in relation to maternity care and birth; however, much of this took place via men's female partners or via responsabilization messaging that failed to account for factors structuring men's reluctance.

Gendered power relations also constitute the social context of HIV prevention, testing, and disclosure within the context of pregnancy and birth. Efforts at HIV prevention need to intersect with efforts to counter gendered violence, as Westerhaus et al. (2005) address:

HIV prevention programs must also target men. In northern Uganda, displacement has compromised male gender roles, creating frustration that manifests itself in violence

against women. HIV prevention programs must acknowledge these realities and attempt to counter this violence by working with men to reshape their gender roles in ways that are acceptable to both men and women. (p. 1185).

The approach to HIV testing during ANC in Amuru sub-county acknowledges the importance of men's role and participation yet also re-inscribes gendered power dynamics within intimate relationships. From my analysis of women's accounts and the structural context of maternity care, I conclude that the intersections of ANC and HIV testing created a coercive context within which women experienced the burden of recruiting men.

Larsson et al. (2012) share the concern that similar approaches to testing fail to integrate the inseparable connection between gender and power. They assert that despite WHO emphasis on integrating gender into health policy, "gender aspects in terms of decision-making power and women's financial dependency on their male partners is rarely integrated in policy development and implementation" (p. 6). Gender-sensitive implementation, they suggest, might target men directly, such as through peer-education or clinics, instead of through their pregnant wives. Gendered power dynamics were evident in the childbearing women's and health workers' data of the current study. In examining these dynamics, I show how HIV testing during ANC was important to the organization of maternity care and birth in Amuru sub-county.

Despite the "bio-technical" (Rose, 2007) character of HIV testing and PMTCT methods, HIV testing takes place in the context of social relationships, those among health workers and patients, but also those among the couples being tested. Gendered power relations within marriage and gendered expectations of men's and women's roles shaped the impact of couples' testing during ANC.

When discussing the difficulties participants face in bringing their husbands to ANC, it is necessary to recognize that gender norms within Acholi culture are neither monolithic nor static.

Participants shared stories of husbands whose involvement was difficult or impossible to negotiate, as well as husbands who approached pregnancy and parenthood with support. Husbands' support was evident, for example, in efforts to save money for supplies for the birth and the new child. The husbands of some participants willingly agreed to participate in the first appointment and to test for HIV, for their own sake and that of their families. For example, Monica said her husband "thinks of his health".

While the reluctance of some men to test can be regarded as irresponsible by their partners and by health workers, another way of understanding it is to recognize that HIV was feared within the community (as elsewhere), and that learning of a positive status was challenging and life-changing. Furthermore, couples' HIV testing occurred within a context that could be difficult for men, in terms of ongoing social distress. Participants linked men's overuse of alcohol to their tendency to have extra-marital sex and to avoiding testing. Alcohol dependency can be understood, in part, as a response to traumas survived during the conflict period as well as the subsequent economic and social impacts on day-to-day life, and is linked to intimate partner violence (Annan & Brier, 2009). Many of the men whom women spoke about were likely to be survivors of, or witnesses to, atrocious violence. Examining the links between the conflict and displacement and how masculinity is expressed, Oosterom (2011) writes that during the protracted conflict:

Unable to meet societal expectations, men became frustrated, which was described by some as prompting feelings of humiliation. This caused various social and psychological problems, such as alcoholism, suicide attempts, and engaging in violence in fights or domestic violence and also caused some men to join the armed forces. It could also lead to the perpetration of psychological violence, through the suppression of the less powerful, such as women and youth. This has affected women's position in Acholi society [. . .]. (p. 400)

Shifting gender roles affected work and power in intimate relationships in ways that made life more difficult for women. Oosterom (2011) found that in the camps, women's responsibilities

increased as they undertook work previously done by men. These changes, she argues, have become entrenched in the post-conflict period (p. 404). Omona and Aduo (2013) similarly found that “with the semi-urban lifestyles that evolved in camps and the impact of globalisation, there are changes to gender roles, with women taking on more responsibilities that used to be exclusively male dominated and the tensions that may arise from this” (p. 132). Further, “the rate of domestic violence increased seriously during the insurgency, and many women still face violence to their bodies on a daily basis. One woman stated succinctly: ‘As long as there is no peace in our homes, the war is not over’” (Oosterom, 2011, p. 404). Such concerns contribute to the everyday social context within which women coordinate their maternity care and birth. Approaches to health care must consider gender relations within the historical and intergenerational effects of conflict that shape the negative dynamics referred to here. Just as a husband’s support is crucial for women during pregnancy and around birth, the consequences of an unsupportive, difficult, or violent marriage can be amplified during this time. Finally, while men’s reluctance can be understood in terms of how gender relations played out within marriages, it is also shaped by forces that included the lack of resources and infrastructure to ensure overall health and wellbeing, as well as health centre practices, politics and priorities.

#### Women’s experiences of male reluctance

While some participants’ husbands were willing to attend an ANC appointment and test for HIV, other husbands’ reluctance to test became a problem for participants. Responsibilization strategies had the effect of making these women responsible both for their husbands’ participation or failure to participate. In this section, I will identify how women accounted for male reluctance to test and to attend ANC, describe how this reluctance manifested itself, and present participants’ reflections on the value of HIV testing for couples as part of ANC.

Women who encountered resistance from their male partners attributed this to the view that pregnancy was a woman's concern, as well as fear over HIV status. In a focus group discussion, Anne situated male reluctance to attend ANC within male apathy towards women's lives during pregnancy:

When you tell some men to go together with you to the hospital, he doesn't accept. You can force him, but he will still refuse. Then you get your own way of going alone to get a card. [. . .]. If you don't go for a check-up yourself he doesn't care. He just sits. Women just struggle for themselves alone.

Health workers as well as childbearing women mentioned a common male disinterest in pregnancy or desire to distance oneself from discussion of pregnancy.

A participant in Rec Kicere, Sara, said her husband had agreed to attend ANC during her second and most recent pregnancy, but in her first pregnancy, he had refused. She recalled his position that “nothing takes me to the hospital”. She focused on attitudes towards HIV, recounting that he had made the case that since he was not sick, there was no point in testing. She believed, however, that he in fact feared he *did* have the virus and that “he would rather not know”. Other women said their husbands feared the lifestyle changes that would accompany a positive status, including the difficulty of “wooing” other women.

Both childbearing women and health worker participants speculated that in addition to fear of the virus and wanting to distance themselves from “women's matters”, men had sometimes already independently tested positive and did not want to disclose this information. For example, Faith, a focus group participant in Pagak said, “There are men when they already know their status as positive, they will not want to be supported by hospital, some may start to go [for ANC and HIV testing], but nearing the hospital they disappear”.

Pretending to attend ANC and alcohol use were other forms of avoidance. Penny described drinking alcohol as similar to a contract, in that it was difficult to break: “Alcohol is a

difficult issue to handle, because even if you stop a man he will not listen. Alcohol is just like a contract that people have signed.” In the focus group held in Pagak, women shared that it was very difficult to get their male partners to attend ANC for an HIV test. They recounted instances in which men had pretended they would accompany their wives, by going with them to the trading centre or health centre and then had disappeared (either before the blood was drawn or before results were shared). For example, Leah said:

It happened to my neighbor, who has just delivered. They went to be tested and the man disappeared when it came to results, so I actually don't know how she delivered or whether he asked [health centre staff] for forgiveness and received [his HIV test] results.

At other times, husbands avoided the issue by drinking for days and not returning home. Still other women had to resort to getting a letter of exemption (a process I describe later) from their local leader, the LC I, when their husbands refused to attend.

Despite such difficulties, some women also viewed couples' testing in positive terms. For example, Mildred, a thirty-year-old mother of five, thought that having an HIV negative outcome as a couple could reinforce prevention strategies for the remainder of the pregnancy: “It helps because . . . if you find that you are still fine then the two of you should stay well in the house”.

Asked to elaborate on “staying well” she stated that:

Keeping oneself well is, when you have both tested and found that you are both healthy, as a woman you should not get many men. The man should not also get many women. You should stay the way you have tested because there isn't anything bad in your body, so you should keep those children you are producing.

Mildred also believed that the negative test was a sign that her husband had been faithful to her and her co-wife:<sup>26</sup> “At the time we began staying with my co [-wife], we went and tested and found that up to now, he has not yet added anybody on to the two of us.” Learning their negative status reassured her about the wellbeing of herself and her unborn baby and the faithfulness

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<sup>26</sup> Polygynous marriages are commonplace in this area, (Westerhaus, 2007; Patel, 2012) including among the study participants.

within her polygamous marriage. For others, too, lack of certainty over their partner's faithfulness made HIV testing valuable. Kelly explained that the testing eased her mind: "When I was pregnant and it had just begun, I thought that I was HIV positive, a disease that people fear so much." She volunteered that, "We had tested and had found out that we were not HIV positive, but only fear existed because my husband is not very morally upright." The link between men's infidelity and the likelihood of contracting HIV made testing a situation in which marriages were under scrutiny in a way that was not always comfortable, particularly for the unfaithful partner. This contributed to male reluctance to test.

The potential for blame or violence was part of the context through which participants assessed couples' testing. Some participants saw couples' testing as ameliorating negative impacts of disclosure, including the potential for blame and violence. For example, Leah shared that: "It is good, because if you went alone he would change to say he was healthy so you are the one who brought the sickness". Worry over violence and blame shaped what was needed from testing, as exemplified by this concern raised by Annette, a focus group participant in Pagak:

Another benefit of going to hospital with the man is that when you find you are positive you can be counseled together, and it is helpful, because if the woman finds she is positive it becomes difficult to tell the man and that is why we hardly tell them. That is why the medics tell us to go together – so that after we may get support and live positively. You may come back and tell him your status and he cuts you with a machete [panga] and you die. So it is better to know together – he could have actually even have brought the sickness.

This hypothetical example demonstrates how fear of violent reprisal for a positive HIV status made testing and disclosure a risky issue for pregnant women.

Violence can also shape women's ability to recruit their husbands to attend care, as Larsson et al. (2012) discuss:

Women felt obliged to accept the request to try and persuade their partners to come for HIV testing. However, the majority described it as a complicated mission and a major

dilemma to try to recruit their spouses while having very limited power to influence their partner's actions. (p. 4)

These authors found that for participants in eastern Uganda: “Being asked to recruit male partners for HIV testing was associated with anxiety due to perceived risk of intimate partner violence among [their] respondents. These findings are supported by studies in similar settings in Botswana, Kenya and Tanzania (Taegtmeyer et al. 2006; Weiser et al. 2006; Msuya et al. 2008)” (Larsson et al., 2011, p. 6). While voluntary couples’ testing can avoid the blame and violence these women describe, compulsory couples’ testing initiated by the women’s health care providers reinforced gendered power relations. In Amuru, women were held responsible for persuading men to test and were then required to live through the consequences associated with positive status and disclosure, or of male refusal to attend.

### **Other Intersectional Axes of Power**

The power relations contributing to the impacts of couples’ testing during ANC extend beyond gender. Health centres and health centre staff held considerable power in comparison to their clients. Health centres were spaces of authority, with brick and mortar buildings, in contrast to the hand-built, grass-roofed huts where rural people lived; health workers typically wore uniforms, distinguishing them from other women and men.<sup>27</sup> Those who did not wear a uniform wore a suit under their lab coat, again a marker of status. There was a class dimension to this power dynamic, since health workers were salaried and educated, in contrast to the financial hardship and illiteracy or poor education of the majority of rural clients. People looked to health workers as their sole or primary source of health knowledge and information, and saw them as having the power to deny, as well as provide, health care. These intersectional dynamics of

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<sup>27</sup> The DHO, Peter, identified such features of the health centre and staff as one reason why TBAs might be preferred, based on their more comfortable and equal relationship with women in their villages.

power limited the extent to which pregnant women could, or were likely to, enact agency. For example, it would be difficult for a woman to assert that she wanted to continue ANC regardless of a husband's participation, or to state that she had no partner and was unwilling to provide a letter to that effect in order to receive care. Such power dynamics, alongside particular policies and practices, act to limit women's agency or shape the coercive – and risky – context for HIV testing, prevention and disclosure.

### **Health Worker Perspectives on Couples' HIV Testing During ANC**

Health workers attributed men's reluctance to some of the same factors as the mothers participating in the study's first stage, including men's tendency to see pregnancy as a "woman's problem" and their fear of a positive test. However, health workers also identified the health centre environment, gender norms, and logistical factors as contributing to men's low participation. To counter male reluctance, health workers employed various methods, including incentives for men to attend, barriers to women whose husbands refused to attend, and punishments for men who refused to attend. Health workers' accounts of male partner reluctance and their strategies in attempting to counter this reluctance to test are examined here.

Dorothy, a nurse aide, said that the difficulty of transportation and male perceptions that pregnancy was solely a woman's concern contributed to the challenges women had in persuading male partners to attend. This was demonstrated in the following exchange:

Say, you tell them [husbands] about antenatal care, some of them may refuse. So some say there's no transport, others they say it's not their problem. (Sarah): It's not their problem. (Dorothy): Yeah, because they are not the one who is pregnant.

Other factors, such as the lack of transportation, intensified the negative effects of the gendered norms around viewing pregnancy and women's health as outside of men's domain. When I asked Amy, a nursing assistant, about men who refuse to attend, she shared two possibilities:

men's knowledge of a positive status that they did not want to disclose, or men's belief that their wife's test would suffice for both partners. She said:

Maybe that husband, you know with men, they are so perseverant, unh? Maybe he had known before that woman is coming to the hospital [health centre] for medical check up, maybe he had known already that he was already positive (Sarah): mm (Amy): and he will not allow, or not involve himself to the hospital just simply because, they will feel ashamed, now, they are going to pinpoint me that 'have you seen that man, that man is already positive'.

Amy further stated that:

“those men eh, they feel, and they always tell their wife, that when ever they check you, that maybe they want to do what, to remove your blood to see if you are HIV negative or positive, it means that 'If you are positive, it means I am positive. And if you are negative, I am negative. Because we are one.' They always tell it like that, you see?”.

She evaluated men's avoidance strategies in her statement: “If I am to tell it they are so negligent, eh, they are negligent. (Sarah): Yes. (Amy): They want to neglect their what? Their wives.”

While she understood that men felt shame or might perceive one test among the couple to be enough, the nurse participant also regarded men who refused to attend in negative terms. In my analysis, assessing male attitudes in terms of negligence or neglect may have detracted from efforts to address men's fears and misconceptions about HIV and testing, particularly in the context where men were being reached indirectly via their wives.

The health centre environment as a factor in male reluctance to attend

Logistical and social factors intersected to create the conditions for male resistance to HIV testing. Logistical factors included lack of privacy at the health centre and the pressures of childcare and farm work at home, which made it difficult for both partners to be away simultaneously.

For example, the DHO, Peter, saw the health centre environment during antenatal visits as reinforcing men's negative perceptions of participation:

. . . the environment in the health centre is not attractive for men. You are going into one room which is full of women only, a man sitting there would definitely feel out of place, is one. Then from the cultural point of view, a man who is seen moving with the wife, moving in the antenatal, and accompanying the wife everywhere, there is belief in the culture that this man has been overpowered by the woman.

Gendered norms of behavior were influential in governing men's view that their role in pregnancy should be limited, Peter argued. This was exacerbated by the unsuitability of the health centre environment, which was conducive to women receiving ANC but not necessarily comfortable for men:

. . . it's a small place, a small area, and the mothers are supposed to . . . expose themselves for examination. Definitely it will not be convenient to have a man in such an environment (Sarah): Right (Peter): If we had better facilities, more space, it was more private, maybe more would be able to attend.

While Peter perceived gender relations and expectations to be influential, he also considered inadequate facilities to be another factor in men's reluctance to attend ANC and test for HIV.

Childbearing women participants also raised this concern over how the health centre facilities impacted male reluctance to attend ANC and be tested. Betty, a focus group participant in Pagak, suggested there needed to be changes to the waiting area; men and women should be instructed to stay together, and a toilet and drinking water should be attached to the waiting area. This recommendation was intended to solve a problem with men running away during testing. With these changes, she felt, men could not pretend to step out for a drink or to use the bathroom.

Other challenges to male ANC attendance (and couples' testing) related to the context of poverty, poor infrastructure, and subsistence-level agriculture. The DHO, Peter, shared that:

. . . there are the economic and social issues. Then instead of transporting the mother alone, you may need two people. The cost involved, the issue of distance. Then you see if they are very far away, the mother can go some days before the antenatal care say from deep in the village she can stay with a relative around the health center. They see you in the clinic you can stay there and go back (Sarah): Okay (Peter): But then you cannot bring a whole couple. At least one person has to stay back to look after the children, the property, and things like that.

Since most families had several children (with an average of 6.8 children born to each rural woman and a national average of 6.7 [Uganda Bureau of Statistics, 2011]) and farmed for a living, these concerns about managing at home were considerable. These responsibilities affected the extent to which couples could attend ANC together.

### **Health Worker Strategies for Couples' Testing in the Face of Male Reluctance**

Strategies to promote male attendance at the first ANC appointment and HIV testing included health education, requiring women to bring a LC I letter stating that their husband was dead or unable to participate, and positive reinforcement for husbands who did participate. The LC I letter functioned as a text in that it coordinated pregnant women's and their partners' activities with the goals of the health centre, and, beyond that, national and international goals on HIV prevention. Local strategies were reportedly effective in increasing male participation in HIV testing during ANC, yet had negative consequences for some women's lives.

The LC I letter was a particular hurdle for women whose partners refused to attend ANC. In collaboration with the LC, health workers at health centres employed the strategy of insisting that women whose husbands would not participate or were absent get a letter from the LC I. This was difficult for women, as they would have to go the LC to make a case. Therefore, the requirement constituted additional work in arranging her ANC care and had the potential to delay or act as a barrier to care. Further, LC I letters did not typically state that the husband had refused to attend; instead, the letters either were expected to, or tended to, make the assertion that the husband was dead or in prison. The assumption was that there was in fact an involved male partner who acknowledged paternity and was in a marriage-like partnership with the mother. However, of course, this was not always the case. The protocol of the LC I letter stigmatized single women. Acero, the study's RA, told me she believed women would prefer not to share

their single status, saying “you don’t pierce your own eye” (which I interpreted as similar to the idea of not airing one’s dirty laundry). Creating additional negative consequences for single mothers such as the LC I letter exacerbates the stigma and exceptionalism directed at them. The way “husbands” were brought into antenatal care reaffirms Christian, patriarchal family norms by reiterating a two-parent heterosexual family as normative. It further marginalized women who are alone due to unwanted pregnancies, family breakdown, or an absent partner. One LC I told me he would not write a letter for a woman with a reluctant husband. Instead, he would request to speak with the husband directly and explain that the child is for the husband as well as the wife, therefore healthy pregnancy should be important to both partners. Requiring the involvement of local leaders in the case of men who were reluctant to attend ANC and test for HIV at once policed women whose families did not fit a certain norm or whose husbands refused to comply, and reinforced the sense that this participation was compulsory rather than voluntary.

Gloria, the midwife quoted earlier, described how an LC I letter was an additional step to take, if necessary, after educating communities to understand that men should attend the first ANC appointment:

So pertaining to the men, in order to come with their women to antenatal care, that one first of all we just health-educate them generally, about the goodness of attending antenatal with their partners together. [. . .] secondly, if a mother comes without the partner, we, at least me, we inquire her to get the letters from the LC [. . .] On that she will find is very difficult, and then she will go back to the husband and say 'let's go to the hospital' and then they will come.

She and Grace, the other midwife, saw the approach of requiring an LC I letter as effective, as demonstrated by the following exchange:

It’s hard to make them come, but we still tell them you have to come. If you cannot come, bring for us the letter from the LC. If today I go to the LC, my husband refuse, tomorrow, do you think again I will go? It’s hard. So by that, few would go. (Sarah): Okay. (Gloria): Very few, those ones who don't have really the husband around which at least go. So that is the only way we could make them at least try their best. So there are some few who

come without. (Grace): Most of them come with their partners. (Gloria): Currently very few come without. Of ten people, only two or one.

In identifying the difficulty of getting an LC I letter, Grace made it clear that the requirement was a way of exerting additional pressure on women to facilitate male involvement. As well as reinforcing the impression that couples' testing was mandatory, the LC I letter acted as a deliberate hurdle to women whose husbands wanted to opt out.

An additional strategy used by one village leader (LC I) was to require any man who refused to attend with his wife to do community service, usually slashing the tall grass surrounding a village compound or path. This LC I told me that at a group meeting of leaders there had been discussion of implementing this strategy throughout the sub-county. This type of punishment was also extended to people who refused to have their homes sprayed with insecticide, a Ministry of Health initiative to prevent malaria. As this example demonstrates, coercive means to promote changes in health-related behavior was a strategy that was not unique to maternity care. However, such strategies impacted pregnant women in particular ways due to local politics, gendered relations, and women's dependence on health care workers for care.

As the LC I letter and the requirement to perform community service demonstrate, the institutional context coordinating maternity health care and birth extends beyond health institutions such as health centres and hospitals. In this regard, the IE process of looking "up and out" – that is, drawing on a broad definition of institutions and examining the interconnections between the immediate interpersonal experience and the broader socio-political and structural context – was fruitful in understanding the discursive production of care.

The nursing assistant, Amy, explained some of the tactics that she used to increase attendance on the part of men. She felt that presenting an LC I letter was not sufficient, since

while the letter would state the husband was dead or in prison, it was more typically the case that he was simply refusing to attend. She said:

And when they say the husband has died, we are going to prove. (Sarah): Okay? (Amy): We prove it in this way: that when did your husband die? They may tell you that “oh my husband, my husband died last year in November.’ For example Now we are in August, eh? We prove it like that, that where did you get this pregnancy. [. . .] And then, if we take it short like that, short-cut, eh they start to tell us the truth. That, “Unh-unh, no nurse, my husband refused to come to the hospital”. (Sarah): Okay. (Amy): They tell you the fact. And that is how we even grab them so they come in. (Sarah): And then you get the husbands. (Amy): We say when you go back home, tell your husband for the next time you come. Some will come, some will still deny. They will tell you that ‘unh-unh, nurse, the husband refuses totally’.

Amy used the LC I letter as an opportunity to get the “truth” about a husband’s whereabouts. However, as her example demonstrates, women experienced facilitating their husbands’ participation similarly to Larsson et al. (2012) participants, as a “complicated mission and a major dilemma” (p. 4).

Amy also discussed incentives as a means of encouraging male antenatal participation. She said that the mama kits were a form of encouragement for men as well as women: “Now that thing [the mama kit] has encouraged those husbands and the wives, to encourage themselves to come to hospital [the health centre]”. Further, she described an example in which the soap from the kits had been provided to men who attended ANC:

I remember one day it was it was antenatal day and those women were coming eh, and many men even accompanied their wives, there were like 20, 25 [. . .]. Afterwards, in-charge [the clinical officer in-charge, Jonas] told us that now, those bars of soap which have been left their in store, the ones for Red Cross, now you give them each and every man you give one bars of soap, one bar of soap. [. . .]And then we saw that one [male attendance of ANC] has been improving really, so seriously. [. . .] And within that week many men were accompanying their what?, their wives to come to the hospital. And that is one side, we always motivate them. When you find something that is providable to them, you always give to them so that they encourage them to visit health centre regularly.

This strategy, while seen by health workers as an effective form of motivation, contributed to the scarcity of Red Cross project supplies since there was a limited amount of soap.

Giving soap or other ‘providables’ to men who attend ANC for couples’ testing and to learn about pregnancy complemented the practice of punishing men who refused to attend. Both were measures to manipulate men into participating in ANC and testing. However, neither practice directly addressed the social and logistical barriers to male participation. These reasons, including gender relations, the difficulty of both adults simultaneously leaving the work of home, and logistical factors at the health centre, were key.

While the LC I letter was coercive, health workers saw such strategies as effective and positive because of a visible increase in the numbers of men participating in couples’ testing, which indicated that a goal was being met. However, in their focus on the numbers of participants, health workers may have overlooked the work and difficulties that happened behind the scenes in the lives of their patients. This involved work for women whose husbands were initially reluctant, as it fell to the women to come up with strategies for persuading the men. For other women, it was the work of obtaining an LC I letter. Beyond the time, effort, and strategizing of work, women risked facing other serious repercussions. These included male drunkenness and violence, evidenced by the participant who mentioned the possibility of being attacked with a machete by a husband.

The difference between valuing the numbers of people tested for HIV and valuing women’s rights and access to health care more broadly was also identified by Angotti et al. (2011):

If increasing the proportion of those tested in the short term were the only goal of routine HIV testing, then its merit is uncontested by our study. But if the introduction of routine testing aims simultaneously to protect the individual rights of pregnant women, then routine testing—in rural Malawi, at least—seems to be imperfect at best and counterproductive at worst. Our analysis shows intended beneficiaries of routine testing perceive HIV testing as compulsory to receive antenatal care. For some, this means they forfeit all access to care, either because providers fail to give them another option or because their partners object to testing. Our study thus suggests that greater attention be given to how health policy is implemented in practice, in the setting in which health

professionals and their clients interact. The social relations in which HIV testing occurs in rural Malawi may not represent the idealized notions assumed by global or national policies. (p. 314)

Similarly in Amuru, when the broader picture of rights, social relations, and access to care is considered, the current policy and practice approach to HIV testing during ANC falls short. Understanding these shortcomings contributes to working towards equitable access to care.

### ***“Without a Man We are Not Going to Give you a Card”*: Male Refusal as a Barrier to Care for Women**

Compulsory approaches to HIV couples’ testing during ANC discouraged or impeded care for some pregnant or birthing women. There were differences between the reports of mothers and health workers as to whether a woman would or could continue to attend ANC if her husband refused to attend and be tested. Being refused care was something women worried and talked about, and planned their approach to maternity care and childbirth around. Health workers used this fear as a strategy to increase male partner participation. Women might opt out of ANC and health centre delivery if they believed they were going to be turned away.

Jonas spoke about the lack of male participation as a barrier to women attending a full complement of ANC:

Men still do not focus much on the health of women during pregnancy [. . .] When these women get pregnant we want them to come for antenatal with their husbands but some husbands they do not turn up during the antenatal so you find that the woman will fear to come also alone and attend the antenatal clinic and this makes most women to come very late for antenatal care. As a result, you find that some attend only once or twice during the pregnancy, which is actually not what is expected.

Jonas was observing that when men did not want to participate in ANC, women’s participation was detrimentally affected. Within focused or goal-oriented ANC, the number of visits is already small in comparison to risk-based approaches or to ANC provision in the global North, as

described in Chapter Four. Missing visits meant that opportunities to identify or treat complications or otherwise meet women's needs were lost, putting maternal-child health at risk.

If it was difficult for women to attend ANC because of male partner reluctance, those who wanted a facility-based delivery had to persevere, since ANC was seen as a gateway to delivery care. Although health centre staff maintained that women without an ANC card would not be turned away at the time of labour, an ANC card was nevertheless perceived by childbearing women and described by health staff as necessary if one expected to receive delivery care at a health centre. The ANC card was an important text coordinating care. One of the two midwives quoted earlier, Gloria, was aware that women who wanted to give birth at the health centre were unlikely to opt out of ANC and would do their best to comply. I asked her: "Do you think women ever avoid antenatal care because of this policy, or not?" She replied, telling me:

They can't avoid, because they know that when they come in labour, or in case of any problem, they need antenatal care, they have to have the card. All of them in the village know that without antenatal care it is not easy to go for delivery when they are in labour.

Gloria's conception of the role of the ANC card echoed that of the women, cited in Chapter Six, who saw the card as a ticket to giving birth in the health centre. This strategy was coercive; care at the time of birth should not be an entitlement women have to earn. Further, rather than emphasizing ANC care, couples' HIV testing, and delivery care as interlocking aspects of health care for pregnant women, this strategy made each stage of care contingent on the prior stage. For woman experiencing a barrier to couples' testing, this barrier was reproduced at later ANC appointments and at the time of delivery.

Participants saw male involvement in ANC as facilitating their future care. A focus group participant, Betty, said that without men's cooperation, women might miss essential care:

Another benefit of going to hospital with the man is that once you are tested, you, the woman, is given some medicine that is said to help even the baby. So the pain is, when

the man runs away and you miss it. Like the vitamins, because they give like three types of drugs which you swallow and it is not good to miss all when the men run away.<sup>28</sup>

Her comment was based on the perception that partner testing was mandatory and that without it, care, such as the medicine she mentioned, might be denied. When HIV testing, ANC, and health centre delivery were seen as compulsory, childbearing women believed each step to be contingent on their compliance with previous stages. These findings echo those of Larsson et al.'s (2012) study: "Further, if testing is perceived as compulsory it could potentially deter some women from seeking ANC services" (p.6). As the participant quoted above observed, missing other elements of ANC has negative consequences for the health of women and their babies.

While ANC care needs to be accessible to women, a barrier existed for women when males refused to participate, as the midwife, Gloria, pointed out. I asked her when the health centre had started to implement couples' testing during ANC. She told me, "It was since before, but no-one really put a male focus on it. Until when we said '*without a man we are not going to give you a card*'. They will try now" (my italics). Making the male partner a gateway to ANC exacerbates gendered power imbalances in relationships as well as barriers in accessing ANC – both constitute the structural context shaping women's experiences of and access to maternity care. Dorothy, a nurse aide, also shared that "If the husband has refused to accompany the mother, we do take the blood of the mother, but ask them for the second time when they come, they need to come up with the husband." However, Amelia, a participant, said: "When you have reached [the health centre] for ANC without your husband, the health worker doesn't test you [for HIV]." Women, she said, were made to wait until they could be present with a husband who was also willing to be tested. Betty said, "They give cards but without results, each time you went they would remind you to go together to receive your results. They actually scare you that

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<sup>28</sup> The three drugs she is referring to might include folic acid, iron, and a malaria prophylaxis.

you won't deliver at hospital if you didn't come for results". These approaches used women to recruit men, with the threat that without male participation access to care would be denied. Instilling such fears was a coercive measure that affects access to care and the relationships between childbearing women and their care providers.

Access to ANC was already challenging for women. As I have described, access was curtailed by poverty, transportation, lack of resources, and other issues discussed in Chapter Four. The importance of PMTCT notwithstanding, encouraging male participation in ANC and HIV testing should not come at the expense of birthing women's participation in ANC and facility-based delivery.

Penny, a twenty-nine-year-old mother who had lost her firstborn and had five living children, explained that she could not persuade her husband to attend ANC or to test for HIV, so she continued care without him. After her first visit, she said:

They told me to go with my husband for the next visit. When I told him to come with me for the next visit he refused. So when I went back alone they didn't disturb me until I completed my ANC. They tested and it was negative, and though they also wanted my husband's results, he did not ever reach there until my due date reached and I delivered without him testing.

Penny indirectly attributed her husband's absence from ANC to infidelity and to alcohol use. Asked why he didn't want to go she said, "Men sometimes don't like to be tested. I think because of the alcohol they take. Sometimes they mess around." Her difficult husband did not become a barrier to her receiving ANC care, although Penny went on to give birth unattended at the health centre. However, the wider context was that women depended on their male partners' compliance to receive care.

Lee, a participant in the Pagak focus group, said a neighbour had been refused care ("chased") at the time of delivery because of this problem. She did not receive an ANC card because her husband refused to participate; as a result, apparently: "they chased her; she

delivered from the trading centre”. The knowledge of such incidents reinforced the sense of obligation among women to ensure that their partners complied with HIV testing during ANC. While no participants discussed being refused care at delivery based on a partner’s refusal to attend ANC for HIV testing, the threat of being refused care was present in their stories about organizing care.

## **Conclusion**

The approaches to HIV surveillance, and specifically access to ANC and male partners’ perceived social roles in their partner’s pregnancy, acted as a structural context within which maternity care and birth are socially organized. The findings indicate how voluntary, provider-initiated couples’ testing, when presented and perceived as mandatory, had negative impacts on women who were pregnant, notwithstanding its positive contribution to PMTCT. Coupled with male reluctance which was shaped by gender norms, patriarchal power relations, and logistical factors, the compulsory approach to testing could result in additional work for women, as well as the potential for blame, violence, and curtailed access to care, all of which could adversely influence pregnancy and birth outcomes. While women were exhorted to seek formal care provision during pregnancy, the ways in which care was offered could present disincentives and barriers to their participation. MacKian (2007) writes: “Although the current policy climate aims to encourage women to utilise formal health provision, they are often the least able to negotiate access effectively” (p. 112). However, she suggests that a supportive community level environment may be key to negotiating care. These gendered and intersectional dimensions of HIV testing have the potential to inform better policy options for women. Both the failures of coercion and the perceived need for such an approach point to the necessity for a more direct

approach in targeting men rather than through their pregnant partners, and more broadly, in facilitating optimal approaches to HIV prevention within the context of pregnancy.

## Chapter Six: NGO Programming and the Translocal Coordination of Maternity Care and Birth –

### The Mama Kits

#### Introduction

In this chapter, I examine differing accounts of the purpose of the “mama kits,” (described below), with attention to knowledge about which mothers received them and how registration was undertaken. These small kits played a large role in linking local and extra-local concerns and practices in relation to maternity care. I describe the work that pregnant women, village health team members, and formal health staff conducted in relation to the kits’ registration and distribution. The competing needs of NGOs, the health centre, and birthing women differentially shaped women’s access to resources and care. Ideologies of scarcity, responsibility, and deservedness characterized the relationship between the mama kits and maternity care.

The mama kits were a bag of basic baby supplies given to women after they give birth. The kits contained: a bar of soap, a washing basin, towels, jelly (baby cream), and sheets, towels, or cloths (for tying the baby to the mother’s back, for warmth, for drying, and to absorb blood), and tetracycline eye ointment (to prevent or treat neonatal eye infections).<sup>29</sup> They were supplied as a project of the Japanese Red Cross and the Uganda Red Cross. The current study findings highlight how the mama kits functioned as a “complex of extra-local relations” (Smith, 1990, p. 6) involving many disparate actors in maternity care and birth, including individual childbearing women; village health team (VHT) members; staff at the health centre (itself run by an international NGO); government health administrators; and international and national NGOs.

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<sup>29</sup> Some participants mentioned the distribution of mosquito nets during antenatal care or at the time of delivery; this was a separate program and was mentioned infrequently. In order to focus on the mama kits and their greater impact on childbirth and maternity care I do not discuss net distribution here. However, it is worth noting that the mama kit was one in a series of interventions that were funded by external NGOs but delivered via health centres.

Significantly, traditional birth attendants (TBAs) were not involved in the registration for, or distribution of, the mama kits. Indeed, for childbearing women participants, TBAs' lack of access to this resource distinguished their care at delivery from that offered by skilled birth attendants at health centres. The discursive and material impact of the mama kits warrants attention in this investigation of how maternity care is organized, controlled and negotiated in Amuru.

Institutional ethnography (IE) focuses on identifying how contemporary ruling relations are constituted through “the complex of extra-local relations that provide in contemporary societies a specialization of organization, control, and initiative” (Smith, 1990, p. 6). These forms of organization and control are “bureaucracy, administration, management, professional organization, and the media” (Smith, 1990, p. 6). Smith describes this form of social organization as “objectified” in that it is external to and “independent of particular individuals and particularized relations” (2005, p. 14). While a rural sub-Saharan setting such as Amuru means fewer encounters with bureaucracy, mass media, or other forms of translocal organization than in the global North, such forms are nevertheless present and influential. This was evident in forms of bureaucracy exemplified by the mama kit registration card and the ANC card, as well as in forms of professional organization within and between the VHT, health centres, and NGOs. As I examine the role of the mama kits project in the coordination of maternity care and childbirth, I pay particular attention to such forms of organization and control.

## **A Reward for Care or a Gift to the Vulnerable? Childbearing Women's Divergent**

### **Accounts of the Mama Kit's Role**

A recurring theme across interviews with childbearing women was that the mama kits were important and valued. They functioned as a form of access to items necessary for post-

partum recovery and newborn care, and thus had an influential role in the context of the poverty and limited access to resources experienced by the majority of childbearing women. In contrast to the agreement regarding the utility and importance of the mama kits, responses regarding receiving the kits, registration issues, and the purpose of the mama kits project varied strikingly. Participants said that the mama kits were distributed as an incentive or reward for attending a full program of ANC (described as three or four visits); as an incentive or thank you for delivering at a health facility; or as support for new mothers generally or for particular groups of mothers. I examine the texts and talk of participants' accounts regarding the kits' purpose and the work involved in registering for and receiving them from a critical and discursive perspective. In particular, I describe how, because they were often perceived to be a reward or incentive for attending ANC or delivering in a health centre, these resources shaped the ways in which maternity care was sought and accessed.

#### The mama kit as creating and rewarding compliance with ANC

Among childbearing women participants, attending ANC – and having the ANC card to demonstrate that they had done so – was seen as a 'key' to health centre delivery. Without this key, one might be turned away or 'chased,' as participants described it. By seeing receiving the mama kit as dependent on attending ANC, women emphasized the importance of health workers' message to attend ANC. Betty, a focus group participant in Pagak who had not received a kit and who mentioned problems with registration, saw the use of the mama kit to be both coercive and helpful: "It is true that when you don't go for ANC three times, they don't give you [the mama kit]. They are right, because we women need orders". Attaching provision of the mama kit to women's participation in ANC was a way of exerting power over women's ANC attendance. Betty's acceptance of the mama kits as a way of giving orders confirmed the mama kits'

influence on the role of the kits in women's self-regulation of ANC participation. Provision of the kits as a reward for compliance with care reinforced power differences between care providers and birthing women.

A first time mother living near the health centre, Rose, explained that health centre staff had told her she received the mama kit because she attended ANC:

They said we followed measurements [ANC] very well. Some people don't follow measurements in the hospital [health centre] well, they don't finish, but for us we finished ours, and we saw our health [tested for HIV and learned status]<sup>30</sup>.

As Rose emphasized, compliance was rewarded with mama kits as well as with praise from care providers. The mama kits were a mechanism signaling that there were positive and negative modes of citizenship with regard to health during pregnancy. Being a good citizen through seeking health care relates to the responsabilization discourses discussed in Chapter Four.<sup>31</sup> Rose emphasized that HIV testing (examined in detail in Chapter Five) was an important reason why ANC was encouraged by health workers and other public health means.

Elizabeth, another participant living near the health centre, stated that ANC was promoted for women regardless of where they would eventually give birth. She had received a mama kit after giving birth. Her newborn had struggled to breathe at the time of birth and she believed he would not have survived without the assistance received at the health centre. She said:

You should have gone for ANC four times in order for you to get those things [the mama kit]. When you have not yet delivered, even those who are not going to give birth from the hospital, it is good if you follow what they have told you to do and finish the ANC very well.

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<sup>30</sup> Acero, the RA, explained that attending ANC was referred to as *pime*, which means measurement, but was also used to refer to a check up. During ANC, fundal height was measured to monitor the fetus' development and estimate due dates. Further, participants typically referred to both a health centre and a hospital in the same way, as an "ot yat," but it was very clear when they were talking about the hospital, since going to a full-service hospital such as Lacor Hospital in Gulu was somewhat exceptional, and required leaving the district at considerable expense.

<sup>31</sup> For a discussion of health, citizenship, and responsabilization see Rose (2007) or Petersen and Bunton (1997).

Here, Elizabeth identifies the mama kits project as reinforcing the importance of attending ANC, regardless of where a mother plans to deliver.

#### The mama kits as an incentive or reward for health centre delivery

Another view was that the purpose of the mama kits was as an incentive or reward for giving birth in a health facility. It is important to note that, due partly to the nature of labour as a process whose timing cannot be planned and which impedes mobility, delivery care was less accessible than ANC. One could walk, bike, or be ‘doubled’ by bicycle to ANC appointments; there was also some (albeit limited) flexibility in when to attend.<sup>32</sup> For labour, a boda-boda (motorcycle taxi) was necessary and added to the expense and logistics of transportation. It was also necessary to bring an attendant<sup>33</sup>, usually a co-wife, sister-in-law, or mother-in-law<sup>34</sup>, increasing the cost of transportation. Since cost depended on distance, those in the most remote households faced the highest costs in getting to a health facility for delivery. Birthing at home assisted by a TBA or a family member continued to be more common in remote places especially compared to in areas close to a fully operational health centre. This finding reflects access issues in the global South generally: “Poor geographic access has its greatest influence on the potential of women to reach a health facility during labour” (Munjanja, 2013, p. 146). As an example of this actuality, Florence described that she completed a full cycle of ANC, but she went on to say:

It’s the delivery that made me not to reach there [the health centre], I did not have money. Moving from here to Amuru needs money for transport [. . .] so it’s true that I gave birth from home.

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<sup>32</sup> Participants in remote villages explained that they attended ANC in person at the health centre, rather than waiting for outreach visits, because they needed to attend their follow-up (i.e., second or subsequent) appointments within a certain time frame of a date indicated, or be fined at the health centre.

<sup>33</sup> Since health centres do not offer food or laundry services, patients needed the assistance of a family member who would prepare food and wash clothes as well as support the patient. These family members were referred to as attendants.

<sup>34</sup> Marriage is generally patrilocal within Acholi communities (Baines & Rosenoff, 2014), hence the importance of in-laws.

She explained that her co-wives assisted at this difficult labour:

The person who helped me? There wasn't anybody, but I was with my co-wives, and they are the ones who helped me. I began pushing the baby at 10 am and delivered at about 1 pm to 2 pm. I was in a very bad condition, but the child came out.

Participants who lived in remote villages where logistics including transportation impeded access to health centre delivery often related such stories of unplanned home births. Due to the greater prevalence of home births in these remote villages, women were less likely to have received a mama kit.

In the focus group situated in Lujoro, four of the five participants had delivered at home. A fifth participant, Julia, gave birth on the way to the health centre. The Lujoro group included a first-time mother and a mother of twins (who had been advised to deliver in a hospital). The focus group situated in Pagak similarly included five women, one of whom also happened to be a first-time mother and another the mother to recently born twins. These five women, however, had all given birth in the nearby health centre (including one woman who was waiting for an ambulance to take her to Lacor Hospital for a C-section when her baby arrived). This stark contrast speaks to the influence of distance on access to care.

I asked Sophie, a 24-year-old with three children, whether mothers in her village (Oberabic) always received a mama kit. She confirmed: "When they have gone to the hospital [health centre], they get, but when you have given birth from home, you don't get." Indeed, I didn't meet any mothers who had received mama kits when delivering at home or on the way to the health centre.

Because of the long distances to a functioning health centre and transportation difficulties, women sometimes gave birth "on the way" to a health facility, also rendering them ineligible for the mama kits. For example, Ellen, who resided in Tedi gave birth as she was returning home from her last ANC appointment. She had been told to return if she was having pain. She spent

the night at a halfway point, because her home was a long walk from the health centre. In the morning, labour came abruptly and she gave birth with the assistance of a stranger. None of her children had been born at a health centre, and this was the first pregnancy in which she had received ANC and HIV testing. Julia from Lujoro also gave birth on the way. She went into labour and began to walk with her co-wives to the health centre. She had just reached the turn off to the paved road (at Otwee) when the baby was born. She returned home, later going to the health centre for the baby's check-up and immunization. Children born "on the way" are often named Oyo or Ayo (born on the way); names associated with the birth location, order, or position are common, demonstrating the importance to families of how and where birth takes place.

Jacky from Tedi was among the participants reporting that they did not receive a mama kit because they delivered elsewhere than a health centre. She said: "I did not get those gifts because when I delivered they should have taken me there [to the health centre], but because it was late they did not take me". Asked whether she was disappointed that she had not received the kit, she replied: "It did not disappoint me. I thought next time I would still get them". By 'next time' she clarified that she meant the next time she had a baby. Such an attitude depended on women's ability to purchase the equivalent supplies themselves. Among women who had very little money, the mama kits were an especially valuable resource on which to depend. Each kit offsets a cost of about \$5 (Mbonye et al., 2013, p. 5), a substantial amount of money.

Birthing at home meant women were denied a mama kit regardless of whether they had attended at ANC. Jane, an 18-year-old first-time mother who had an older co-wife, said that she had been unhappy to be pregnant and to (therefore) marry. She had been afraid of giving birth. She had struggled to walk between her home in Tedi and ANC visits (after the first visit to which her husband had doubled her by bike). The walk was so long that she had to spend the night at a relative's home after each ANC visit. She wanted to go to the health centre to deliver as well, but

the labour progressed very quickly, such that her husband was concerned that she would give birth on the way if they tried to reach the health centre. The baby was, in fact, born before the TBA they had called could arrive. Jane did not receive a mama kit when she took her baby to the health centre for a check-up following his birth. If the purpose of the kit was to reward compliance with ANC, as some posited, this woman “deserved” a kit. However, because she “failed” to deliver at a health centre, she was not eligible. In such situations, the mama kits held a punitive power over women who “chose” to give birth at home despite the health message that one should deliver at a health centre. However, for women like Jane or Jacky, birth location was determined by circumstances including remote location, financial hardship, or precipitous labour, rather than by preference with regard to birth location or birth attendant.

For Jane’s neighbor, Janet, the mama kits were part of what distinguished health centre delivery from home delivery. She had given birth to eleven children, all of whom were still living (remarkable in the context of high child mortality). Her first nine children had been born at home, and the two most recent at the health centre. I asked her about the difference between giving birth at home and at the hospital. She said:

Yes, there is some difference, as I saw with this child from the health centre. They gave some medicine for the eye, they gave soap, a bag, jelly, a basin, towels, and a pillow [case], which I saw as being different from the health centre as compared to the TBA. Also the delivery service at birth is different from the TBA, where they squeeze you for long to get the child out, while at the health center they use some modern ways, and if they find that there is a difficulty they would then check up to know what could be the problem.

While she was aware of clinical differences between the care provided at the health centre and that provided by TBAs, the difference that first occurred to her was the mama kit, which highlights its importance.

## The mama kits as support for 'vulnerable' women

Despite the commonly held belief that the purpose of the mama kits was to incentivize the uptake of formal health care, many women also understood the mama kits as a form of economic support or help. For example, when I asked Margaret, a mother of five with one co-wife, why the mama kits were distributed, she said:

The hospital [health centre] has thought of helping mothers, that they should be helped, because some might be having a lot of problems and might not be able to buy those things, so they should be helped. Even if you will buy yours, that of the hospital should also be there.

It made sense to Margaret that mothers were offered some material assistance when having a baby, perhaps due to the post-conflict induced poverty and experiences of humanitarian aid. Such an interpretation is supported by Hazel's suggestion, cited in Chapter Four, that nutritionally-enhanced foods distributed in the camps and during the return period should still be offered. Despite this view of the mama kits as providing material assistance for mothers, it was not the case that all mothers received mama kits.

Florence had heard that the mama kit was specifically for those with HIV:

To me they just told me right to my face that the [registration] card is for people who are HIV positive. That if you were positive then they would register you when you are pregnant but if you were healthy then you would not be registered. . . . She told me with her own mouth, that person registering.

As I later learned, understanding the mama kit as a form of assistance to mothers who were HIV positive accurately reflected one of the NGO's project goals. However, this was not a widespread understanding among childbearing women. Another resident of Lujoro, Rose said she had learned the mama kit was for child mothers, older mothers, or mothers with disabilities. Outside of Lujoro, in the other five villages where I spoke with childbearing women, participants

did not refer to the mama kits as a targeted program. Most participants viewed them as a gift for new mothers, rather than as targeting particular sub-groups.

Florence's response indicated her insight into the collusion of forces and discursive practices shaping maternity care and childbirth. She suggested that the most needed change was transportation between a nearby health centre where delivery care was unavailable to the functional health centre. In clarifying, she contrasted transportation with the mama kits:

Yes, [a vehicle] that comes and gets people to take us there. But not like cloths or what, because those things will not help us. That's the help they give when they've seen how different you are. But what connects us [i.e., transportation] should at least be there.

For her, facilitating access to care was more important than the material goods offered via the mama kits. She identified that the mama kits operated as a strategy of difference. NGOs were often associated with Westerners or non-community members: for this participant, the mama kits re-inscribed the differences, including wealth and poverty, between those supplying and those receiving NGO resources. While marking local women's poverty and lack of access to basic supplies, the mama kits had little capacity to address the causes of this poverty or to significantly change women's circumstances. In the absence of help that could facilitate access to care in a practical manner, she rejected the idea of 'cloths or what,' as offered in the mama kits. If the purpose of the kits as coordinated by registration and the registration cards was to assist vulnerable women, it is significant that the kits operated to reward women who gave birth in the health centre.

The mama kits as a gift or charity

Despite recognizing that the mama kits play a role as an incentive to access care, for childbearing women participants, the primary utility of the kits was for the material goods to help with the new baby. These were some of the same material goods for which women took on

additional jobs such as selling snacks or plowing a neighbor's field. Women sometimes referred to the mama kits as a gift<sup>35</sup>, calling to mind anthropological theories on gift exchange (Mauss, 1990), in which gifts are constructed as voluntarily and freely given yet also set up a social obligation for some form of reciprocity (Mawdsley, 2012). In this case, the obligation could be seen as the requirement to comply with care. However, another form of giving in this setting is charity or humanitarian aid, which can be construed as different from a gift in being offered altruistically, without the expectation of reciprocity (Zarowsky, Witeford & Manderson, 2000). Familiar with humanitarian aid delivered in the IDP camps on the basis of need and suffering, childbearing women continued to foreground their need for material goods when interpreting this new "gift," the goals of which appear to be developmental rather than humanitarian. This exemplifies a disjuncture between childbearing participants' understanding of the gift as useful and necessary, and the extra-local attempts to use the gift as a means to promote skilled attendance at birth and knowledge of ANC.

### **Registration and Distribution of Mama Kits**

The registration and distribution of the mama kits was a topic of concern for participants, as it was neither straightforward nor predictable. To receive the kit, women were required to have a registration card, distinct from the ANC card. Registration cards were white or yellow with a Red Cross logo and were given to expectant women by a VHT member. The pregnant woman's name was recorded in a registration book, so that health centre staff distributing the kits could cross-refer. The requirement to register occurred in addition to any other actual or perceived requirements for receiving the mama kits, such as attending ANC or giving birth at the health centre. Registration for the mama kits took place as outreach (i.e., the VHT member

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<sup>35</sup> The Acholi word is "mic".

would visit households), or on a given day at the health centre (i.e., women would be informed that their local VHT representative would register people every Thursday at the health centre).

The mama kit registration card functioned as an IE text in that by receiving these cards women were being brought into a form of social organization that relied on extra-local bureaucracies, discourses, and goals. In this case, the Red Cross programming and its implementation of global health goals were an extra-local force; in order to receive the mama kits, women had to meet the standards required to get the registration cards and the mama kits. When registration was routine, it meant women were coordinating their care around the requirements they saw as necessary to be registered and to receive the kits. When the process of registration failed or excluded women, it left them without access to the mama kits, a resource they felt entitled to and were frustrated not to receive.

Participants described the process of receiving a registration card for the mama kits as complicated. One mother did not receive a card but nevertheless received a mama kit:

I didn't get that card in my hand. I was told if you go for ANC four times you receive the card, but I didn't receive [it], even after we were told they [the VHT] would come here and give us it. So I went [to ANC] four times and they stopped me. I went and stayed home only for 3 days and delivered at hospital [health centre]. I had to go back home, because that day there was no immunization, because they were immunizing within villages for a week [i.e. the health centre was understaffed due to outreach] so I went back after they had called us. Then we were given the white card [mama kit registration card] but the person in charge said their home was far behind Otwee so they distributed the things and collected back the card. So they gave us a bag, soap, baby clothes and one carrier.

This woman's persistence and the initial work she had put into complying with ANC attendance paid off. Her story demonstrated the unpredictable work involved in trying to link to the system of the card and the mama kit.

Other participants who were not registered during pregnancy were less fortunate and did not receive a kit. For example, Isla from Rec Kicere shared that:

I have heard about that gift, but the person in charge of registering here is up to Mutema [a remote village] while others stay at the hospital [health centre], so we in Rec Kicere are to be registered in Mutema, the lady does not like being at the hospital [health centre].

Or, on a similar note, her neighbor Beryl did not get registered or get a mama kit:

Whenever I went to the hospital [health centre], they would tell us that registration is always on Thursdays and if we went on Thursday we would find those who register from the local village around but [a VHT member] from our side would not be around.

In such circumstances, participants did not know where to turn and had to give up on the idea of receiving the mama kits.

In three of the six villages, the women identified the registration problem as stemming from particular VHT members. In two neighbouring villages, the VHT member lived in a remote part of their area, possibly making outreach for registration difficult for her.<sup>36</sup> It was in the most remote villages where many women experienced barriers to registration and did not receive the mama kits. In these villages, giving birth at home, sometimes with a TBA attending, also appeared to be more prevalent. If the mama kits were intended as an incentive, they might have the most impact in such areas; however, it was in remote areas that access to the kit seemed most problematic. Participants said the particular VHT member, Justine, did not like to travel in order to register people, or to go to the health centre in order to meet women and register them. This would have been a considerable distance for her to travel. Further, some participants mentioned that the VHT member herself had a small baby, which might be keeping her close to home. While it is possible that the registration problem stemmed from this VHT member's unwillingness or inability to register women, there is also another possibility. One health worker explained to me that each VHT member was given a limited number of registration cards (to correspond with the limited number of mama kits available). Justine might have used up her

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<sup>36</sup> In the third village, the VHT member responsible for registering pregnant women for the kits had moved, and had not been replaced.

supply of cards, and therefore was no longer registering people. Limited provision of the mama kits and registration cards meant that their registration and distribution regulated women's activities in relation to maternity care.

This scarcity of registration cards and kits created inequitable access. Ingram (2013) writes that:

as deployed within neoliberalism, scarcity is a discursive practice that pathologizes the poor while diverting attention away from questions of inequality and distribution. In a climate of austerity, the neoliberal discourse of scarcity risks complicity with a politics of abandonment. (p. 450)

The items women received in the mama kits were valuable for their practical use. However, these items could neither substantially alleviate poverty nor significantly impact maternal-child health issues. Yet in the context of constrained access to material goods and scarcity, the kits became something women worked for and organized their care around.

The problems with the mechanisms of registration and distribution of the mama kits were located in the inequitable power arrangements between childbearing women, the VHT, health centre staff and the NGOs. Tracing the texts involved in registration and the sequences of activities it coordinates allowed a view into how extra-local activities and priorities influenced activities and priorities at the local level. The activities of the local middle-people (the VHT and health centre staff) were constrained by professional organization. For example, the Red Cross initially identified VHT members responsible for registering women for the mama kits.

However, when individual VHT members' capacity to perform this task changed, the Red Cross were not locally present to re-appoint someone (focus group in Pagak; Peter). Based elsewhere, NGO work had little continuity within Amuru. The district health officer and the health centre had limited control over the organization and scope of the mama kits project. This form of NGO involvement, however, shaped the way the health district and health centre provided care. For

local VHT members, health workers, and administrators, the capacity to do health work was organized within parameters defined by outside forces. Discourses of scarcity and deservedness contributed to how these parameters were defined.

### **Health Centre Staff and Administrators on the Mama Kits' Role: Helping the Vulnerable, or Motivating Care-seeking?**

Health centre administrators and staff differed in their understandings of the mama kits' purpose. Those with an administrative role identified two purposes: one stated by the donor organization – providing assistance to vulnerable women – and one developed through local practices – providing an incentive or reward to those women who completed antenatal care and delivered in the hospital. Junior staff who worked more directly with pregnant and birthing women spoke only of the second purpose.

“In our setting, who is the most poor?” Health administrators' perceptions of vulnerability as a distribution criteria

The two health care administrator participants, Jonas and Peter, were the clinical officer in charge at Lacor Health Centre III and the district health officer (DHO) respectively. The most senior health worker at the health centre, Jonas was both the manager and a clinician. As DHO, Peter was a government employee overseeing health services in Amuru district, in which Amuru sub-county is situated. Jonas answered my question about whether or not the mama kits project was universal by stating “[who receives one is] selective, yeah, the ones who have been identified and seen that they really need these”. However, as he later described, selection criteria were neither clearly articulated nor followed. Peter had a similar view about how need was determined: “yes, [. . .] that was why I said they should expand it, they were targeting the most

vulnerable . . . the most poor. But in our setting here, who is the most poor?” In a setting of widespread poverty, a targeted project in which the resource distribution takes place under an ideology and practice of scarcity makes distribution competitive and inequitable. Peter’s interview also highlighted the fact that despite his senior role as DHO, it was external NGO actors, and not government health officers, who controlled how the mama kits were deployed with regard to childbearing women.

The responses of the health administrators demonstrate problems with “vulnerability” as a criterion for distribution. In a setting of such widespread poverty and poor infrastructure, it was difficult and counterproductive to determine who was most vulnerable. This is not to suggest that everyone lived in absolute poverty: the ability to afford supplies certainly varied from household to household, depending on factors including income, intra-household income inequities, and the number of children. Also, those responsible for registering women were local lay VHT health workers, which would further challenge efforts to identify whom among their neighbours was most in need. Further, this type of intervention does little to address the inequities that increase such vulnerabilities.

An additional problem with vulnerability as a basis for distribution was that it limited supplies, so that there were shortages when those distributing the mama kits try to do so based on different criteria (such as whether birth took place at a health facility). When asked about distribution, Peter acknowledged the inconsistencies and lack of clarity about implementing the mama kits project goal of assisting vulnerable women, and the difficulty identifying those women most deserving of the mama kits:

The concept of the project was to help the vulnerable women, those women who fear to come to the health facility because they cannot buy the plastic sheeting, they have no soap, they have no baby clothes. It was primarily to remove that barrier. But you see, everybody needs those things, and they have a big challenge, who to give, who to not give. And I think they almost give to everyone. The VHTs are supposed to have been the

ones to sort out: “you, you are in a better situation, you should not. Let another woman who is in a worse off situation than you get it”. But of course it is not easy.

The sheeting Peter refers to was a length of heavy black plastic to be used as a bed cover, in order to prevent cross-contamination of the delivery bed. Each woman was required to bring her own length of heavy plastic sheeting at the time of delivery; this was something women saved for as a delivery expense. The poor were not a sub-group; rather, the population at large was experiencing poverty in the aftermath of war. Asked by an NGO representative to assess the program, Peter had spoken of its positive impact and requested that it be expanded. But ultimately, this was not within the jurisdiction of local health workers and administrators, but in the hands of the Red Cross.

Health centre staff on the mama kit: ‘Motivating’ women to deliver at a health facility

While acknowledging that the NGOs intended the mama kit program to intervene in situations where women were vulnerable, both Jonas and Peter saw the kits as a means by which to create an incentive for attending health centres. Jonas summarized this as follows: “So these women who live very far now tend to say ‘Okay, since I have been registered, let me go and deliver there and I get these items, because if I deliver from home I will miss these items’”. Peter similarly stated: “That small thing really helps women come [to the health facility].” His perspective is corroborated by Ediau et al.’s (2013) finding that “provision of free delivery kits to mothers who delivered at the health facility significantly increased skilled attended delivery” (p. 19) in Kitgum, a northern Uganda town. However, using the kits to promote facility delivery overlooks barriers to reaching the health facility.

Peter claimed that while the mama kits or gift was small, it was helpful and perhaps necessary: “They need those mama kits! They cannot afford it. And even if you have saved some money and you can afford, it is not there!”. His phrase “not there” introduces a common Acholi

phrase into English, and refers to the fact that most of the villages were not near shops that sold cloths, basins, or baby jelly. As with the mother participants in the study's first phase, Peter saw the kits as necessary and useful. Peter and Jonas leveraged the kits' utility to create incentives to participate in health care.

The health workers caring directly for birthing women who did not have an administrative role or the opportunity to interact with NGO staff, saw the purpose of the mama kits primarily in terms of being an incentive or reward, not providing resources to vulnerable women. This excerpt from my interview with Amy, the nursing assistant, was typical:

Why they give them, eh? Motivation is why. Just to motivate them. (Sarah): Motivation to deliver here? (Amy): Eh [agreement]. Because they give that [those] things just simply for those ones who come to deliver in the hospital. And for you, if you want that mama kit, you should make sure you come and deliver in the hospital.

Other staff used terms like “a morale booster” (the public health educator, William), “encouragement” (William, midwife Grace, nurse Nancy), and “to motivate” (midwife Gloria, Amy, above). Grace clarified that the reason for such encouragement was the goal of reducing maternal and infant mortality through an increase in health-center birth, when she said: “The main reason, eh? In order to encourage the mother to deliver in the hospital [health centre]. By that it will reduce maternal and child what? Death. That is the main purpose.”<sup>37</sup> The midwives repeatedly spoke about avoiding maternal and infant death; a dominant discourse shaping their work and the goals of the health centre and an issue of critical concern.

### **The Goals of the Uganda Red Cross**

To clarify the mama kits project's goals, I contacted Red Cross Uganda. I learned that the Safe Motherhood Project, as it is called, had as a goal that “pregnant women in Amuru and

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<sup>37</sup> The “what” is a rhetorical strategy for emphasis.

Kitgum district<sup>38</sup> give birth safely under the sanitary environment”. Its objective was “to contribute to the increase in health center delivery and antenatal care attendance up to four times by pregnant mothers”. The outputs for the project were to promote formal delivery care and knowledge of the need to attend ANC. The project activities were described as follows: “Register vulnerable pregnant women who would be supported by this project. Procure and distribute mama kits per year to vulnerable pregnant women. Procure and distribute essential sanitary materials and delivery equipment to health center” (Uganda Red Cross Society).

Based on these program objectives and activities, operating as an incentive to ANC and particularly delivery care was in keeping with the project’s goals. However, the particular ways in which childbearing women experienced the mama kits project implementation as a form of work to prepare for birth, the uncertainties created by registration processes and discourses of scarcity and vulnerability, and the barriers to complying with the requirement to deliver in the health centre did not appear to have shaped the project. “Vulnerability” was not defined or differentiated in the document outlining the project goals, perhaps contributing to the ambiguity regarding how and to whom the kits should be allocated. The project did not appear to take into account women’s different social and geographic locations with regard to access to ANC and delivery care. Similarly, while suggesting that women would be “supported” by the project, the extent or limitations that such support might constitute were absent in the document. While all stakeholders shared a broad concern over maternal health, in other instances, the lack of shared concerns was evident in the different ways “vulnerability” or “support” were operationalized.

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<sup>38</sup> Kitgum is another northern district, similarly impacted by the conflict and ongoing social distress.

## **NGO - Health Centre Partnerships: Problems with Withdrawal and Shortages**

With NGO projects like the mama kits, program closures and supply shortages are a constant threat. The issue of closure was raised by several of senior health staff. The clinical officer in-charge, Jonas, framed his concerns in reference to a previous Northern Uganda Malaria Aids and Tuberculosis Program (NUMAT) project: “These mosquito nets we used to distribute during antenatal clinic, and then the mama kits we would give at delivery. And this one ended because the program also ended.” While distributing the mosquito nets was part of the ANC goal to reduce the incidence of malaria among pregnant women (a major cause of infant death), it was not a health centre initiative but an NGO initiative. Its sustainability, as Jonas described, was beyond the control of the health centre.

Peter also talked about the closure of the NUMAT program, which had offered sleeping nets and something similar to the mama kit, pointing out that the transitory nature of program support was typical. He began by saying it had increased women’s attendance at health centres:

So because of that they will come in big numbers and it was something really the government will provide, they were providing, but you know our government. Things are not ... they usually end, even if the idea is very good, somewhere the idea breaks.

The withdrawal of NGOs or closure of particular NGO programs are something that health workers anticipate, but cannot plan for. As the public health educator, Alex, explained: “so you know, with the Red Cross, they may withdraw, if they find that their work is needed somewhere else”. Such comments revealed the overall structure of health centres delivering NGO projects alongside maternity and delivery care. This unpredictability was one of the negative consequences of NGO interventions in maternal health. When projects on which women rely end or have limited reach, this contributes to the fragility of the health system, rather than bolstering it. Many NGO programs had moved on now that the war was over and resettlement was well

underway, such that NGO withdrawal was a particular feature of Amuru and post-conflict northern Uganda. McElroy (2012), in her study of early childhood in the transition period following conflict, notes the problem of rapid NGO withdrawal and points out that “A gradual withdrawal of services that is responsive to the rate of transition” would be preferable to rapid withdrawal of services on which people still depend (p. 147). The gradual withdrawal of aid was also a key recommendation of Patel’s (2012) dissertation examining HIV among young people in post-conflict Gulu district. If the mama kits project were to stop, the health centre staff would seek new strategies to provide resources or incentives, and childbearing women would be left without this support.

In addition to the problem of NGO withdrawal shaping health care delivery, health care providers faced the challenge of managing the stock of the mama kit. As Jonas described it, the number of kits supplied was too low, because it did not take into account the large area and population served by Lacor Health Centre III. All health centres received the same number of kits, without regard to the numbers of deliveries taking place in the facility. The large number of births Lacor Health Centre III was related to lack of capacity in neighbouring health centres. As Jonas pointed out: “They [NGOs] do their calculation uniformly, with all the other health facilities in the other sub-counties, not knowing that other sub-counties have like two HCIIIs or one HCIII plus three or four HCIIIs that are well-functioning.” Jonas indicated this left him and his staff in the position of having to explain to mothers when the mama kits ran out.

Another strategy for managing the limited supply was to divide the kits, which partly accounted for the discrepancies participants reported in what they received. Jonas explained that:

The Red Cross provides mama bags with a basin, a baby gel, 2 towels, a dress for the baby. That is what is in the bag, then outside the bag they have a piece of bathing soap, and we give them two bars of soap. Sometimes when the bags are few we give them one-one [i.e., the contents of the kit are divided].

This strategy stretched supplies, to come closer to being able to offer one at each health centre birth, but contributed to the confusion over what women received. Similarly, when they had supplies, the health centre staff sometimes gave bars of soap to husbands who had attended ANC and tested for HIV, in order to encourage this practice (the role of male partner HIV testing is discussed further in Chapter Five). Dividing the kits in these ways may have accounted for one participant who had received most items in the kit, but who complained that a staff member had stolen the soap. Using limited resources to leverage or promote a wide range of health efforts contributed to their scarcity and the effects of that scarcity.

The mama kit was an intervention from the “outside,” which was introduced by national and international NGOs, and carried with it the outside agency’s beliefs and discourse about the experiences and needs of local women. For example, the attempt to identify and assist vulnerable individuals was not acceptable to childbearing women or health workers in this setting, despite the prominence of vulnerability as a criteria on which humanitarian and development interventions are based. While people were differentially socially located, all families were willing to organize their activities around receiving the kit, since they valued its goods and regarded them as useful. Health administrators and workers had discarded aspects of the program that they had discerned as having little local relevance (such as a focusing on identifying especially vulnerable women). Health workers who delivered the program adapted it to reflect and support their own goals; in particular, increasing the number of women attending ANC and delivering in a health care facility. While this was a valuable goal, the mama kits did not address the primary reasons that women do not access care. In this way, local health workers and administrators met the requirements of administering the NGO program while adapting it to best suit their own goals and the needs of local childbearing women and their households. These goals included increasing the rate of participation of women in ANC and the numbers of women

giving birth in health facilities. The mama kits could play a role in providing an additional incentive to seeking professional care, but they could not address all the access problems.

Health worker adaptations of the mama kits project to their own professional goals was creative and resourceful whilst acting as a coercive measure to leverage pregnant women's material need as a means of getting them to attend health centre care. At the same time, the need for creative adaptation indicated a mismatch between health centre and NGO goals. This mismatch, and lack of health centre authority in delivering the NGOs' project, caused problems for the adapted version of the mama kits project. For example, when creatively reinterpreted as a more universal program for those attending ANC and delivering in a facility, a shortfall occurred in the number of kits available. As I argue below, when registration cards or kits ran out, women hoping to receive this 'gift' saw the process as arbitrary. These negative consequences of the mama kits project indicated a discordant vision between NGOs such as the Red Cross and other stakeholders including health providers and clients. This was exacerbated by inequities in these relationships.

The problems for health providers working with NGOs, including a lack of overlap in goals, instability, lack of continuity, lack of autonomy on the local partners delivering the project are widespread according to Pfeiffer and Nichter (2008) who assert:

We are concerned by reports of wasteful spending, poor planning, and uncoordinated project development, which suggest a growing anarchy on the ground in global health efforts. This state of anarchy is fueled by an avalanche of resources landing on neglected health systems facing workforce shortages and crumbling infrastructure unprepared to manage this largesse, having been weakened by two decades of macroeconomic reforms (known as structural adjustment programs or SAPs) promoted by the World Bank and International Monetary Fund (IMF), and sometimes referred to as the 'Washington Consensus.' (pp. 410-411)

The mama kits, taken together with other products and projects of NGO, such as mosquito nets, therapeutic feeding products, and others, demand significant resources and staff time.<sup>39</sup> It is even more significant when one considers that the project has been taking place at time when there was one doctor practicing in Amuru District, a district of 135,723 people, and when the government health centre has been operating without a bed in the labour room (to the protest of local parturient women).

While participants wanted and appreciated the mama kits, it was clear that medical staff, adequate facilities and transportation are needed in this neglected health system. Divergent vision, supply shortfalls, lack of input from the local partners or childbearing women, and the potential for projects to abruptly end were understood as an inconvenient logistical challenge. When considered as an overall approach, the layering of a marginal form of social support onto a health care system that is not working can be seen to contribute to the ongoing pathologizing of poverty (Farmer, 1999, 2005) and governing through scarce resources in this marginalized region. As Pfeiffer and Nichter (2008) explain:

There is growing recognition of the urgent need to build or rebuild health systems, yet the increasing flow of aid from donors continues to promote narrow interventions and specific projects. This “stove-piping” of projects creates additional stress on government health infrastructures while providing little in the way of institution building. (p. 411)

The mama kit exemplifies such a specific project in that it takes considerable resources yet does not develop health care institutions.

### **Unpredictable Distribution Affects how Women Perceive Formal Care and Health Workers**

Variance in whether women received a kit, when they received it, and what it included, coloured women’s perceptions of health workers. While participants had diverse understandings

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<sup>39</sup> In my field notes, I wrote: “the kids (of the health centre staff) are snacking on plumpynut today (the sachets for therapeutic feeding for malnourished children). That’s got to be a frustration for the WHO or whoever supplies these...” (July 2012).

about how distribution worked, it also appeared to participants that health workers had the power to arbitrarily determine how and to whom supplies would be allocated. This reinforced the health centre as a site of difference and power. Participants said that receiving a kit depended on the following: luck; having an appropriate registration card; the location of the birth; women's HIV status; whether or not staff were overtired; and/or whether supplies were available. Participants thus viewed the kits themselves positively but had less positive accounts of their distribution. This lack of transparency eroded the trust or common ground between birthing women and health facilities or staff. The lack of consistency in registration and distribution had an alienating effect.

For example, Beryl, an Alur woman who had moved to Tedi in Amuru from the West Nile area to be with her husband when she was fourteen and was now twenty-three, found the unevenness and unpredictability of distribution frustrating. She said:

That friend of mine who is wearing the kitenge [African fabric] blouse registered together with me because we live together. She was given a gift and I wasn't given [. . .]I was so hurt. And yet my friends are getting, and my name was registered, then they did not give me... I was so annoyed.

The inequity of being excluded was unsettling.

One of the two midwives working at Lacor Health Centre III, Gloria, acknowledged that women could experience the health centre as a place where they were judged or discriminated against. In response to a question about misinformation or misunderstandings maternity care recipients had, she said: "that they don't want to give them [the mama kits], they think, 'there, they segregate people. They give [the mama kit] to others, they don't give to others,' not knowing what the reason is." She saw this as a misunderstanding that affected care, whereas birthing women found the unpredictability frustrating or unfair. Gloria saw the difference in how women encountered health centre care caused by unknown criteria in the distribution of mama kits as contributing to a negative perception of the health centre and its staff.

## **Conclusion**

The mama kits project provides a window into translocal aspects of the organization of maternity care and birth in Amuru sub-county. Through this window we can see how the goals and values of extra-local groups and local people competed, and where local activities were coordinated by translocal groups through the regulations and texts governing the purposes and practices of the mama kits. In this chapter, I have described how the mama kits were sometimes referred to as a ‘gift,’ yet operated as a form of textually mediated power governing access to care through discourses of scarcity and deservedness. Access to care, coercive power, and translocal goals are themes that follow through from the examination of couples’ HIV testing during ANC in the previous chapter and that were prominent within the current study.

## Chapter Seven: Implications and Conclusion

### Introduction

At the outset of this dissertation, I described a legal struggle to recognize the deaths of two women in childbirth as the Ugandan government's failure to provide care. The allegations were underpinned by the claim that a lack of basic supplies including sutures had compromised care. Yamin (2013) has cited the case as an example of "landmark litigation . . . brought at both domestic and international levels, establishing important precedents regarding the obligation of government to provide reproductive health care" (p. 2). This litigation calls to mind observations made by Farmer (2008), who witnessed the poor conditions in a Malawi maternity ward and attributed the country's shocking maternal mortality rate of 18,000/100,000 to intersecting oppressions constituted by gender inequity and poverty. Farmer (2008) stated that the reduction of maternal mortality is a human rights issue that depends on access to quality care. He asked: "Should there be a right to sutures? To sterile drapes? To anesthesia?" (p. 4). This rhetorical question inspired Venkatapuram, Bell, and Marmot to extend this inquiry in an article titled "The Right to Sutures: Social Epidemiology, Human Rights, and Social Justice" (2010). Collectively, these authors argued that social justice issues, access to basic maternity supplies, and the provision of care in clinical settings were interrelated forces shaping maternity health care and maternal mortality. It is therefore necessary to ask how such factors interrelate in order to create and sustain healthcare that upholds human rights.

The current study mapped the social constitution of childbirth and maternity care in Amuru sub-county, northern Uganda. The findings demonstrate how factors in health care provision and social conditions at the community level inform maternity care and childbirth practices. These factors in health care provision and the community have in turn been shaped by

the past LRA conflict, the current context of rebuilding in northern Uganda, and by inadequate public resources. In answer to the research question, *How is maternity care and childbirth socially organized in the context of Amuru sub-county, a rural area recovering from conflict in northern Uganda?* the current study delivers empirical evidence that responds to a significant call for context-specific research on maternity care (Kyomuhendo, 2003; MacKian, 2008; Say & Raine, 2007; Spangler, 2011). In addition to contributing empirical weight to an important and neglected area of research, this study is the first to focus on community level childbirth and maternity care in this area since armed hostilities ended in 2006.

### **Overview of Findings and Contributions**

Throughout this dissertation, I have focused on the interplay between material conditions, health care provision, and the operations of power. These central themes incorporate an emphasis on how the post-conflict context and the lack of access to resources (especially transportation) shaped how and where women access care. A discussion of the continuing role of traditional birth attendants (TBAs), the impact of a material resource distributed by NGOs (the mama kits), and the impact of compulsory, sometimes punitive, approaches to couples' HIV testing was situated within these social contexts. Discursive constructions related to how access to care is framed and how people and populations are represented – including representations that are problematic in terms of how they reference choice and culture – will be discussed towards the end of this section.

The findings depict how the past LRA conflict and current post-conflict setting have imposed individual and material hardships, which have affected maternity care and childbirth. In particular, the conflict has affected gender dynamics, contributed to poverty and lack of access to resources, shifts in work responsibilities, and health concerns. Armed conflict, abduction, and

internment in internal displacement (IDP) camps have contributed to individual and social traumas, which have in turn altered social relationships, particularly between men and women. Altered gender dynamics affect men's and women's activities in relation to pregnancy and birth. Some participants struggled with men's reluctance to attend antenatal care (ANC) or assist with work. For participants whose husbands had been disabled in the conflict and could not work and/or those who were raising the children of a deceased relative, these circumstances added to the workload and to the difficulty of managing pregnancy and related health care. For example, Betty, whose experience was discussed in Chapters Three and Four, was raising ten children, some born to a deceased relative, with her husband, who was badly injured; neither partner was able to adhere to medical advice to rest; ensuring nutrition was also a challenge.

The upheavals of war contributed drastically to ongoing poverty; both public investment in infrastructure and family rebuilding of homes and farms post-2006 were relatively new and incomplete. Land disputes are a major concern and contribute to ongoing social and economic insecurity: for example, a participant whose husband was in jail for poaching attributed his arrest to a land dispute. Because of poverty and a lack of resources, childbearing women organized their approaches to care and birth around factors such as avoiding arduous work, ensuring adequate nutrition, and arranging transportation.

Participants described the arduous and complex work they undertook to care for their health and access to health care. This work included: trying to eat well and rest, advice some participants found contradictory; coordinating and saving for transportation to and from antenatal and delivery care; managing their husbands' participation in HIV testing during ANC; and coordinating supplies for a safe delivery and for newborn care. Their time, effort, and money spent on coordinating access to the most basic resources can be understood in terms of power. Lack of infrastructure and resources in the post-conflict setting, an authoritative and sometimes

coercive approach to health care provision, and patriarchal power within marriages coalesced to diminish the ease with which women could care for their pregnancies and access maternity health care. Within IE, work is understood to be an intentional activity that “is done in some actual place under definite conditions and with definite resources, and it takes time” (Smith, 2005, p. 154). This study’s investigation of the conditions under which, and resources with which, childbearing women undertook work to coordinate care during pregnancy and birth points to power inequities, including resource inequities, as key contextual factors.

The current study offers insight into how gender, poverty and other aspects of the social context shaped by the past conflict and post-conflict setting are implicated in the organization of maternity care and birth. People’s experiences during the conflict affected how they approached care and their concerns regarding pregnancy and birth. Those who had lived in IDP camps had had access to formal health care at Lacor Health Centre III (HC III), which was located within Amuru IDP camp (now disbanded). This access helped familiarize residents with such care, but access was removed for those who relocated far away. Lay care was the norm for those who had lived in the community during the conflict because it was too dangerous to travel to health care facilities. Some women’s experience of the war led them to worry about the visitation of bad spirits during pregnancy or labour, while women who had abdominal or genital injuries expressed their fears of miscarriage or other complications.

Transportation was one of the most complex logistical challenges of accessing care in a low resource setting. Participants noted that access to the health centre for ANC or delivery was significantly impacted by the cost and availability of transportation, as well as the time of day, the weather, the season, and cell phone reception. Transportation problems overlapped with another challenge, the fact that facilities within the sub-county that should have been able to

support ANC and labour care were not actually equipped to do so.<sup>40</sup> Had such facilities been operational at the levels to which they had been designated, travel distances would have been shorter and more manageable, since women would not have had to make the longer trip to an operational health facility. Gaps in service provision and transportation challenges that were exacerbated by past conflict and the limited rebuilding of infrastructures disproportionately affected families living far away from the operational health centre and trading (market) centre of Amuru. Munjanja (2013) discussed the disproportionate access challenges faced by women in remote communities, noting that delays in arrival at a health facility were “most common and severe in rural areas” (p. 140).

The ability to access transportation to health centres impacted whether or not the women gave birth at home with the assistance of a TBA. However, international, national, and local approaches to maternity care discourage the attendance of TBAs, although the practice has not been limited or banned by official policy. At the international level, there is evidence of a shift away from TBA training and towards the development of skilled birth attendants (Say & Raine, 2007; Wirth, 2008). On a national level, there have been announcements of a ban against TBAs, and other public announcements discouraging TBAs’ practice (as discussed in Chapter Four). Locally, TBAs have been encouraged to refer women to a health centre rather than attend the births in their villages. Despite the policy preference for facility-based delivery, health care administrators in Amuru sub-county have recognized that some women will inevitably give birth at home due to limited health services, poor transportation, or other conditions. Health care administrators have therefore made the case that it was preferable to have a TBA in attendance rather somebody without any birthing skills, or nobody at all. In addition, TBAs have requested

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<sup>40</sup> Any HC II should be able to offer antenatal services, while an HC III should be able to offer antenatal and delivery care. The various HC levels are described in Chapter Two.

that some supports be put in place to make their services safe. In particular, they indicated that they needed to be trained in how to read the HIV status on an ANC card in order to protect themselves from transmission, and also needed rubber boots (for protection from snakes), gloves (for hygiene), and flashlights (for travel and as a light source for delivery care). These modest supports were not, however, provided.

The findings from the current study associated TBA-attended births with women's inability to reach a healthcare facility. This is particularly significant given that several studies have associated reliance on TBAs with cultural preference (Ensor & Copper, 2012; Izugbara, Ezeh & Fotso, 2009; Montagu et al., 2011; Vallieres et al., 2013). For example, a systematic review of qualitative studies on women's perceptions of obstetric services reported that "the mistrust of the modern healthcare system, coupled with a cultural preference for traditional medicine, leads to preferential use of TBAs" (Brighton, D'arcy, Kirtley, & Kennedy, 2013, p. 225). Such findings often generate recommendations that are related to education and other "demand-side" interventions (Ensor & Cooper, 2012; Konde, Dolomo, & Monareng, 2011). In contrast, the current study findings indicated that barriers to accessing formal care shaped both where and under whose supervision birth took place. If access challenges played a more important role than cultural factors in determining where as well as with whom birth took place, it suggests that health administrators who conduct analyses and design interventions should reduce their focus on cultural preference. Instead, they should renew their attention on the need to make formal care accessible to women, particularly those residing in remote communities.

At the outset of the current study, I anticipated that transportation problems, the location of birth, and birth attendants might be potentially significant to participants, based on the existing literature on maternity care in Uganda and the region. The prominence of particular local and politicized practices such as the mama kits and their distribution, however, was a significant

finding. The relationship between mama kits and women's care-seeking practices was complex. While the kits were useful and valued, how registration and distribution occurred impacted maternity care in ways that do not appear to have been adequately considered. This lack of consideration was evident in the way that mama kit registration and distribution governed how care was sought, accessed and delivered. The manner in which kits were distributed exemplified how strategies of scarcity, led to competition for resources among childbearing women and inequitable access, both to these resources and to maternity care.

One aspect of ANC provision, couples' HIV testing, was a site of responsabilization for both women and men. According to Rossiter (2012), responsabilization is a situation "in which the weight of responsibility for health is borne by the individual, rather than larger social structures and institutions" (p. 180). As such, it is a practice supported by neoliberal approaches to care and often associated with the discourse of consumer choice (Brown & Baker, 2012; Davies & Burns, 2013; LeBesco, 2011; Mykhalovskiy & McCoy, 2002). Rabinow and Rose (2006), for example, claim that within the context of new reproductive technologies "apparent choices entail new forms of 'responsibilization' and impose onerous obligations," particularly for women (p. 209). In the current study, however, responsabilization occurred in tandem with a paternalistic and directive approach to testing, which did not include a rhetoric of choice. Instead women were expected to comply with top-down directives. The top-down approach and compulsory approach to couples' HIV testing also promoted responsabilization. The requirement that women bring their male partners for testing led some to fear being denied care, while male reluctance to participate raised concern over potential violence targeted at women. Couples' testing represented a discursive site where global and national policies were (imperfectly) translated into local practices. Men's HIV testing was treated as ancillary to women's ANC, and men were targeted through their pregnant partners, rather than as individuals or as a group.

Given that the approach was compulsory, recruiting men via their partners was problematic. As Rossiter (2012) argues, responsabilization acts “to download responsibility from the collective to the individual” (p. 182). Responsibilization strategies were used to coordinate the behavior of individual women and, by proxy, their partners, but not to address problems within the health care system or structural factors that affect care.

### **Implications of Findings: Representation and Framing**

This study’s findings extend beyond identifying barriers and cultural preferences as factors that shape where birth takes place. Barriers to care exist, but are often discussed from the point of view of care providers and not childbearing women. Discussions of barriers and preferences often fail to adequately account for the institutional practices that produce the local politics of maternity care. The current study addresses this gap by foregrounding the knowledge of childbearing women, examining the experiences of women as they are constituted within local networks of power and relating those power relations to broader socio-political forces within the post-conflict context. Kumar (2013) identifies that “focusing on proximal determinants of health, such as access to healthcare, without giving due consideration to distal factors such as poverty and economic exploitation on a global and/or national scale” can be a form of colonial representation (p. 22). Understanding how maternity care and birth are constituted in Amuru sub-county, northern Uganda, through women’s own expertise is of critical importance to meeting women’s needs. A focus on birth and maternity care as a social rather than primarily technical and individual process has shown that the organization of maternity care and birth is discursively produced through local networks and extra-local power relations.

This social dimension of maternity care and birth, however, should not be conflated with culture, as is sometimes the tendency in the literature that examines approaches to care provision.

This is exemplified in the previously cited literature on TBAs (Brighton, D'arcy, Kirtley, & Kennedy, 2013; Ensor & Copper, 2012; Izugbara, Ezeh & Fotso, 2009; Montagu et al., 2011; Vallieres et al., 2013). In the current study, the social is made up of the everyday work, activities, texts and talk which pregnant women and health care workers enact in coordinating care for pregnancy and birth. I have been cautious of employing notions of “tradition” or “culture” as explanatory of approaches to maternity care and birth, even though the literature on maternity care and birth in the global South emphasizes this. Approaches to care are dynamic rather than static, and are coordinated by factors that cannot be reduced to culture. In “Writing Against Culture,” anthropologist Lila Abu-Lughod (1991) argues that, within anthropology, the term “culture” operates “to enforce separations that inevitably carry a sense of hierarchy” (p. 466). In making the case against “culture,” she identifies three problems: culture assumes “coherence, timelessness, and discreteness” (p. 472). Abu-Lughod thus suggests a focus on discourse and ethnographies of the particular as strategies of writing against culture. Rather than emphasizing culture as a basis, the current study employed IE sites analysis, including of work and talk, in seeking to describe how approaches to care were shaped. These activities are not only powerful constituents of social practices, but are also viable places to introduce changes. A focus on how culture shapes preference is associated with recommendations to educate childbearing women. A specific example of this is provided by the literature recommending education or demand-side interventions as a means by which to reduce reliance on TBAs. In contrast, the current study focused on the everyday work, talk, texts and practices, and led to findings that demonstrate where the need for social and institutional change lies. When culture is identified as a cause of certain approaches to health care, there is an implicit suggestion that any given approach is entrenched in the local people. In order to better understand the social constitution of maternity care and birth, it is necessary to reframe the interaction between culture

and such social constructs. The current study findings on couples' HIV testing, for instance, point out that marital discord and barriers to maternity care increased when a compulsory approach to testing, coupled with responsabilizing women for men's attendance, was employed. This goes beyond suggesting that men who are reluctant to test need education to change their cultural approach to antenatal care.

“Choice” and “preference” are frequently the loci of analysis for research on maternity and childbirth care and the decisions and/or policies concerning where that care takes place and who provides it. For example, Amooti Kaguna and Nuwaha (2000) take the approach that one can describe where, and under whose care, women give birth as primarily a choice, and Gebrehiwot, Goicolea, Edin and San Sebastian (2012) center their analysis of delivery care in northern Ethiopia on “making pragmatic choices” (p. 1). In fact, Guo et al. (2014) argue that the discourse of consumer choice is now taken for granted in Western health contexts although it is not shared by all health care consumers. Rebeck (1993) is critical of the rhetoric of choice for obfuscating how state power operates to limit or determine health care access for women. Her argument that limited health care options detract from the value of a rhetoric of choice is relevant to the Amuru context, where health care can be difficult to access and where patients exert such limited control over how it is provided. Angotti et al. (2010) were also concerned with power when they suggest that “constraining choice may be especially likely when clients are women, rural and relatively uneducated compared to health personnel (Rutenberg and Watkins, 1997; Booth, 2004; Datye et al., 2006)” (p. 313). For the foregoing reasons, knowledge of where and under whose care women give birth is not reducible to the analysis of women's choices. Participants in the current study recounted experiences with regard to location of birth which suggest that framings such as choice, preference, or decision making misrepresent critical

contextual factors in coordinating approaches to care, such as transportation, cost, and proximity to health facility.

The trend in Uganda has been to give birth at home, and media or research studies have sometimes framed this trend as refusal or reluctance on the part of childbearing women to engage with formal care.<sup>41</sup> In some instances, the continued reliance on TBAs for labour support is described as an entrenched preference. For example, Akpabio, Edet, Etifit, and Robinson-Bassey (2012) contend that birth location is a matter of cultural preference. This framing of birth location is not supported by the current study; I found little evidence that women are either refusing services or exhibiting a reluctance to participate in formal care. When women gave birth outside a health facility, it was often despite their best efforts to secure access to care. In fact, participants identified the health centre as the norm for birthing location among their “fellow women”. This finding is consistent with Koblinsky et al.’s (2006) conclusion that “for those who do not access care, the argument that services are available to meet their needs but are underused because of reluctance on the part of women is unlikely in countries where mortality rates are high” (8). Further, the fact that health centres were widely accepted as a desirable location to deliver does not diminish the importance of community-based TBAs who provide care to their neighbours. However, it does not suggest that public health interventions should be based around cultures of care or women’s reluctance to give birth at health care facilities but on improving access to care. Kornelsen and Grzybowski (2005) have also suggested such a focus, finding that in the context of rural communities in Canada “being able to give birth in their own community or in a nearby community was necessary if [women’s] obstetric needs were to be met” (p. 554).

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<sup>41</sup> For example, newspapers in Uganda have reported on women in various areas “shunning” formal care: Pregnant women shun hospitals. (2010, New Vision); Kaberaido mothers shun hospitals (2010, New Vision); Why K’jong women still shun the labour ward (New Vision 2006); Pallisa mothers shun antenatal care (2011 the Monitor)

Hussein (2012) also argued similarly in the case of sub-Saharan African communities. The current study indicated that, in contrast to choice or preference, a lack of operational care facilities and the cost, lack of availability, and general difficulty of transportation to health care facilities were the most prominent issues raised by women who gave birth at home.

### **Methodological Context**

Several aspects of the current study's research strategy contributed to this its strength, and further, extended existing methodological practices in innovative ways. By conducting seven months of fieldwork while living within the rural sub-county, rather than in nearby Gulu town, I accessed opportunities for observation, relationship building, and learning about communities and health services. The extended period of fieldwork in this remote location allowed me to reflect on my analysis, assumptions, and prior knowledge, while seeking out or having the good fortune to encounter relevant data in the form of local happenings. In my field notes, for instance, I wrote about being called over to an outdoor area to meet newborn twins; their mother's joy and desire to share it with me was evident. Another day, I saw a woman leaving the health centre with a small baby on her back and an even smaller baby in her arms, and learned that her sister had died in childbirth; since she was already nursing her own baby she was adopting the newborn. These women were not formally part of the study, yet my encounters with them shaped my understanding of care and birth in the area. This immersion in the field contrasts with typical institutional ethnography (IE) practices in which researchers live at home while visiting a site for interviews, observations, or other research practices. By overlapping IE practices with other critical ethnographic practices, this research broadened the lens of study, allowing for a clear and complex picture of the organization of maternity care and birth.

My interviews and focus groups were situated in multiple sites throughout the sub-county. While this meant I faced transportation logistics myself, it also ensured the inclusion of participants with a greater range of experiences in terms of how maternity care and birth were organized. Working with both Local Council (LC) I and Rwot Kweri (RK) as village contacts also helped ensure a diversity of community size and remoteness. I learned that other researchers or NGOs who primarily worked through LC I were sometimes limited to the contacts of the LC Is, to the exclusion of the RKs' contacts, who were often more remotely located. Being able to speak with women in remote locations, partly as a result of my association with the RKs, gave me much greater cognizance of the contexts of maternity care and childbirth in the sub-county. The inclusion of two focus groups in addition to the thirty-five interviews in the study's first stage, which focused on the expertise of childbearing women, created an opportunity to validate my analysis and expand upon the initial themes. The childbearing women who attended these remotely located focus groups contributed perspectives that extended the study's depth.

Further, the inclusion of a second research stage, in which I spoke to health care workers and health care administrators, allowed me not only to follow up on concerns of childbearing women, but also to learn from health care providers and administrators about how maternity care and birth were organized within communities and via formal health care. While I had not anticipated speaking to health care administrators, my research design's open approach to the second stage of research and broad definition of health care workers made this possible. This valuable second research stage at times corroborated, contradicted, and/or helped to explain the data from the first stage. For example, health workers corroborated the data pointing to transportation as a major challenge; some health workers contradicted the finding that nutrition was an insurmountable challenge for some childbearing women; and health care providers helped explain why soap was sometimes missing from the mama kits women received (as had been

reported by participants in the study's first stage). My epistemological perspective did not require a precise overlap or singular explanation about the knowledge and beliefs of these two groups. Instead, my theoretical position oriented me to multiple truths as co-existing in the accounts of participants; searching for the 'most' truthful account was neither epistemologically congruent with my orientation nor was it compatible with an IE approach. Since their respective work was shaped by differing institutional processes, it was logical that health workers and childbearing women had differing experiences and accounts. An openness to contradictory data contributed to the complexity of the findings.

Institutional ethnography is based on insights from European and North American philosophy, history, and social organization; it nevertheless is an approach to research which offered many benefits to the current study. One aspect that stood out as a difference between Amuru sub-county's health care setting and the Western/global North ones in which IE has typically been applied, was the role of texts. In the global North, communications technologies have a different use from that which shapes media and bureaucracy in Amuru, where personal computers are unusual, cell phones are common, media consumption is not built into daily lives, and literacy rates are low. Low literacy and a less saturated media environment influence approaches to care and relationships between patients and providers; the persistence of a relatively paternalistic approach in Amuru restricts to people's ability to be well-informed health care consumers. Adopting IE methods has allowed me to explore the role of texts in a low-literacy setting where media and other communications are much less ubiquitous than in the global North.

## Recommendations

In this section, I make recommendations for changes related to maternity care and childbirth that mitigate or solve some of the challenges identified and described in the current study. The potential consequences of any change must be thoughtfully considered before any strategies are implemented. The negative impacts of what are sometimes referred to as “unforeseen consequences” of health interventions are described in Chapters Five and Six, and are extensively documented in public health literature (e.g. Yamin and Boulanger’s [2013] writing on the intended and unintended consequences of the selection of Millennium Development Goal 5 as a global goal). Some recommendations will require significant investment of time, money and resources, or require further research. In other cases, however, the relatively minor changes and upgrades recommended would have significantly positive impacts on pregnant women and their access to maternity care of improved quality.

While investment in health facilities is key, other needs in the community are also imperative. Meeting the most prominent of those needs would require changes include providing or facilitating transportation, enabling pregnant women to avoid heavy work, and ensuring adequate nutrition. Each case of these changes require resources as well as shifts in gender dynamics and male understandings of how to support women’s health needs during pregnancy. This latter goal of sensitizing men on women’s needs during pregnancy has already been identified in local health care provision. An opportunity to further this goal could be coupled with work on engaging men more directly to promote couples’ HIV testing during pregnancy.

Reducing direct and indirect (proximal and distal) barriers to ANC and delivery care should continue to be a priority. For example, current approaches to overcoming barriers to care include providing outreach and encouraging TBAs and other village health team (VHT) members

to refer pregnant women for care. These provisions could be supplemented through greater attention to transportation logistics, and investing in existing health facilities that are not currently operating to capacity such that women in remote areas have closer access. When improving the operational capacity at health centres, it will be important to ensure high quality of care and consistent staffing; if health care centres are perceived as offering low-quality care, some women will bypass them to seek better quality care further away. It is also important to eliminate disincentives to care such as the pressure to bring a male partner to ANC and couples' HIV testing, or the problems with the registration and distribution of mama kits.

Health care workers' concerns about program closures, as well as the value childbearing women place on the mama kits and on previously available food aid, suggest that any withdrawal of NGO programming in this community should be gradual. This is true whether or not such programming is intended to relate to maternity care and birth, since income and education also support healthier pregnancies. Further, the distribution of mama kits and soap should be carefully managed in recognition of the fact that such distribution affects attitudes about care and how care is accessed. This strategy requires changes to how VHT members are engaged and supported, whether this takes the form of ongoing monitoring of VHT members involved in registration or empowering the VHT as an organization to monitor registration itself.

At present, skilled attendance at birth is encouraged as a norm and TBAs are called on to refer pregnant and parturient women to the health centre. At the same time, it is recognized that TBAs do attend births and will continue to do so when necessary. What is needed is a means of supporting their work while promoting safety measures and concurrently expanding their role in referrals and endorsing the norm of skilled attendance. The TBAs interviewed for this study had recommendations that included: being able to read the HIV status on an ANC card, and being provided with basic supplies to promote their own safety and capacity to provide safer care

(rubber boots, gloves and flashlights). These minimal supports could protect TBAs and birthing women by preventing infections and transmission of HIV. However, any support given to TBAs should in no way undermine the message that for women who can access it, skilled assistance at a health centre is the safest option for delivery care.

The approach to couples' HIV testing needs reform in order to account for access challenges and gendered dynamics in intimate relationships and to prevent the compulsory approach from turning health care into a site of coercive power, as indicated by the findings in Chapter Five. Emphasis should be placed on identifying various means of ensuring the strong participation of male partners other than through their pregnant wives. Remote areas where women have the most difficulty accessing care are in the most need of support or change. While outreach remains an important tool, general investment in facilities, roads, and transportation is crucial; within this investment, priority should be given to remote areas where exacerbated barriers to care currently exist.

Approaches to supporting maternity care and birth need to be intersectoral, as aspects outside of the domain of medical services shape how maternity care and birth are socially constituted and can promote or limit the accessibility of care. In particular, transportation issues cannot be neglected. One strategy to address transportation challenges occurring at the time of delivery is establishing 'waiting homes'. Munjanja, Magure, and Kandawasvika (2012) describe waiting homes as "[facilities] within easy reach of a hospital or health centre. Women use the waiting homes at the end of their pregnancy, while awaiting labour" (p. 147). The clinical officer in-charge spoke about raising funds to construct such a home outside Lacor Health Centre III, Amuru. This option could address the problem of transit for women in labour. However, it would require increasing capacity at one health centre rather than spreading capacity among several health centres in the sub-county, which would be preferable. One disadvantage to waiting

homes is that delivery dates can be difficult to track, since women may not be recording their menstrual cycle or may not have resumed menstruating since their previous child's birth (and since ultrasounds are not part of standard ANC and are not available in the sub-county). This means that many women would not be able to plan the dates of their stay at the waiting home with enough accuracy to arrive before going into labour.

Other strategies for improving transportation relate to basic infrastructure, such as improving road surfaces and extending the cellular network (so that all areas have mobile phone access to call for transport). Participants in the current study put forward innovative ideas on transportation, and these require further consideration. For example, the district health officer suggested that for functional ambulance transportation to be available at government-run health facilities, local community members might have to pool their savings to purchase fuel. In some communities, TBAs were active in organizing emergency community funds, to be accessed by women in need of (non-ambulance) transportation. In one focus group in this study, participants discussed the possibility of having transportation shuttles between nearby but non-fully-operational health facilities and the more distant facility where birth could be attended. In other Uganda districts, a system of transportation coupons for boda-boda (motorcycle taxi) use by pregnant women was piloted (Pariyo et al., 2011). An example of a health centre meeting the transportation challenge is Ot Nway Me Kuch (House of Birth and Peace) located in Amuru district near the border with South Sudan. Run by an international NGO and recognized as a Health Centre II by the government, this centre provides transportation to laboring women. They facilitate this by sharing their phone numbers with pregnant women who can then call when the time comes, and by maintaining more than one truck, as well as bicycle ambulances. In addition to transportation, Ot Nway Me Kuch provides food to women in post-partum recovery and their

attendants. On my visit, their services stood out to me as having considered the social and material needs of childbearing women.

Transportation interventions will likely need to be multi-pronged in order to facilitate access, but for women to fully take advantage of health care services during pregnancy and birth, the complex challenge of transportation must be addressed. Coordination or resource sharing between the various NGO health centres and with government-run facilities is worth investigating for its value in mitigating transport difficulties by spreading the distribution of services between several health centres, rather than relying on one health centre in the sub-county with a strong capacity to support ANC and delivery care.

A final recommendation concerns the representation of maternity care and childbearing women. Social contexts, including poverty and post-conflict rebuilding, are not just a backdrop to, but an essential part of what organizes, maternity care and approaches to birth. Power relations and social justice issues are important considerations when planning care. Dying in childbirth is *not* part of any culture. Researchers and members of the health care sector need to accord respect to birthing women when thinking about where and under whose supervision they give birth. While health education efforts remain important, childbearing women also should be recognized as competent and knowledgeable when it comes to their own care needs.

While the fieldwork of this study was still in progress, changes were being implemented that might ultimately impact maternity care and birth, but I did not have the opportunity to assess them. Of particular note was Lacor Health Center III Amuru's plan to implement a one-time fee from pregnant women accessing ANC and delivery service. This fee was being levied in the final month of my fieldwork, and while health care workers I spoke to suggested that the cost was too minimal to be a barrier or deterrent to women, I did not have the opportunity to discuss this with any maternity care clients paying the fee. The fee was low, but might nevertheless present a

barrier to those already struggling with the costs of preparation for birth and the new baby. Due to the timing, assessing this small but possibly significant change was beyond the scope of this project. The way care is provided is not static, and changes to staffing, facilities, and so on impact the social organization of maternity care and birth.

### **Study Limitations**

My participation criteria excluded women under age eighteen. Research with childbearing youth would have ethical and practical dimensions beyond the scope of this study, and eighteen was an accepted norm for becoming a mother (Baines & Rosenoff Gauvin, 2014, p. 17). Therefore, this study didn't learn about particular approaches to maternity care and birth among mothers younger than eighteen. However, mothers under eighteen and first-time mothers may have particular concerns with [maternity] care that were not identified here. The exclusion of women under eighteen also means that the inclusion of first-time mothers was relatively low in the group of participants. Many of my participants had still been teenagers when they had given birth to their older children, and mentioned some distinct concerns of first-time mothers, such as not realizing they were pregnant, and not wanting to be pregnant because it would mean they would have to leave home and marry the father. The approaches to care necessary for first-time mothers may be different from others in ways that this study does not fully examine.

Birth control, or family planning as it is often referred to in the context of development, was a topic that was frequently raised, but which I decided was beyond the scope of analysis for this dissertation. It was clear from what participants said, however, that this was a major concern among women in this area. Maternity care is best understood within the wider context of women's reproductive health care; the way I write about it as isolated somewhat parallels the way maternity care was delivered – without strong integration of related health concerns. Sexual and

reproductive rights are included in MDG 5, but were only added in 2005 after lobbying from reproductive rights groups; indicators were not added until 2007 (Yamin & Boulanger, 2013). Their late inclusion as well as opposition from conservative leaders to a broad focus on reproductive health has resulted in a lack of focus on family planning and a narrow focus on maternal health, which Yamin and Boulanger (2013) argue “does not address the root causes even of maternal mortality” (p. 82). As these authors suggest, women would be better served by a broader approach to reproductive health, and one with a “strong narrative of social transformation” (p. 82).

Representation can be challenging. A limitation I have encountered in writing is how to foreground the social organization of care without obscuring the hard work, commitment, and compassion of many of the health workers providing maternity care. Gawande (2013), writing in *The New Yorker*, expresses a similar dilemma:

Even the youngest nurses had done more than a thousand child deliveries. They’ve seen and learned to deal with countless problems—a torn placenta, an umbilical cord wrapped around a baby’s neck, a stuck shoulder. Seeing the daily heroism required to keep such places going, you feel foolish and ill-mannered asking how they could do things better” (para. 22).

While I have been necessarily critical about the organization of care, I also acknowledge the dedication and work of care providers. In my conversations with TBAs, their pride in and commitment to their work was evident when they shared the accomplishments of children at whose births they had assisted years before, telling me that one was attending university in the capital, or that another was now a mother herself. When I closed my interview with Amy by asking if there was something that she needed to add, she told me about her journey to become first a nurse aide and then a nursing assistant. She said that as an orphan, it had been a challenge to complete her education, and she finally had to stop on completing senior four (equivalent to junior high school or to an O-level). She had worked as a nursery teacher, but felt called to serve

as a nurse, and applied to the nurse aide position about ten times. She told me: “And then at last I got that job. And I am so proud of it. And whenever a patient, a woman, wants help from me, I will give it so gladly. I give it so gladly.” While the commitment and working challenges of health care workers have not been my focus, I hope my respect for their work is evident.

### **Directions for Further Research**

The role of husbands and male partners in how maternity care and birth are socially constituted in Amuru warrants further investigation. In participants’ discussion of HIV testing, avoiding heavy work during pregnancy, and preparing for delivery, men’s roles were frequently mentioned. Couples’ HIV testing is an important means of preventing mother-to-child transmission (PMTCT). Further research is needed to identify how participation in couples’ testing can be promoted with greater sensitivity to gender and power dynamics. Research investigating male partners’ own perspectives, particularly on HIV testing, would contribute to the discussion of how a male partner’s role in pregnancy and birth is currently enacted and help identify how to best facilitate increased participation in couples’ testing, a necessary PMTCT measure. How can men’s participation be promoted without this being a burden on women and on intimate relationships? Is a compulsory approach ethically acceptable? These questions require further consideration. Further, women who do not have a partner or whose partner is absent at the pertinent times have needs that are worth investigating, particularly in view of the way male participation in ANC continues to be promoted as a norm.

I have identified transportation as a central and complex factor shaping how and whether formal health care was accessed, particularly at the time of giving birth. Some potential strategies are outlined above in the recommendations section; research identifying which strategies would be feasible and have the greatest impact in Amuru would be very beneficial. As

I have identified earlier, the challenge of transportation was exacerbated by the state of health facilities that are not operating to standards identified as optimal in terms of staffing and capacity to provide care. Further study would help determine how to balance the need to support better transportation with the need to increase the capacity of existing rural health centres to provide care.

## **Conclusion**

While the context of high maternal mortality is one compelling reason to work towards a better understanding of how maternity care and childbirth are socially constituted, there is a range of less dramatic reasons for making this a focus of study. For a mother and her family, the birth of a child, whether a first or subsequent child, brings changes – some welcome and some stressful. Maternity care and birth are also times when women deliberately seek out additional health care, and this can lead to new or changed relationships with health care providers. A positive and healthy experience with care can support these transitions and contribute to ongoing wellbeing and health care. In contrast, when the organization of care makes pregnancy and birth more difficult and stressful or less healthy, there can be ongoing negative impacts on the social and physical wellbeing of citizens. This study can be brought to bear on both the dramatic and the everyday consequences of how care is organized. How maternity care was socially constituted in Amuru was complex and sometimes unpredictable. While the changes required to decrease the incidence of maternal mortality and to support positive experiences of care are therefore difficult, we know that such changes are possible and that they will have tremendous impact on women, families, and communities.

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## Appendix 1: Interview Guide

This interview was revised after my first 10 interviews. The bracketed questions are follow-up questions or probes and were not used in every instance. This guide was revised after the first 10 interviews and includes a follow up question about the mama kit.

1. What does 'maternal health' mean to you?

(What makes a healthy pregnancy?)

2. How do you get information about pregnancy and birth? (Are there any other ways? Did you hear anything from a VHT, a TBA, or on the radio?)

3. How do you take care of yourself during pregnancy?

(What about ANC, or self-care?)

(Why did you go to ANC?)

(Are there any difficulties in requiring the husband to go for ANC? Is it helpful?)

4. What do you normally do to prepare for childbirth?

(What did you do to prepare in the case of the pregnancy we are discussing (the birth of your youngest child)?)

5. Apart from the things that you prepared, what is important to you, personally, at the time of birth?

6. Was there anything that you were afraid of, or worried about, during the pregnancy?

7. Was there anything unusual about this pregnancy?

8. Can you tell me the story of this birth?

(Who was there at the birth of your youngest child? Who was helping you?

Was that who you had planned or hoped would be there? Where did you give birth?)

(If they were given a 'gift': Why does the HC give women these things at birth?)

9. Before the time of birth, did you consider other places you might have gone to give birth, or other people who might have helped you?

(What other places or people did you consider? What are your thoughts on these other options?)

1. What are your thoughts on the place you gave birth in, and the people who were there?

10. What went well with this birth?

11. What could have gone better during this birth?

12. Thinking about your family, as well as any health workers, were you satisfied with the care and support you received during pregnancy and birth?

(Can you talk about what was good about the care you received, and what could have been better?)

13. Which people are most important to a pregnant woman? Who is there to talk to if you are worried, or if you have health concerns?

14. What can be done to improve maternity care in your village or in Amuru sub-county, in your opinion?

15. Is there anything else you want to add, or to tell us about pregnancy, birth, and care?

**Appendix 2: Table with Participant’s Village, Age, Number of Children, and Location of Birth**

Name (Pseudonym)	Village	Age	No. of Children	Birth Location			
				Health Centre	Home	On- the- way	Hospital
Lila	Turdakatuba	22	4	X			
Arlene	Turdakatuba	35	7	X			
Rose	Turdakatuba	18	1	X			
Maureen	Turdakatuba	38	8		X		
Hope	Turdakatuba	25	5		X		
Erin	Turdakatuba	28	4				X
Monica	Pagak/ Labongo	30	8 (pregnant)	X			
Pauline	Pagak/ Labongo	22	1 living; 1 deceased	X			
Faith	Pagak / Labongo	24	4	X			
Tillie	Pagak / Labongo	26	4	X			
Rachel	Pagak / Labongo	20	3	X			
Elizabeth	Pagak/ Labongo	25	3	X			
Penny	Oberabic	29	5 living 1 deceased	X			
Sophie	Oberabic	24	3	X			
Jill	Oberabic	18	1	X			
Kelly	Oberabic	19	1	X			
Penny	Oberabic	24	3	X			
Hazel	Oberabic	19	1	X			
Mary	Tedi	38	6 living 3 deceased	X			
Grace	Tedi	25	6	X			
Jacky	Tedi	28	3		X		
Janet	Tedi	41	11	X			
Ellen	Tedi	38	6 living 5 deceased			X	
Jane	Tedi	18	1		X		
Hope	Rec Kicere	26	5	X			
Sara	Rec Kicere	19	2	X			
Lynn	Rec Kicere	21	2		X		
Beryl	Rec Kicere	23	3	X			
Isla	Rec Kicere	20	1	X			
Amelia	Rec Kicere	Not recorded	1 living 1 deceased Pregnant	X			
Lily	Lujoro	22	3	X			
Jean	Lujoro	38	5	X			

Name (Pseudonym)	Village	Age	No. of Children	Birth Location			
				Health Centre	Home	On-the- Way	Hospita l
Mildred	Lujoro	30	5	X			
Jeanette	Lujoro	23	6		X		
Anita	Lujoro	20	2	X			
Anne	Lujoro FGD	32	4		X		
Julia	Lujoro FGD	30	? eldest was 13; twins under 2			X	
Sally	Lujoro FGD	26	? eldest was 9, one under two		X		
Mildred	Lujoro FGD	19	1	X			
Florence	Lujoro FGD	36	? eldest 13, one under 2		X		
Betty	Pagak/ Labongo FGD	32	5	X			
Leah	Pagak/ Labongo FGD	28	5	X			
Lee	Pagak/ Labongo FGD	30	6 living 1 deceased	X			
Faith	Pagak/ Labongo FGD	Faith was not sure. 38?	5 living	X			
Annette	Pagak/ Labongo FGD	26	3	X			