

Understanding the reproductive health needs of displaced Congolese women in Uganda

Thesis

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Abstract

Uganda currently hosts 1.4 million refugees and conflict-affected people. Known as the “best place” in Africa to be a refugee, Uganda’s policies encourage self-sufficiency and local integration. However, many refugees, particularly women and girls, face persistent challenges. Understanding the reproductive health needs of this population and exploring the accessibility of services for conflict-affected populations in this low-income host country is a priority. This multi-methods study aimed to assess the reproductive health needs of displaced Congolese women in camp- and urban-based settings in Uganda. We interviewed key informants, facilitated focus group discussions with refugee women, and conducted in-depth interviews with Congolese women of reproductive age to better understand knowledge, attitudes, practices, and services. Our results suggest that Congolese refugees have significant unmet reproductive health needs. Maternal health and delivery care is characterized by insufficient human resources, inconsistent medication availability, discrimination, bribery, and communications challenges. The availability of contraceptive products, including emergency contraception, is limited in camp-based settings due to supply-chain management challenges and theft by staff; lack of contraceptive knowledge among Congolese refugees shapes use. Finally, the legal restrictions on abortion lead to unsafe practices among refugees and pose a barrier to the provision of post-abortion care. This study provides insight for opportunities to improve the delivery of sexual and reproductive health services to refugees in Uganda to ensure that the infrastructure and processes align with national policies and international guidelines.

Résumé

L'Ouganda accueille environ 1,4 million de réfugiés et de personnes touchées par le conflit. Connu comme le « meilleur endroit » pour être un réfugié en Afrique, les politiques de l'Ouganda encouragent l'autosuffisance et l'intégration locale. Cependant, de nombreux réfugiés, en particulier les femmes et les filles, font face à des défis persistants. Comprendre les besoins en santé reproductive de cette population et explorer l'accessibilité des services pour les populations touchées par le conflit dans ce pays hôte à faible revenu est une priorité. Par conséquent, cette étude multi-méthodes vise à évaluer les besoins en matière de santé reproductive des femmes congolaises déplacées dans les camps et les zones urbaines en Ouganda. Nous avons interviewé des informateurs clés, animé des discussions de groupe avec des femmes réfugiées et mené des entretiens approfondis avec des femmes congolaises en âge de procréer pour mieux comprendre les connaissances, attitudes, pratiques et services. Nos résultats suggèrent que les réfugiés congolais ont d'importants besoins non satisfaits en matière de santé reproductive. La santé maternelle et l'accouchement se caractérisent par des ressources humaines insuffisantes, des médicaments incompatibles, des problèmes de discrimination, de corruption et de communication. La disponibilité des produits contraceptifs, y compris la contraception d'urgence, est limitée dans les camps, en raison des problèmes de gestion de la chaîne d'approvisionnement et du vol par le personnel; manque de connaissances en matière de contraception chez les réfugiés congolais. Enfin, la restriction légale de l'avortement conduit à l'avortement à risque parmi les réfugiés et constitue un obstacle à la fourniture de soins post-avortement. Cette étude donne un aperçu des possibilités d'améliorer la prestation de services de santé sexuelle et reproductive aux réfugiés en Ouganda afin de

s'assurer que l'infrastructure et les processus s'harmonisent avec les politiques nationales et les directives internationales.

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Abbreviations and acronyms

DHS	Demographic and Health Survey
DRC	Democratic Republic of the Congo
EC	Emergency contraception
FGD	Focus group discussion
ICPD	International Conference on Population and Development
IDI	In-depth interview
IDP	Internally displaced person
IYAFP	Youth Alliance for Family Planning
SDGs	Sustainable Developmental Goals
SGBV	Sexual and gender-based violence
SRH	Sexual and reproductive health
STI	Sexually transmitted infection
UNFPA	United Nations Population Fund
UNHCR	United Nations High Commissioner for Refugees
UYAFPAH	Uganda Youth Alliance for Family Planning and Adolescent Health
WHO	World Health Organization

Chapter 1: Introduction

As stated by the United Nations Populations Fund (UNFPA), “good sexual and reproductive health is a state of complete physical, mental and social well-being in all matters relating to the reproductive system” (UNFPA, 2017). Reproductive health encompasses a number of different components including family planning, sexual health, and maternal health; and plays an important role in psychosocial comfort and personal and social maturation. Therefore, poor reproductive health can have detrimental consequences, which can be associated with or manifested as disease, abuse, exploitation, unintended pregnancy, disability, and death (United Nations Inter-Agency Task Force on Implementation of the ICPD Programme of Action, 2016). Factors affecting reproductive health include cultural, political, economic, and social circumstances. War and conflict can also affect reproductive health negatively (World Health Organization, 2000). Conflict-affected areas essentially reduce the availability of sexual and reproductive health services and rights and simultaneously place women at greater risk of sexual and gender-based violence (SGBV) (Marsh, Purdin, & Navani, 2006).

The current refugee crisis is the largest the world has experienced since World War II. Globally, there are approximately 125 million people who require humanitarian aid (United Nations, 2016) and over 75% are women and children (UNFPA, 2016). By the end of 2017, 68.5 million people were forcibly displaced and 25.4 million are refugees (United Nations High Commissioner for Refugees [UNHCR], 2018a). Low and middle income countries host the overwhelming majority of these displaced people which burdens already limited infrastructure and services. In conflict-affected situations, reproductive health needs tend to increase but access to services and resources decrease (Austin, Guy, Lee-Jones, McGinn, & Schlecht, 2008).

Women and children are especially vulnerable when safety is not guaranteed, and the environment is volatile.

Background

The Democratic Republic of the Congo (DRC) is the second largest country in Africa and the 11th largest country globally (Central Intelligence Agency, 2017a). With a population just over 81 million, the DRC is one of the world's least developed countries (United Nations Committee for Development Policy, 2017) and has long been plagued by war, corruption, and poverty. After 75 years of colonial occupation and administration, the Belgians relinquished control of the country in 1960. The newly independent DRC was left with minimal political, financial, and social structures where riots and protests were common and had a destabilizing effect on the country as a whole (Alemazung, 2013). The dictatorship that emerged in 1965 exacerbated existing instability and created governance and economic systems based on corruption and exploitation of both human and natural resources (Kabemba, 2005). Over time, the redirection of resources to the military and the coffers of political elites led to the impoverishment of the nation and continuous unrest.

Despite accomplishments and the inroads made toward unifying the country, President Joseph Kabila's administration continued a long tradition of providing minimal social services and support to the population (Stearns, 2007). According to the World Health Organization (WHO), in 2015 the maternal mortality ratio in the DRC was 693 deaths per 100,000 live births (World Health Organization, 2015a). The World Bank reported the 2014-2015 contraceptive

prevalence rate as 20% (World Bank, 2016a) and the prevalence of HIV as 0.8% among persons aged 15 to 49 years old (World Bank, 2016b).

Additionally, the army is widely recognized for routinely terrorizing the population that it is meant to serve and protect, resulting in the displacement of half a million people in 2006 (Stearns, 2007). In the past, the DRC has been cited as the “rape capital of the world” (BBC News, 2010) and currently, systematic rape is a weapon of war that is employed by many armed forces in the eastern DRC and women are at considerable risk of being forced into sexual slavery by armed groups and other traffickers (United States Government Accountability Office, 2011). Indeed, the United States Government Accountability Offices estimated that 8% and 6% of women in conflict-affected North Kivu and South Kivu, respectively, experienced sexual violence in 2006 (United States Government Accountability Office, 2011). The 2013 Demographic and Health Survey (DHS) that sampled 18,000 households from all provinces of the DRC revealed that 27% of women in the DRC experienced sexual violence and that 57% had suffered physical or sexual violence (U.S. Agency for International Development, 2016). Evidence suggests that the prevalence of SGBV is highest in conflict-affected regions and among internally displaced persons (IDPs) and the consequences of sexual and gender-based violence (SGBV) are extensive. Physical effects include the contraction of sexually transmitted infections (STIs) and HIV, fistulas, and unintended pregnancies. An unintended pregnancy can have a significant impact on reproductive health, as abortion is only legally permissible to save the life of the woman in the DRC. As such, women who become pregnant as a result of rape are unable to obtain safe and legal abortion care.

Currently, the DRC hosts more than 4.49 million IDPs, of which 2 million were displaced in 2017 alone (United Nation Office for the Coordination of Humanitarian Affairs, 2018). Further, 630,000 Congolese refugees live in neighbouring countries such as Uganda, Rwanda, Tanzania, Burundi, Kenya, Congo (Brazzaville), Central African Republic, Ethiopia, and Sudan (European Civil Protection and Humanitarian Aid Operations, 2018). The Congolese population from the DRC primarily immigrates to Uganda in the east, which as of July 31, 2018 hosted 316,968 Congolese refugees (United Nations High Commissioner for Refugees & Government of Uganda, 2018).

Refugees in Uganda

Uganda is a landlocked country in Africa that borders 877 km of the DRC to the west, South Sudan, Kenya, Tanzania and Rwanda (Central Intelligence Agency, 2017b). As a result of the global refugee crisis, Uganda hosts just over 1.4 million refugees and asylum seekers from 13 different countries (Norwegian Refugee Council, 2017). It is now the fifth largest refugee-hosting country in the world and the largest refugee-hosting country in Africa (United Nations Development Programme, 2017). Although there have been allegations that members of the Ugandan government have inflated refugee figures to secure aid (BBC News, 2018; Biryabarema, 2018), the refugee population in the country is significant. In collaboration with the government of Uganda, the United Nations High Commissioner for Refugees (UNHCR) operates a number of refugee camps throughout Uganda. Refugees from Burundi, the DRC, and South Sudan receive refugee status on a *prima facie* basis (Office of the Prime Minister, 2016). This means that asylum seekers from these countries are granted refugee status based on

“readily apparent, objective circumstances in the country of origin giving rise to the exodus. The purpose is to ensure admission to safety, protection from *refoulement* and basic humanitarian treatment to those patently in need of it” (United Nations High Commissioner for Refugees, 2001, p. 1-2).

Uganda is considered one of the most hospitable places in sub-Saharan Africa to seek asylum (BBC News, 2016; Titz & Feck, 2017; World Bank, 2016c). With its progressive 2006 Refugee Act and the 2010 Refugee Regulations, refugees have a number of rights, including access to healthcare and education in refugee settlements, and are given land (Government of Uganda, 2006, 2010). Refugees also have the freedom of movement in Uganda, but they are “subject to reasonable restrictions specified in the laws of Uganda, or directions issued by the Commissioner” (Government of Uganda, 2006, p. 25). Hence, refugees are permitted to live beyond refugee settlements, but they must demonstrate that they have employment and a place to live (Bernstein & Okello, 2007; Pangilinan, 2012). This often means that refugees relinquish any external assistance and must be completely self-reliant. Within settlements refugees often face challenges and thus many decide to self-settle in urban areas such as Kampala, Uganda’s capital city (Hovil, 2007).

Challenges for displaced women and girls

Although this contemporary response to the humanitarian crisis encourages refugees to become self-sufficient and essentially start a new life in Uganda, many still face persistent challenges, particularly refugee women and girls. Women and girls in refugee camps in Uganda are at risk of (SGBV), including rape, early marriage, forced impregnation, sexual slavery, and

domestic abuse (University of Waterloo, 2016). To collect firewood, women in refugee camps in Uganda often travel outside the camps on foot (Ilcan, Oliver, & Connoy, 2015), which can make them vulnerable to various abuses. In 2013, 85% of the 716 SGBV cases reported in refugee settlements in the southwestern region of Uganda were against women and girls (United Nations High Commissioner for Refugees, 2014a).

In Uganda, some displaced persons self-settle in areas beyond refugee camps. Reasons for this include “inter-ethnic tensions or discrimination, not to mention inadequate humanitarian assistance, medical care, and educational opportunities” (Human Rights Watch, 2002). Many refugees from the DRC and from larger towns in the eastern region of the DRC such as Goma, Bukavu, and Uvira, in particular, choose to settle in Kampala, in hopes of finding employment, education, and business opportunities (Kigozi, 2015). Therefore, increasing numbers of refugees “unofficially” navigate their way around the demonstration of self-reliance and “simply slip out of the camps” (Human Rights Watch, 2002; Kigozi, 2015) and end up in the capital. Many also arrive in Kampala directly from their country of origin on trucks, trolleys, and buses that have a final destination of Kampala (Human Rights Watch, 2002). As such, although they may fit the legal definition of a refugee, they are not officially recognized as refugees. The absence of legal documentation results in their ineligibility for humanitarian assistance (Hovil, 2007). Although research on these self-settled refugees in Uganda is limited, there is some evidence suggesting that these urban refugees have difficulties accessing basic health services, finding shelter, and securing protection (Bernstein & Okello, 2007; Human Rights Watch, 2002; Kobia & Cranfield, 2009; Women’s Refugee Commission, 2011a). Compounded issues of

language and identification as foreigners places them at greater risk for xenophobic and discriminatory actions (Kigozi, 2015).

Furthermore, these women may engage in remunerative sex work to gain a livelihood and shelter (Women's Refugee Commission, 2016). In a study conducted by the Women's Refugee Commission, 62% of 91 urban refugee respondents in Kampala indicated that they have been pressured to engage in sexual intercourse to acquire money for rent or safety or to secure employment (Women's Refugee Commission, 2016). This exposes refugees to a plethora of problems, from contracting STIs, to heightened risk of SGBV and unintended pregnancy. Unfortunately for these women, there is inadequate provision of reproductive health services (Women's Refugee Commission, 2016), leaving displaced women with minimal options of addressing the physical, mental, and emotional consequences of their encounters. It is important to note that in Uganda sex work is illegal; and as a result, women fear reporting incidences of violence (Women's Refugee Commission, 2016). Abortion is also illegal, except in a limited number of circumstances (Prada et al., 2016). Therefore, women may resort to various methods to induce an unsafe abortion, which is a leading cause of maternal death and disability and moreover, they may not seek follow-up care for fear of being reported.

Rationale

The 1994 International Conference of Population and Development (ICPD), organized by the United Nations, ushered in a new emphasis on the reproductive rights of displaced persons globally. Over 20 years ago, the ICPD lawfully outlined the reproductive health rights of refugees and IDPs internationally. Since then, we have observed the growth of a body of

research focused on addressing the comprehensive sexual and reproductive health needs of these populations. Most studies focus on refugees in camp-based settings; these refugees usually have greater access to health care than they did in their conflict-affected home country (McGinn, 2000). Far less is known about urban refugees, their reproductive health needs, and their access to and use of available services (Austin et al., 2008; Women's Refugee Commission, 2016). Despite international legislation and great efforts to improve access over the years, there is still inadequate provision of reproductive health services to displaced populations whose numbers are only increasing globally (Cohen, 2009a).

This multi-methods qualitative study assessed the sexual and reproductive health needs of displaced women from the DRC in camp- and urban-based settings in Uganda. Also, this study explored the factors affecting decision-making and access to reproductive health services for these populations in Uganda. To perform this assessment, we conducted fieldwork in both Kampala and the UNHCR-operated Nakivale refugee camp in the Isingiro district of Uganda.

Research objectives

The study focuses on maternal health and delivery care, contraception (including both long-acting reversible and emergency contraceptive methods), and abortion/post-abortion care. Importantly, this project also specifically explores the intersection of these reproductive health issues with sexual and gender-based violence and the rape-unintended pregnancy-abortion nexus. Specifically, through this qualitative study we aimed to:

1. Explore the state of reproductive health of displaced Congolese women of reproductive age (15-49) in both urban and camp settings in Uganda;

2. Document displaced Congolese women's maternal health, contraception, abortion/post-abortion, and SGBV experiences and their opinions of available services, facilitators and barriers to access, and how service delivery could be improved; and
3. Identify avenues for improving service delivery and accessibility at the policy, systems, and institutional levels.

Thesis outline

I have chosen to write a thesis-by-articles consisting of six chapters.

1. Chapter one: The first chapter, which is the introduction, provides background information on the project and the local context. This chapter describes the global humanitarian crisis, the violence in the DRC that has resulted in the migration of its people, and the challenges refugee women and girls face in Uganda. This section also includes the study rationale and objectives of the project.
2. Chapter two: The second chapter presents the methods. This chapter provides details about the study location, methods of data collection, and analytic approach employed. I conclude the chapter with a statement of contribution.
3. Chapter three: The third chapter presents the first article which focuses on maternal health and delivery care. This article presents the service delivery and utilization challenges experienced by refugees and is formatted for submission to *Maternal Child Health Journal*.

4. Chapter four: The fourth chapter presents the second of three articles drafted for submission to pre-selected peer-reviewed journals. This article focuses on emergency contraception and is formatted for submission to *Contraception*.
5. Chapter five: This chapter presents the third article in this thesis which focuses on abortion and post-abortion care. This article has been formatted for submission to *Reproductive Health Matters*.
6. Chapter six: This is the final chapter which integrates all the findings from the project, explores the implications of those findings, and offers recommendations for improving the provision of sexual and reproductive health services to refugees in both camp and urban settings in Uganda. I conclude this chapter with a brief discussion of positionality and reflexivity.

Chapter 2: Methods

Study design

The approach of this reproductive health needs assessment has been modified from the standards developed by the UNFPA (United Nations Population Fund, 2010) and previous assessments with refugee and displaced populations conducted by Dr. Angel M. Foster's research group (Hobstetter et al., 2015; Sheehy, Aung, Sietstra, & Foster, 2015). The project comprised of four distinct components: 1) Collecting and reviewing both published and unpublished literature, reports, and organizational data; 2) Interviewing key informants; 3) Facilitating focus group discussions (FGDs) with married and unmarried women; and 4) Conducting in-depth interviews with displaced women. To assess the needs of both urban and camp populations, I conducted fieldwork in both Kampala and at the Nakivale Refugee Settlement.

Field sites

Kampala, centrally located in Uganda, is the largest city in the country as well as the nation's capital. Situated on Lake Victoria, one of the African Great Lakes, Kampala has five boroughs: Kampala Central Division, Kawempe Division, Makindye Division, Nakawa Division, and Lubaga Division (Kampala Capital City Authority, n.d.). With a population of just over 1.5 million, it is one of the fastest growing cities in Africa (Uganda Bureau of Statistics, 2016). Many refugees settle in slum areas and aggregate according to country of origin. Congolese refugees populate various neighbourhoods such as Katwe, Makindye, and Masajja (Women's Refugee Commission, 2016).

The Nakivale refugee settlement, often the site of research studies, is located in the southwestern region of Uganda in the Isingiro district and is operated by UNHCR. Recent figures suggest that the Nakivale Refugee Settlement hosts 101,403 refugees and asylum seekers; approximately 48,061 of these people are refugees from the DRC (United Nations High Commissioner for Refugees, 2018b, 2018c). The Nakivale Refugee Settlement was established in 1958, but officially recognized in 1960; making it one of the oldest camps in Africa and Uganda's oldest camp (Bøås, 2014). The Nakivale camp hosts refugees from Burundi, the DRC, Eritrea, Ethiopia, Kenya, Liberia, Rwanda, Somalia, South Sudan, Sudan, and Tanzania (United Nations High Commissioner for Refugees, 2014b). The figure in **Appendix A** shows the location of our field sites.

Data collection methods

Collecting and reviewing existing data

We began by systematically reviewing the existing published literature and collecting and reviewing information from local organizations that currently provide health services to displaced persons. This component of the project aided in establishing the overall reproductive health picture of displaced Congolese women in Uganda. In collecting information, we engaged with local stakeholders which facilitated relationships that were vital to completing other components of this project and recruiting interview participants.

Interviewing key informants

Using a purposive and snowball recruitment strategy, we conducted 11 interviews with well-positioned key informants to explore the perspectives of different individuals and agencies regarding the reproductive health needs and services for displaced women. These professionals included representatives from the Ministry of Health, health service providers, non-governmental organization (NGO) representatives, and community leaders. Using publicly available information, study team contacts, early participant referral, and the support of a local research assistant we identified appropriate individuals to conduct interviews.

Key informant interviews allowed us to document available services and explore professional perspectives on availability, accessibility, and priorities for improvement. We used a semi-structured interview guide developed specifically for this study and adapted the guide to different participants. With permission, I audio-recorded all interviews and conducted them in English.

Facilitating focus group discussions with displaced women

We facilitated four FDGs, each of which included 5-10 displaced women of reproductive age (15-49) for a total of 36 participants. In order to create a degree of homogeneity within groups, we designed the FDGs around marital status and location. We conducted two discussions, one with married women and the other with unmarried women, in each location. We recruited participants through two local and refugee-focused organizations, through word-of-mouth, and participant referral. Discussions focused on the central topics (maternal health and delivery care, contraception, abortion/post-abortion care, and SGBV) and explored community knowledge, access to and utilization of reproductive health services, facilitators and

barriers to access, and priorities for improvement. As is true of FGDs in general, this component focused on eliciting community norms and standards but did not focus on detailed individual experiences. We audio-recorded all discussions which we conducted in French, Lingala and/or Swahili (with the aid of an interpreter). To thank participants for their participation in this study, we offered participants refreshments and reimbursements for any childcare or transportation costs.

Conducting in-depth interviews with displaced women

Finally, we conducted 21 in-depth interviews with displaced women, aged 15-49. We recruited participants through two local and refugee-focused organizations through word-of-mouth and early participant referral. These interviews focused on women's individual sexual and reproductive health experiences both before and after displacement. These interviews followed a semi-structured format and provided information about the care and services available as well as individual perspectives on areas for service delivery improvement. With one exception, all in-depth interviews were audio-recorded and interviews were conducted in Lingala, French and/or Swahili (with the aid of an interpreter). To thank women for their participation in this study, we offered reimbursements for any childcare or transportation costs.

Data analysis

We employed an iterative analytic process and began data analysis during the data collection phase. Throughout the project, I formally memoed after each encounter, a process which allowed for the ongoing identification of emergent themes and patterns as well as

reflection on the researcher-participant (and sometimes interpreter) dynamics (Birks, Chapman, & Francis, 2008). I also took extensive notes during each interview and discussion and debriefed with interpreters immediately after each interaction. All audio-files were translated and transcribed into English and we used *Nvivo 11.4.3* to manage the data, which include transcripts, notes, and memos. We first developed a codebook with *a priori* codes derived from research questions and the literature, and later added emergent codes and categories as we familiarized ourselves with the data. We resolved differences in interpretations through regular meetings with my supervisor, which guided the identification of themes.

Theoretical framework

Practical action research, situated within an interpretivist paradigm, serves as the theoretical foundation for this project (Masters, 1995). As is characteristic of action research, in general, the design embraces planning, acting, observing, and reflecting throughout the life of the project (Zuber-Skenitt, 1993). In consultation with humanitarian sector stakeholders, the very practical concern that we addressed was defined and the project acquired knowledge with the aim of effecting social change.

Ethics clearance

This project complies with the standards set forth in the Tri-Council Policy Statement 2 (TCPS-2) for Research Involving Humans. Core principles of the TCPS-2 were upheld and

maintained throughout this project including respect for persons, concern for welfare, and justice.

We received ethical clearance from the Social Sciences and Humanities Research Ethics Board at the University of Ottawa (File #: 04-17-15). To ensure that this project met appropriate local standards, we also obtained ethical clearance from the School of Medicine Research Ethics Committee at Makerere University in Uganda (File #: 2017-073) and the Uganda National Council of Science and Technology (File #: SS-4321). Letters of approval are included in **Appendices B-D** respectively. Additionally, given the nature of this project and the participants, we also obtained research clearance from the Office of the Prime Minister in Uganda; this allowed us to conduct research at the Nakivale Refugee Settlement.

Statement of contribution

As the principal investigator of this project, I designed the project, developed the study instruments, obtained Canadian and local ethical clearance, conducted data collection and analysis, and drafted three articles for submission to specific peer-reviewed journals.

Throughout all phases of this project, my supervisor Dr. Foster provided significant guidance. She supported the development of the proposal, research tools, ethics applications, and funding applications, as well as drafting of the articles. Furthermore, Dr. Foster led a two-day qualitative workshop where I participated in 16 hours of interactive training on qualitative study design, instrument development, in-depth interviewing techniques, and focus group discussion facilitation. She has also provided significant training on dissemination.

My research assistant for this project, Amanda Banura, assisted in obtaining local ethical clearance and facilitated my connection with two organizations that later helped with participant recruitment and provided Swahili-English interpreters for interviews and FGDs. As the country coordinator for International Youth Alliance for Family Planning (IYAFP) and a member of the Uganda Youth Alliance for Family Planning and Adolescent Health (UYAFPAH), her experience with various local grassroots organizations provided guidance on various sexual and reproductive health networks in Uganda. She also contributed to all three articles presented in this thesis.

Chapter 3: Article #1

We will be submitting this article to the Maternal Child Health Journal in September 2018. Therefore, this article has been formatted for submission to that journal and the manuscript adheres to the style, word limit, and citation guidelines for this journal.

“Women give birth from the floor and others lose their children in the womb because there is no one to help them”: A multi-methods qualitative study of the pregnancy and delivery care experiences of Congolese refugees in Uganda

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“Women give birth from the floor and others lose their children in the womb because there is no one to help them”: A multi-methods qualitative study of the pregnancy and delivery care experiences of Congolese refugees in Uganda

Abstract

Introduction: Uganda hosts just over 1.4 million refugees and is widely regarded as one of the most hospitable places in the world for displaced populations. Despite a multitude of global efforts to reduce displaced women’s risk of maternal death and disability, and policies in Uganda that entitle refugees to free healthcare, the availability and accessibility of safe and professional delivery care remains inadequate. Using a multi-methods approach we aimed to explore the pregnancy and delivery care experiences of Congolese refugees living in Uganda as well as ways that services could be improved.

Methods: In 2017, we assessed Congolese women’s reproductive health needs in Kampala and the Nakivale Refugee Settlement. Our assessment included a review of the published literature and institutional records, 11 key informant interviews, four focus group discussions with married and unmarried Congolese women, and 21 in-person in-depth interviews with Congolese women. We analyzed these data for content and themes using inductive and deductive techniques. In the final phase of the analytic plan, we integrated findings from each study component to identify concordant and discordant results. In this paper, we focus on maternity care-related results.

Results: Our findings indicate that Congolese refugees in Uganda experience significant challenges accessing delivery care in both camp-based and urban settings. The availability of trained healthcare staff is limited, health facilities and the supply of medications are inadequate, and referral systems are deficient. Refugee women report that corruption and bribes, discrimination, language barriers, and lack of privacy characterize their delivery experiences.

Conclusion: Efforts to increase trained healthcare staff, improve supply-chain management, and maintain infrastructure and equipment are imperative. Ensuring compliance with anti-bribery and anti-corruption policies, and respectful maternity care is also important. Finally, creating approaches to overcome language barriers is crucial to minimizing miscommunication and building patient-provider trust.

Keywords

Democratic Republic of the Congo, maternal health, pregnancy, qualitative research, refugees, Uganda

Significance

Understanding the barriers that refugee women face when seeking safe delivery care in both urban and camp settings is critical for improving the quality of and facilitating access to services. Addressing these service delivery challenges through fortifying the supply chain and supporting the training of health service professionals are clear priorities, combined with efforts

to combat discrimination, and provide culturally and linguistically responsive care could improve service utilization.

Introduction

By the end of 2017, approximately 68.5 million people had been forcibly displaced globally as a result of insecurity, war, and natural disasters compared to 65.6 million people in 2016 (United Nations High Commissioner for Refugees [UNHCR], 2018a). Newly registered refugees accounting for this 2.9 million increase largely came from South Sudan, Myanmar, Syria and several countries in central and eastern Africa including the Democratic Republic of Congo (DRC) (UNHCR, 2018a). Of those displaced, 25.4 million are refugees and 52% are children below the age of 18 (UNHCR, 2018a); women and girls make up approximately 50% of the refugee population (UNHCR, n.d.). Low- and middle-income countries host the overwhelming majority of displaced people (UNHCR, 2018a), a dynamic that further burdens already limited and weak health systems and infrastructure. For example, in 2017 Uganda, a lower-middle income country was the largest refugee-hosting nation in Africa (UNHCR, 2018a; United Nations Children's Fund [UNICEF] Uganda, 2017). With a population of just over 41 million, Uganda hosts approximately 1.4 million refugees from 13 different countries, and the number of refugees is only increasing. (UNICEF, 2018; UNHCR & Government of Uganda, 2018)

Historically, lack of prioritization of comprehensive reproductive health care characterized the humanitarian sector (Austin, Guy, Lee-Jones, McGinn, & Schlecht, 2008). However, over the last two decades, the global community has focused considerable attention on responding to the reproductive health needs of refugees and displaced populations. The creation of global networks (Inter-agency Working Group on Reproductive Health in Crises, 2018), the development of global guidelines (Foster et al., 2017), and the launch of global and setting-specific initiatives (Al-Makaleh, Howard, & Ateva, 2017) have collectively aimed to

reduce maternal death and disability in refugee, crisis, conflict, and emergency settings. Yet despite these efforts, in 2015, 61% of global maternal deaths occurred in 35 countries affected by humanitarian crises and/or defined as fragile states (United Nations Population Fund [UNFPA], 2015). Thus the availability and accessibility of safe, high-quality delivery care remains inadequate in many humanitarian settings (UNICEF, 2016). In general, women in conflict-affected settings are at higher risk of unintended pregnancy, as a result of the increased risk of rape, coerced sex, and engagement in transactional sex, disruptions in contraceptive supply and use, and changes in pregnancy intentions from the pre-displacement period (Cohen, 2009). These women are also at greater risk of dying during pregnancy due to unsafe abortion, pregnancy-related complications, and delivery complications, especially post-partum hemorrhage (UNFPA, 2016).

Refugee women and girls residing in Uganda face similar challenges. Uganda is widely recognized for its positive response to humanitarian crises and its progressive refugee policies, which encourage self-sufficiency and local integration and offer free healthcare (World Bank, 2017). With the recent influx of refugees into Uganda, reproductive health services are stretched thin (Ekayu, 2017; Fossvik, 2017). The migration of Congolese populations into Uganda has been consistent since 2012, but recent armed conflict in the eastern DRC region of Ituri has displaced even more people and Uganda hosts the largest Congolese refugee population of 316, 968 which constitutes 21.1% of all refugees in this resource-strapped country (UNHCR & Government of Uganda, 2018). The majority of these Congolese refugees reside in rural refugee settlements in central and western Uganda; about 41,000 reside in Kampala, the capital city (UNHCR, 2018b). Women and girls in refugee settlements in Uganda

are at risk of sexual and gender-based violence (University of Waterloo, 2016) and while research on urban refugees is limited, there is some evidence suggesting that urban refugees face difficulties accessing basic health services, finding shelter, and securing protection (Bernstein & Okello, 2007; Human Rights Watch, 2002; Women's Refugee Commission, 2011).

This context motivated our decision to undertake a multi-methods assessment to better understand the comprehensive reproductive health needs of Congolese women living in Uganda and explore avenues by which services could be improved. In this manuscript, we focus specifically on the results related to delivery care.

Methods

Our multi-disciplinary, multi-national, multi-lingual study team collected data in the summer of 2017. We based our study design on the reproductive health needs assessment standards developed by the UNFPA (UNFPA, 2010) and previous reproductive health needs assessments conducted with refugee and displaced populations (Hobstetter et al., 2012; Sheehy et al., 2015). Our assessment included a review of published literature and institutional reports and statistics, interviews with 11 key informants, four focus group discussions (FGDs) with married (n=2) and unmarried (n=2) refugee women, and 21 in-depth interviews with Congolese women. RN, a Canadian-Congolese master's student in the Interdisciplinary Health Sciences program at the University of Ottawa, led data collection for all study components after receiving training from AMF, a medical anthropologist and medical doctor who has conducted reproductive health-related research with refugee populations in multiple countries.

Study sites

In order to understand the needs and capture the experiences of both camp- and urban-based refugees, we conducted our study in the Nakivale Refugee Settlement and Kampala (see Fig. 1). The Nakivale Refugee Settlement was established in 1958 and officially recognized two years later. Located in the Isingiro district in the southwestern region of Uganda, the Nakivale Refugee Settlement is one of the oldest camps in Africa and the oldest camp in Uganda (UNHCR, 2018c). Currently, it is operated by UNHCR and hosts just over 100,000 refugees and asylum seekers (UNHCR, 2018c). The camp stretches 185 square kilometres and is divided into 79 villages (UNHCR, 2014). Characterized by hills, streams, and fertile land, with homes made of brick with corrugated tin roofs, the camp hosts refugees from Burundi, the DRC, Eritrea, Ethiopia, Rwanda, Somalia, and South Sudan (UNHCR, 2018b); Congolese refugees constitute about 47.4% of the camp population.

Kampala, Uganda's capital is the largest city in the country. Situated on Lake Victoria, the city is divided into five boroughs: Kampala Central Division, Kawempe Division, Makindye Division, Nakawa Division, and Lubaga Division. With a population of just over 1.5 million, Kampala is one of the fastest growing cities in Africa (Uganda Bureau of Statistics, 2016). Many refugees choose to self-settle in Kampala due to both discrimination and limited services in refugee camps (Human Rights Watch, 2002) and the employment, education, and business opportunities available in the city (Kigozi, 2015). Refugees often reside in slum areas of Kampala and typically aggregate in areas according to country of origin. Congolese refugees from the eastern region of the DRC primarily populate neighbourhoods in the Makindye Division (Women's Refugee Commission, 2016).

Data collection: Key informant interviews

We conducted 11 in-person interviews with well-positioned key informants including policy makers, health service providers, and non-governmental organization (NGO) representatives working in the humanitarian sector or with refugees. We purposively recruited participants based on publicly available information, study team contacts, and early participant referral. Using a semi-structured interview guide, we aimed to explore key informants' perspectives on the availability, accessibility, and affordability of comprehensive reproductive health services, facilitators and barriers to service utilization, and priorities for improvement. RN conducted all interviews in English with AB present. Interviews took place at a time and location convenient for participants and lasted an average of 45 minutes. We audio-recorded, took notes during, and formally memoed after each interview.

Data collection: Focus group discussions

We worked with two local NGOs to recruit women of reproductive age (age 15 to 49, inclusive) for our focus group discussions. In order to ensure some degree of homogeneity, we stratified discussion groups by marital status and geography. Thus, as indicated in Fig 2, we conducted two FGDs in Nakivale Refugee Settlement and two FGDs in Kampala; a total of 36 women participated in the four FGDs. RN facilitated the discussions, which took place in a combination of French, Lingala, and Swahili, with the assistance of one female Congolese research assistant at each site. We used an FGD guide, developed specifically for this study, that explored central topics (maternal health and delivery care, contraception, and abortion/post-abortion care) and

community knowledge of, access to, and utilization of reproductive health services, facilitators and barriers to access, and priorities for improvement. We audio-recorded all FGDs; RN also debriefed with each research assistant after each discussion and formally memoed soon thereafter.

Data collection: In-depth interviews

Finally, our team conducted 21 in-person in-depth interviews with refugee women from the Nakivale Refugee Settlement (n=10) and Kampala (n=11). RN conducted interviews in French, Lingala, and Swahili (with assistance from one of two local research assistants). We recruited participants with the assistance of two local NGOs as well as through flyers at health facilities and word-of-mouth. The interviews followed a semi-structured format and focused on women's individual sexual and reproductive health experiences both before and after displacement, the care and services available, as well as individual perspectives on the ways in which services can be improved. Interviews lasted an average of 50 minutes; we audio-recorded all but two. RN took notes during the interviews and formally memoed immediately thereafter.

Data analysis

We employed an iterative, multi-phased analytic plan that began during data collection. Based on our research objectives, interview and discussion guides, and knowledge of the literature we developed an initial codebook comprised of a priori (predetermined) codes and categories. We then used inductive techniques to add emergent codes and categories. We coded our data,

which included transcripts (translated to English), notes, and memos, first for codes and categories and then later for themes (Denzin & Lincoln, 2011; Elo & Kyngäs, 2008); we used *NVivo 11.4.3* to manage our data. Team meetings between RN and AMF guided our interpretation; we resolved differences through discussion.

We initially analyzed each study component separately; the final analytic phase included combining our findings, paying specific attention to concordant and discordant results. In 2017-2018, we presented our preliminary findings to stakeholders at several international meetings; we incorporated the feedback we received into our final recommendations. Triangulation of multiple data sources allowed us to identify prominent themes, which we present in the results section.

Ethics

The Research Ethics Board at the University of Ottawa approved this study. We also received ethics approval from Makerere University and the Uganda National Council of Science and Technology, and research permission from the Office of the Prime Minister in Uganda. In this manuscript, we have removed or masked all personally identifying information and used pseudonyms for our participants.

Results

Availability of trained healthcare staff is limited

Our findings suggest that the availability of trained healthcare staff in health facilities is limited in both refugee camp and urban refugee settings. Key informants reported that health care

facilities are significantly understaffed. As explained by a physician at the Nakivale Refugee Settlement, “[The recommended] clinician-patient ratio per day, for UNHCR, it's 1 to 50...But you will find in Nakivale, you have 1 to 80 per day, 1 to 100 per day.” In Kampala, key informants highlighted the same challenges. As one service provider from Kampala mentioned, “There are many women who need care and the providers are not enough.”

Consistent with our key informants, women who participated in both our FGDs and in-depth interviews repeatedly reported that upon arriving at maternity wards, there were no trained professionals to provide delivery care. Indeed, multiple women in both Nakivale Refugee Settlement and Kampala explained that health service professionals would often ask women in the facility to help patients in labour. As Josephine, a 34-year-old woman from Kampala reported during an interview. She said that if a woman “[has] not given birth, the doctor sometimes will not [see] you.” Rather, physicians will instead ask the person accompanying the patient to provide care even though those women are not trained healthcare staff. This was consistent with several refugee women who explained that they had assisted each other with delivery because health service professionals were unavailable or indisposed. As Prudence, a 48-year old refugee from the Nakivale Refugee Settlement explained:

There was a day I accompanied a woman who was going to give birth [to the health facility]. There was only one nurse who was alone and already tired and she had to go and get lunch. But there was a woman who was already giving birth and she was shouting, “Doctor! Doctor!” So I entered and got some materials and when the nurse came in she asked if I was a nurse, I said yes. I could not see a woman suffering.

Health facilities, equipment, and medications are inadequate to meet existing needs

Women and key informants alike reported challenges surrounding health facility infrastructure, emphasizing the small size of delivery rooms and the inadequacy of equipment. For example, a physician in Nakivale Refugee Settlement explained that there are only two delivery beds, even though approximately 150 women deliver in the facility each month. This information is consistent with the experiences of refugee women; many participants reported having witnessed women giving birth on the floor due to the lack of hospital beds. Patricia, a 15-year-old from the Nakivale Refugee Settlement, described her experience when she accompanied her friend to the hospital: “Women give birth from the floor and others lose their children in the womb because there is no one to help them.” Participants also reported being asked to move to the floor so that a labouring woman who was, further along, could use the bed. As described by Nadia, a 30-year-old refugee woman living in the camp, “Women here do suffer. First of all, there are only two beds. If you are in pain and you are on the bed, [and] someone else who comes in, is [worse] condition, they will ask you to go down and sleep on a plastic bag”. One unmarried participant in the FDG from the Nakivale Refugee Settlement described her experience: “I gave birth at the hands of the person who was with me. There are only two beds which are used to give birth from. There was a woman who came in [after me]. They told me [to move] to the ground, and as I stood up, my child came out and went down [on the floor].”

But this lack of infrastructure was not unique to camp-based refugees. Indeed, both key informants and Congolese women raised concerns about health facilities in Kampala as well. A key informant working for a non-governmental reproductive health service provider in Kampala

explained that because of the sheer number of women seeking maternal and delivery care, “[A woman in labour] has to delay and sleep on the floor because there are no beds in the facility.”

Further, women also mentioned that facilities lacked the necessary equipment to ensure the provision of high-quality maternal health care. As 42-year-old Aminata from the Nakivale Refugee Settlement explained, “Here there are no machines that operate. There is no echography here. They don’t have machines!” Key informants confirmed that women’s individual experiences were reflective of a common problem. As one physician at the Nakivale Refugee Settlement explained, “There are moments when the resources are inadequate and, in reality, you will find [that in] the facilities, there are no medicines, there are no supplies.” These supply-side challenges were echoed by another physician in the Nakivale Refugee Settlement:

And of course, like in a refugee setting like this, we really have challenges in service delivery. The resources are always limited; mainly, medicine. [Here], we mainly target the refugee population, but if you go to most health facilities [in Uganda], you find that some of them will also [serve] more nationals and the host community.

Referral systems for complicated pregnancies are deficient in the camp

Women in the Nakivale Refugee Settlement consistently reported that obtaining a referral due to a pregnancy-related complication is a significant challenge. As one FGD participant stated, “The challenge we have here giving birth is related to transfer, especially when your case cannot be handled by that specific hospital. It has been difficult to get a transfer and we don’t know what to do.” Another woman during a FGD at the Nakivale Refugee Settlement described taking her friend to the hospital when she was in labour and doctors told them to go home as she was not ready to give birth. They returned to the hospital within three days, and she still had not given birth. “They told us to go back home yet the child was about to be born and had a

big head, so it could not come out...[Then] I told them to help us they refused and I asked them to transfer us [to another hospital] and after pleading they just kept quiet.” She continued to plead for her friend’s case and in the end, they were transferred to a regional hospital in Mbarara, approximately 74 kilometres away. They were finally able to obtain care and the baby was delivered safely.

Unlike our other service delivery-related findings, key informants did not feel that there were systematic problems with referral systems. While physicians acknowledged that referral systems and transportation out of the Nakivale Refugee Settlement can be challenging to navigate, they reported that the Ugandan government had made an effort in recent years to improve the referral system by providing ambulances.

Women are required to offer bribes to receive care

Both camp-based and urban refugee women reported that if and when there is a health service professional at the facility, in order to obtain care or be seen urgently, they must offer some sort of “incentive.” One married FGD participant from Kampala reported to lots of nods of agreement, “I have accompanied at least three women to deliver. You reach the hospital and the doctors will not take care of you. They will see you suffering and in pain and they will not mind. Sometimes the doctor will come in if you give them something and that is [a] bribe.” This sentiment was echoed by Imani, a 33-year-old Congolese woman living in Kampala, “Look even at the way they give medicine. They will want you to give them money despite the fact that these drugs are from the government. They will ask for a bribe, but at the same time they are

the ones [prescribing] the medicine and [asking] you to go and buy [the medication] at their pharmacy”.

Women from the DRC face discrimination and language barriers when accessing care

The Congolese women in our study repeatedly reported experiencing discrimination when seeking care. As Marie, a 33-year old refugee living in Kampala explained, “You go to the hospital and you have [an] emergency case, but they will not mind. Sometimes they will ask you for money and you don’t have it. Or sometimes they will say, ‘Ah, leave that Congolese’. When they hear you are a Congolese, they always increase the price.” Marien, a 23-year old refugee also residing Kampala said:

Sometimes when you arrive at the hospital, the first person you meet asks you ‘Where do you come from?’ When you say you are Congolese...it’s something. There is no warm welcome. They say ‘ah this Congolese.’ But they also want your money, so they do their job and that’s why they receive you. But it’s not to say that they receive you like in a good way. Other nationalities are fine, but [for] Congolese and Sudanese, it’s much worse.

That many refugee women are unable to communicate effectively with their health service professionals overlaps with the issue of discrimination. As Josephine described:

The problem we always get first [is] the language barrier. If you manage to get someone who can interpret for you, you can be helped. But when the doctor asks you, he or she realizes that you don’t know the language and then asks people to jump in and [interpret]. So if God helps you [and sends] you someone who can interpret for him, then you can go in and talk to him. But if not, sometimes the doctor can only look...and sometimes the doctor will test what he wants and sometimes the doctor will write what he thinks and you will not be able to tell the doctors what you need.

The language barriers compromise the quality of care as well as the rapport between health service professionals and women requiring services. Consequently, many women

recognized the importance of having someone present who is able to understand the language a woman is speaking when she presents herself at the hospital. As 33-year old Georgina, a refugee in Kampala, said, “It is easier to communicate and explain the whole situation [to an interpreter]. [Then] you can tell the nurse about the situation...and she can easily understand. If you cannot communicate with the nurse, you may risk losing the baby.”

Women lack privacy during delivery

In focus group discussions and interviews, refugee women often raised concerns about the lack of privacy in the maternity ward. As Prudence stated,

[T]he room where women give birth from should be private and should not be the same place for other work. Here you find that the [maternity ward] is more of a public place. [A woman] is giving birth and other people that she doesn't even know are there looking at her, even the cleaners”

Although refugee women in our study appreciated the necessity of having health service providers in the room, they were shocked that “anyone” could enter the maternity ward and therefore see women in labour. Congolese women who had experienced delivery in the DRC were particularly surprised by the contrast. As Josephine, explained:

To the issue of those giving birth here, I don't understand. Because this is not our country, maybe they have their own way of doing things. For example, in Congo, if you are in the labour they put you in a room and that room is only for you and the doctor, no one else can enter there. Maybe if it is another doctor because he or she has to come for the work-related issues. [And] in case there is another woman who is also in labour they [may] also bring her in but when it comes to the time of giving birth they will put you in a separate room. In Congo, a woman cannot give birth when others are looking at her, but the problem which is where you enter the labour unit and it is like a public place, everyone is passing by, it is same room – doctors, men and children.

Discussion

International standards prioritize the provision of respectful maternity care (RMC) (World Health Organization, 2016) and Ugandan legislative provisions state that refugees have a number of rights, including access to Ugandan social services such as healthcare and education (Government of Uganda, 2006, 2010). Moreover, section 29 (1)(b) of the 2006 Refugee Act, states that refugees are entitled to fair and just treatment without discrimination. However, our study reveals that Congolese refugee women living in both the Nakivale Refugee Settlement and the capital of Kampala experience significant challenges in accessing high-quality maternal health and delivery care in Uganda related to both service delivery and service utilization.

Notably, this study shows that there is a great need for trained healthcare professionals in both camp-based and urban health facilities. This lends support to Okello and colleagues study (1998) that highlighted that a shortage and inequitable distribution of qualified health staff in Uganda affects service delivery. Moreover, in 2006 Uganda was listed as one of 57 countries in the world that had a shortage of health workers even though training of health care workers had increased (World Health Organization, 2006). This shortage has remained persistent in the Ugandan health system and has been attributed to unemployment, poor staff motivation due to low salaries, and inadequate maintenance of facilities (Madinah, 2016). This, in turn, contributes to the migration the healthcare workers, including physicians, who seek “better terms and conditions of service” (Omaswa et al., 2017, p.6). It is clear that insufficient human resources delays access to basic care; efforts to reduce the brain drain through

appropriate incentives and retention strategies and to diversify the cadre of health service professionals could also alleviate this burden on other healthcare professionals.

Our study also highlighted drug stock-outs as a challenge in service delivery. Our findings are consistent with results from previous facility surveys that explored the availability of medicines present on Uganda's essential medicines list (Armstrong-Hough et al., 2018; Masters et al., 2014). Results from both studies indicated that medication availability remains inadequate across different facilities in Uganda and that stock-outs remain a common challenge. The lack of drug availability is a direct barrier to care; better management of supply chains should be encouraged.

Finally, our results are consistent with previous studies (Madinah, 2016; Okello, Lubanga, Guwatudde, & Sebina-Zziwa, 1998) that suggest health facilities in Uganda are often ill-equipped, and not adequately maintained, to provide quality care. Our final recommendation on the service delivery side is that facility condition assessments should be conducted on a regular basis so that actionable improvement strategies can be developed. It would also be useful to further explore the dynamics surrounding referrals, as women and key informants had decidedly different perspectives on how complicated pregnancies and deliveries were handled.

Internationally, there increasingly discussions surrounding RMC to ensure safe, accessible, and quality maternal and newborn health care (Reis, Deller, Carr, & Smith, 2012; World Health Organization, 2016). RMC extends beyond simply preventing maternal morbidity or mortality; rather RMC incorporates basic human rights for the woman, including her autonomy, dignity, and feelings (Reis et al., 2012). Despite these international discussions, and

the number of tools and frameworks that define, measure, and aim to prevent disrespectful treatment of women seeking maternal and delivery care (Bohren et al., 2015; Shakibazadeh et al., 2018), our study suggests that RMC is not actively practiced in Uganda for Congolese refugee women. Indeed, the experiences reported by women in our study suggest that mistreatment and discrimination are common.

Bohren and colleagues (2015) outline seven categories of mistreatment, including verbal abuse, stigma and discrimination, failure to meet professional standards of care, and poor rapport between women and providers, and argue that these dynamics significantly shape maternal health and delivery care outcomes. For example, women may be reluctant to seek help from a trained professional in anticipation of negative treatment and may instead seek care from an unskilled individual or forgo care entirely (Bohren et al., 2015). Therefore, it is imperative RMC be an integral component of maternal and delivery care, for all women – including refugee women. Unfortunately, our results are consistent with several studies and reports show that refugee and non-refugee women alike are not receiving respectful and dignified care (Al-Makaleh et al., 2017; Bohren et al., 2015; Bowser & Hill, 2010; Shakibazadeh et al., 2018).

Our study also suggests bribery is a problem. A study by Hunt (2010) showed that healthcare workers, particularly in the public sector, extort bribes from richer Ugandans and also seek payments from the poor, even though policies are supposed to ensure free care. Our findings indicate that this same dynamic is impacting refugees and displaced populations as well. Acknowledging this problem is a necessary first step in developing, implementing, and ensuring adherence to anti-bribery and anti-corruption policies.

Finally, recognizing that refugees in Uganda come from 13 different countries, and are not a homogenous group, engaging healthcare professionals in cultural sensitivity training could help address discrimination. Identifying creative strategies to address the evident language barriers would also help build trust between patients and providers.

Limitations

While we are confident in the themes identified, this multi-methods qualitative study was not meant to be representative or generalizable (Crouch & McKenzie, 2006). We only recruited participants from Nakivale Refugee Settlement and Kampala, therefore, the perspectives of Congolese women living in other areas of Uganda are not reflected in our findings. Nonetheless, based on the rigour of our approach we are confident that these results are transferrable to other Congolese populations in Uganda. Further, we conducted this study in multiple languages (English, French, Lingala, and Swahili). Although this allowed us to engage with a range of participants in the language that was most comfortable for them, it is certainly possible that some nuance or subtlety was lost in translation. We tried to minimize this limitation by working with local NGOs and research assistants. Finally, we recognize that RN's positionality as a Congolese-Canadian woman influenced her interactions with Congolese participants, but also Ugandan stakeholders. Through memoing, debriefings, and regular team meetings, as well as including local research assistants in the team, we believe that we were able to understand these influences and increase the credibility and trustworthiness of this study.

Conclusion

The global humanitarian crisis has left many populations displaced worldwide; Uganda is the leading refugee host nation. But despite its progressive refugee policies, our study suggests there are considerable service delivery and service utilization challenges in both camp and urban settings. Efforts to improve the accessibility and quality of respectful maternal health and delivery care in Uganda should be a priority.

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Figure 1: Map of Uganda and location of study sites



Figure 2: Composition of FGDs (N=4)

FGD	Type	Number of participants	Location	Age range
1	Married women	10	Nakivale Refugee Settlement	27-48
2	Unmarried women	10	Nakivale Refugee Settlement	16-23
3	Married women	6	Kampala	27-46
4	Unmarried women	10	Kampala	15-25

Chapter 4: Article #2

We will be submitting this article to Contraception in October 2018. This article has been formatted for submission to Contraception and the manuscript adheres to the style, word limit, and citation guidelines for this journal.

Assessing the availability and accessibility of emergency contraception in Uganda: A multi-methods study with Congolese refugees

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The authors declare that they have no conflicts of interest, financial or otherwise.

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Assessing the availability and accessibility of emergency contraception in Uganda:

A multi-methods study with Congolese refugees

Abstract

Objectives: In this study, we aimed to understand the availability and accessibility of emergency contraceptive pills for Congolese refugees living in both camp and urban settings in Uganda.

Methods: In 2017, we conducted a multi-methods assessment in the Nakivale Refugee Settlement and Kampala. Our study included a review of the published literature and institutional reports and statistics, key informant interviews (N=11), focus group discussions (FGDs) with married and unmarried Congolese women (N=4) and in-person in-depth interviews with refugee women (N=21). We analyzed these data for content and themes using deductive and inductive techniques and triangulated our findings.

Results: Our findings show that the availability of emergency contraception (EC) in the Nakivale Refugee Settlement is inconsistent and theft of product by health center personnel is a significant problem. Congolese women living in Kampala reported that the cost of EC pills is prohibitive for many living in the urban capital. A number of Congolese women living in both settings lacked accurate knowledge about post-coital contraception and reported using a range of other drugs to prevent pregnancy after sex.

Conclusion: Emergency contraception has long been incorporated into the standards of care for sexual and reproductive health in humanitarian settings. However, results from our study indicate that Congolese women face a range of challenges accessing EC. Strengthening supply chain management, examining and addressing the dynamics underlying product theft, and

increasing awareness of effective post-coital methods are priorities for expanding reliable access.

Implications: The inconsistent availability and accessibility of EC has significant implications for refugee and displaced populations. Supporting efforts to ensure that humanitarian stakeholders in Uganda are adhering to global standards of care is critical.

1. Introduction

Emergency contraceptives are medications or devices that are used to prevent pregnancy after sex. Globally, the most commonly used modality of emergency contraception (EC) is the progestin-only pill. As of 2018, nearly 150 countries had registered least one dedicated emergency contraceptive pill [1] and at least 60 countries included progestin-only EC on their national Essential Medicines Lists [2]. For more than two decades EC has also been integrated into the humanitarian response and progestin-only EC pills are available through the Inter-Agency Reproductive Health Kits [3-4]. Thus even in countries where there is no dedicated product registered refugees and displaced populations should have access to EC. However, a number of studies have shown that EC is not consistently available in humanitarian and conflict-affected settings [5-7].

Provision of EC to displaced women and girls is of critical importance. During displacement and resettlement, women and girls are at heightened risk of sexual violence, exploitation, and engagement in transactional sex [8,9] and often experience disruptions in ongoing contraceptive use [10]. These dynamics place refugee and displaced populations at increased risk of unintended pregnancy and their consequences, including maternal death and disability [10-11]. Consequently, emergency contraception is considered a life-saving intervention and is expected to be available during all phases of complex emergencies [8].

Since the mid-2010s, the world has been embroiled in the largest humanitarian crisis since World War II [12]. Uganda, a lower-middle income landlocked country in Sub-Saharan Africa, hosts the largest number of refugees on the continent; as of 2017, 1.4 million refugees

and conflict-affected people resided in Uganda [10]. Widely known as the “best place” to be a refugee in the region, Uganda is recognized for its policies that provide free social services, encourage local integration, and support self-sufficiency [13]. However, a number of studies conducted in recent years suggest that refugees residing in Uganda face persistent challenges accessing health care and other essential services [14-16].

Understanding the reproductive health needs of refugees and displaced populations has repeatedly been identified as a global priority [17]. In 2017, we undertook a multi-methods qualitative needs assessment in Uganda to explore Congolese refugees’ sexual and reproductive health experiences, needs, and opinions with the aim of informing programs, systems, and policies affecting this population. In this manuscript, we focus specifically on the findings related to emergency contraception.

2. Methods

As we have described elsewhere [18], in the summer of 2017 we conducted a multi-component study derived from the standards developed by the United Nations Population Fund and several previous needs assessments in humanitarian settings [19-21]. After reviewing the published literature as well as the reports and statistics from institutions serving refugees in Uganda, our project comprises three distinct components: 1) Interviews with 11 key informants; 2) Four focus group discussions (FGDs) with married (n=2) and unmarried refugee women (n=2); and 21 in-depth interviews with Congolese women.

2.1 Study population and settings

We specifically focused our project on refugee women from the Democratic Republic of the Congo (DRC) where ethnic and sexual violence against civilians, perpetrated by civilians and armed forces alike, are very pervasive. Since the protracted conflict in the eastern region of the country, Uganda has seen a steady influx of Congolese men, women and children into Uganda over the last 6 years resulting in a significant Congolese refugee population of 316, 968 in Uganda [22].

Many Congolese refugees reside in camp-based settings in the western region of Uganda, but others choose to self-settle in slum areas of Kampala, Uganda's capital [15], in hopes of employment, educational and business opportunities [23]. As a result, we wanted to include both camp-based and urban populations in our assessment. To explore the experiences, needs, and opinions of camp-based refugees, we recruited participants from the Nakivale Refugee Settlement, a camp operated by the United Nations High Commissioner for Refugees (UNHCR) in southwestern Uganda. We also recruited participants from Kampala.

2.2 Data collection: Key informant interviews

Using a purposive and snowball recruitment strategy, RN conducted 11 interviews in English with key informants to explore the perspectives of different individuals and agency representatives about the reproductive health needs of and services for displaced women. Our informants included policy makers, health service providers, and non-governmental organization (NGO) representatives. We identified key informants through publicly available information, study team contacts, and early participant referral. Interviews lasted between 60-90 minutes and explored the key informant's background, work experience, and experiences

working in the field of reproductive health in Uganda. We also asked key informants to share their perceptions of barriers to service delivery and accessibility, and how services can be improved.

2.3 Data collection: Focus group discussions

We conducted two FGDs with Congolese women from the Nakivale Refugee Settlement and two FGDs with Congolese refugees residing in Kampala. In order to establish some degree of homogeneity and in recognition of power dynamics within the community, we divided groups by marital status. RN facilitated the discussions in French, Lingala and/or Swahili with the assistance of AB and a local research assistant. We recruited women through refugee-led and refugee-focused organizations, word of mouth, and study team contacts. RN and AB took extensive notes during and RN wrote a memo after each discussion. The discussions centered on community needs, service availability and accessibility, and ways that services could be improved.

2.4 Data collection: In-depth interviews

Finally, our team conducted 21 in-depth interviews with refugee women from the Nakivale Refugee Settlement (n=10) and Kampala (n=11). We recruited women through refugee-led and refugee-focused organizations, word-of-mouth, and early participant referral and conducted the interviews in French (n=5) and Swahili (n=16). We audio-recorded all but one interviews; they last between 30 and 60 minutes. RN took extensive notes during each interview and memoed after each interview; local research assistants served as interpreters for the Swahili

interviews. These interviews followed a semi-structured format and focused on women's individual sexual and reproductive health experiences both before and after displacement.

2.5 Data analysis

A member of the study team transcribed all discussions and interviews; we also translated them to English (as necessary). We employed an iterative analytic approach and began data analysis during the data collection phase [24-25]. Throughout the project, memoing allowed for the ongoing identification of emergent themes and patterns as well as an opportunity to reflect on participant-research-interpreter interactions. Using a priori codes based on the study aims and research questions as well as from emergent ideas, we analyzed our data for content and themes using deductive and inductive techniques; we used *NVivo 11.4.3* to manage our data. RN coded all data and team meetings and debriefing sessions between RN and AMF guided the identification of themes and our interpretation. We initially analyzed each component of the project separately and in the final phase we brought together the different components and reviewed the results for concordant and discordant findings.

2.6 Ethics

The Social Science and Humanities Research Ethics Board of the University of Ottawa, the School of Medicine Research Ethics Committee at Makerere University, Uganda and the Uganda National Council of Science and Technology approved this study. Additionally, we also obtained clearance from the Office of the Prime Minister in Uganda to conduct research at the Nakivale Refugee Settlement. In this manuscript, we present the results of all study components and use

quotes to illustrate findings and themes related to emergency contraception. Throughout this article, we have removed or masked all personally identifying information and use pseudonyms for our FGD and in-depth interview participants.

3. Results

3.1 Participant characteristics

Our 11 key informants represented agencies operating in both Nakivale Refugee Settlement [n=4] and Kampala [n=7]. A number had experiences with multiple refugee populations and sexual and reproductive health-and thus brought multiple perspectives to the interview. Our FGDs included 36 married and unmarried women who ranged in age from 15 to 48. We provide information about the composition of our FGDs in Table 1. Finally, our 21 in-depth interview participants spanned the full reproductive age range included in the study (15-49 inclusive) and reflected a range of educational backgrounds and DRC regions of origin (see Table 2).

3.2 The availability EC is limited in the Nakivale Refugee Settlement

Yeah, it's available, but to be honest, sometimes [EC is] out of stock. They are not [available] on a regular basis. It is one of the products that is highly abused by the partner staff, to be honest. It is highly abused actually.
– Key informant, the Nakivale Refugee Settlement

According to interviews with key informants, the availability of emergency contraception appears to be limited in camp-based settings in Uganda. Key informants reported that the lack of availability of emergency contraceptive pills is due to inconsistencies in the supply chain as well as by staff. These dynamics contribute to frequent stock-outs. Consequently, women in

both FGDs and in-depth interview shared conflicting reports on the availability of EC; several of our FGD participants were able to obtain the product when needed, but others reported that despite their need for EC pills, they were not available. As one married woman from the Nakivale Refugee Settlement said: “They are not here. Please give us those ones so that we can use [them]. We don’t have them, those ones are good. Pregnancy is almost like dying.”

3.3 The out-of-pocket costs for EC is prohibitive for urban refugees

I have heard about it [EC] and I know someone who has used it, but it is expensive.
– Unmarried FGD participant, Kampala

Key informants, FGDs participants, and individual Congolese women were consistent in their reports that the availability of progestin-only EC was not an issue in Kampala. According to our study participants, EC pills are available at a variety of different service delivery points, including retail pharmacies. However, women in our FGDs and in-depth interviews repeatedly mentioned that EC was prohibitively expensive; although EC may be available at a pharmacy, for women with no income the typical price of 10,000 Ugandan Shillings [USD2.66] is too costly. As a consequence, some women are unable to purchase the drug. As stated by Marien, 23, unmarried: “[Emergency contraceptive pills are] not very expensive, but for some people, they cannot afford it.”

3.4 Women use other medications in place of EC for post-coital pregnancy prevention

We did not know if [the other medications] were effective. Sometimes we would use Quinine; you swallow it and it works. But [I would also use] paracetamol.
– Married FGD participant, Kampala

Through FGDs and interviews with refugee women residing in Kampala, the use of other medications as emergency contraception appears to be quite prevalent. Refugee women mentioned using malarial medications, and analgesics such as paracetamol and aspirin as a method to prevent pregnancy post-coitally. Based on our discussions with refugee women, using other drugs as EC allows for a woman to prevent a pregnancy, with a medication that is familiar and that does not have the same side effects of a dedicated contraceptive product. As 29-year old Georgette from Kampala shared: “When you take contraception every day, I find that well...there are consequences and because I want to have children one day, [I] can take the medication instead. It is medication for malaria.”

3.5 Contraception knowledge amongst refugees is limited

There is minimal knowledge...some women don't know all the different types of contraception.

– Key informant, Kampala

Most of the key informants we interviewed noted that contraceptive knowledge is lacking among Congolese refugees in both camp and urban settings. This was echoed by women in both the FGDs and the in-depth interviews. Indeed, many of our participants had not heard of any modality of emergency contraception. Moreover, those who had “heard” of EC often described incorrect drugs or inaccurate regimens. As explained by one FGD participant: “It is like this, before having sex with a man you take the one of yellow [pills], and after having sex with a man and you are in the period of ovulation, you take one red and one yellow.” The lack of knowledge appears to be coupled with minimal contraceptive counselling. As described by a FGD participant from the Nakivale Refugee Settlement:

I wanted to say about family planning. Here they do not take care of us and they don't give us information about it. We fear to give birth because we fear dying. So women are struggling by themselves...because they don't know what to take.

Throughout FGDs and interviews, women consistently reported that they are not given information on different types of contraceptive methods, their respective mechanisms of actions, or common side effects. As a result, women attempted to seek information on their own and created bespoke regimens of oral contraceptive pills (OCPs) and other drugs.

4. Discussion

Humanitarian settings often lack resources to provide comprehensive sexual and reproductive health services, including safe delivery and abortion care [26-27]. Consequently, access to contraceptives, and emergency contraception, in particular is critical and has long been prioritized in humanitarian settings [28]. The inconsistent availability of EC in camp-based settings in Uganda represents a considerable barrier to women obtaining the services they need. Ensuring a consistent supply chain, an effort that should include building the capacity local stakeholders' forecasting skills, is an important first step. Additionally, reminding providers of the Yuzpe Regimen [29], that is the post-coital use of combined OCPs, when a dedicated progestin-only product is unavailable could meet a significant need. Finally, acknowledging that theft of EC products by providers and staff is a problem and developing measures and organizational protocols to discourage theft could help ensure that EC is available to refugees when needed. It would also be worthwhile to explore why it is that providers and staff are taking EC pills and think through strategies to make the medication available to those working in implementing agencies.

Our study also indicates that the price of EC is prohibitively expensive for some urban refugee women. In Uganda, urban refugees not only experience challenges accessing services, obtaining protection, and being safe, but they face a multitude of structural and operational barriers that impact their economic stability [15]. Challenges such as discrimination, language, and lack of legal documentation impede refugees from securing formal sector employment and income generating opportunities. Thus EC may be out of reach for this population because of the financial realities. Implementing an EC-centered subsidy for women in urban settings, including refugees, could eliminate this barrier.

Finally, the lack of contraceptive counselling appears to further entrench the poor reproductive health knowledge that we found in this study. Our results highlight that there is an imperative need to expand and increase access to evidence-based and low-literacy materials and information on sexual and reproductive health, including all forms of contraception. Given the context and lack of financial resources, women may resort to unsafe methods to attempt to prevent a pregnancy such as using other drugs as EC. The incorrect drug regimens used creates an unnecessary risk and will likely not prevent pregnancy. The provision of educational resources and counselling can help dispel myths and misperceptions related to contraception.

4.1 Limitations

In this study, we aimed to explore experiences regarding the reproductive health needs for refugees amongst a range of participants, therefore, this study was not meant to be generalizable or representative as is true with qualitative studies [30]. Rather our study sought to “a rich, contextualized understanding of human experience through the intensive study of

particular cases” [31: page 1452]. We only recruited Congolese refugees in the Nakivale Refugee Settlement and Kampala, therefore the perspectives presented in this paper may not reflect experiences other refugees in other areas of Uganda. However, because we were able to triangulate our EC findings we feel confident that they are transferable. RN’s positionality as a young Congolese-Canadian woman and her educational background undoubtedly influenced interactions with refugee participants and Ugandan stakeholders. We also conducted this study in multiple languages (English, French, Lingala and Swahili) to engage with participants in the language(s) that was/were most comfortable. It is possible that subtle nuances may have been lost in translation. By working with local NGOs and research assistants from the community, we tried to minimize this limitation. We were able to understand these influences and navigate such dynamics through regular memoing, debriefings, and team meetings with local research assistants which also helped to increase the credibility and trustworthiness of this study.

5. Conclusion

Emergency contraception is an important component of the humanitarian response. Although Uganda has favourable refugee policies and dedicated EC products are registered and available in cities, our study suggests that there are still gaps in EC knowledge and service delivery. Identifying ways to ensure adherence to the global standards and improve access to refugees in both camps and urban areas appears warranted.

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Table 1. Composition of focus group discussions with Congolese refugees (N=4)

Group	Number of Participants	Age Range	Gender	Marital Status	Geographic Location
1	10	15-25	Female	Single	Kampala
2	6	27-46	Female	Married	Kampala
3	10	16-23	Female	Single	The Nakivale Refugee Settlement
4	10	27-48	Female	Married	The Nakivale Refugee Settlement

Table 2. Demographic characteristics of in-depth interview participants (N=21)

		Kampala (n=11) n (%)	Nakivale Refugee Settlement (n=10) n (%)
Age	15-25	2 (18%)	2 (20%)
	26-35	5 (46%)	2 (20%)
	36-45	3 (27%)	2 (20%)
	45 -49	1 (9%)	4 (40%)
Marital Status	Single	2 (18%)	2 (20%)
	Married	6 (54%)	3 (30%)
	Widowed	3 (27 %)	5 (50%)
Education	Nursery school to 8th grade	1 (9%)	2 (20%)
	Some high school, no diploma	3 (27%)	4 (40%)
	High school graduate	4 (36%)	1 (10%)
	Some university credit, no degree	0 (0%)	1 (10%)
	Trade/technical/vocational training	2 (18%)	0 (0%)
	Bachelor's degree	0 (0%)	2 (20%)
	Post-graduate degree	1 (9%)	0 (0%)
Origin from the DRC	Bukavu (South Kivu)	4 (36%)	1 (10%)
	Rutshuru (North Kivu)	2 (18%)	1 (10%)
	Beni (North Kivu)	1 (9%)	4 (40%)
	Manyema (South Kivu)	0 (0%)	1 (10%)
	Uvira (South Kivu)	1 (9%)	0 (0%)
	Goma (North Kivu)	3 (27%)	3 (30%)

Chapter 5: Article #3

We will be submitting this article to *Reproductive Health Matters* for the November 1, 2018 deadline. Therefore, this article has been formatted for submission to that journal and the manuscript adheres to the style, word limit, and citation guidelines for this journal.

Exploring Congolese refugees' experiences with abortion care in Uganda: A multi-methods qualitative study

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Conflicts of interest: The authors declare that they have no conflicts of interest, financial or otherwise.

Keywords: Abortion, Africa, the Democratic Republic of the Congo, post-abortion care, refugees, Uganda

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Abstract

Uganda currently hosts 1.4 million refugees and conflict-affected people. Known as the best place in Africa to be a refugee, Uganda's policies encourage self-sufficiency and local integration. However, abortion is legally restricted and recent studies suggest that displaced women and girls have persistent unmet sexual and reproductive health needs. In 2017, we embarked on a multi-methods study to assess the reproductive health needs of displaced Congolese women in camp- and urban-based settings in Uganda. Our project focused on maternal health and delivery care, contraception, and abortion/post-abortion services and the intersection of these issues with sexual and gender-based violence. We interviewed key informants, facilitated focus group discussions with refugee women, and conducted in-depth interviews with Congolese women of reproductive age to understand better knowledge, attitudes, practices, and services. Using both inductive and deductive techniques, we employed a multi-phased analytic plan to identify content and themes and triangulate and interpret findings. Our results suggest that Congolese refugees in Uganda are unable to navigate the legal restrictions on abortion and are engaging in unsafe abortion practices; this appears to be the case for those living in both camps and urban areas. Moreover, the legal restrictions on abortion pose a barrier to the provision of post-abortion care. Efforts to ensure access to comprehensive abortion care should be prioritized and providing information and support to women in need of post-abortion care remains imperative.

Introduction

By the end of 2017, the global humanitarian crisis had left 68.5 million people displaced, the majority of whom are hosted in low-income and lower-middle-income countries [1]. Trends suggest that those in need of humanitarian assistance, including health, food, security, and protection services, has continued to grow [2]. Women and girls constitute a large portion of this population and are more vulnerable to sexual violence and exploitation than their pre-displacement counterparts [3]. Moreover, the systemic use of sex as a weapon of war during conflicts increases the risk of unintended pregnancy.

Despite the overall reduction in global maternal mortality and the increase in the provision of sexual reproductive health (SRH) services to displaced populations [3-4], unintended pregnancy is a continued problem [5]. Indeed, recent estimates suggest that 44% of pregnancies in 2010-2014 were unintended [6]. More than 50% of these unintended pregnancies ended in abortion (Bearak et al., 2018). In areas where abortion is legally restricted, women often turn to unsafe methods of pregnancy termination [7] and are at considerable risk of negative reproductive health outcomes, including disability and death [5,8].

Reliable information about abortion in refugee and conflict-affected settings is limited. However, displaced populations are recognized as being at increased risk of sexual violence, lacking to access to ongoing contraceptive methods, and experiencing changes in pregnancy intentions which in turn increase the risk of unintended pregnancy [9]. Consequently, refugees and displaced women who reside in countries where abortion is legally restricted face considerable barriers accessing safe abortion care [10]. Evidence from a number of refugee and displacement contexts indicates that women are employing unsafe practices to terminate unwanted pregnancies [11-13]. Further, even when are eligible for safe abortion care, refugee women may not be able to navigate local health systems to obtain legal services [14-15].

Refugees and displaced populations living in Uganda have limited access to abortion care. Article 22[2] of the Ugandan Constitution states: “No person has the right to terminate the life of an unborn child except as may be authorized by law” [16]. However, this law has not been enacted since 1995, and consequently, there is significant reliance on the provisions of the Penal Code Act 1950 [17-20]. According to this Code, attempting to abort a pregnancy is subject to 14 years in prison, attempting to induce a miscarriage is subject to seven years in prison and providing a medication that induces an abortion is subject to three years of prison [21]. It is worth noting although these legislative provisions are quite conservative, the National Policy Guideline and Service Standard for Sexual and Reproductive Health and Rights issued in 2006 allows for exceptions under which abortion services can be provided. This policy stipulates that termination of a pregnancy is permissible in cases where the life of the woman is threatened, of fetal anomaly, where the pregnancy resulted from rape or incest, and when the woman is HIV positive [17,19]. While these exceptions exist, the Ugandan Ministry of Health indicated that this policy is subject to interpretation. The ambiguity between the legislative and policy provisions means that women and providers alike are often unaware of the circumstances

when an abortion is permitted [19]. These policies impact both Ugandan and displaced populations living in the country and the prevalence of unsafe abortion is high [22].

Uganda is increasingly welcoming refugees and has become the largest refugee-hosting country in Africa. Uganda is considered to be one of the most hospitable places to seek asylum in the region as it has progressive policies; refugees are entitled to free education and healthcare [23,24]. Of the nearly 1.4 million refugees from 13 different countries [25-26] living in Uganda, approximately 316, 968 are from the Democratic Republic of the Congo (DRC); the many of displaced Congolese are concentrated in the Makindye district of Kampala (Uganda's capital) and the Nakivale Refugee Settlement. Although a number of studies in recent years have focused on the sexual and reproductive health of refugees living in Uganda [27-30], little work has explored displaced populations' abortion experiences. Our study aimed to fill this gap.

Methods

From June to August 2017, we undertook a multi-methods reproductive health needs assessment with Congolese refugees living in Kampala and the Nakivale Refugee Settlement [31-31]. Modelled after other needs assessments conducted in refugee and displacement settings [12,13], our study consisted of four components: 1) A review of published documents as well as internal reports, statistics, and documents from institutions working with refugees in Uganda; 2) Interviews with well-positioned key informants; 3) Focus group discussions (FGDs) with Congolese women; and 4) In-depth interviews with Congolese refugee women of reproductive age.

Interviews with key informants aimed to explore a range of perspectives from individuals and agency representatives working with refugees and/or in the field of sexual and reproductive health. Our semi-structured interviews focused on the availability of, accessibility of, and avenues for improving reproductive health services to Congolese refugees in particular. Our key informants included policy makers, health service providers, non-governmental organization (NGO) representatives. We purposively recruited interviews by utilizing publicly available information, study team contacts, and early participant referrals.

For both our FGDs and our in-depth interviews, we recruited Congolese women of reproductive age (15 to 49 inclusive) who resided either in Kampala or the Nakivale Refugee Settlement. We worked with two refugee-focused organizations to recruit these women and supplemented this strategy with flyers, word-of-mouth campaigns, and early participant referral. Focus group discussions with women focused on maternal health and delivery care, contraception, and abortion/post-abortion care and explored community knowledge, access to and utilization of reproductive health services, facilitators and barriers to access, and priorities for improvement. In the FGDs we aimed to solicit community norms as well as identify outliers. In-person interviews with women focused on individual-level experiences with sexual and reproductive health, including abortion and post-abortion care, in both the pre-displacement and displacement periods. We also asked women to reflect on the ways in which services could be improved.

RN, a tri-lingual Congolese-Canadian master's student at the University of Ottawa (Canada) led all components of data collection after being trained by her thesis supervisor, AMF, a medical anthropologist and medical doctor with expertise in sexual and reproductive health. RN conducted all of the interviews with key informants, which lasted 60-90 minutes, in English and later transcribed the interviews herself. Focus group discussions lasted an average of one hour and were conducted in French, Lingala, or Swahili; RN led the discussions with the help of a local research assistant who was able to interpret from Swahili to English. These discussions were translated into English by translators hired from the two refugee-focused organizations and transcribed verbatim. RN also led all of the in-depth interviews, which she conducted in French and Lingala. These interviews lasted 30-60 minutes and were later translated and transcribed by local research assistants. We offered both the FGD and in-depth interview participants a small honorarium to reimburse them for their transportation costs and cover any child care-related expenses.

RN took extensive notes during each interaction, debriefed with local research assistants immediately after each FGD or interview, and debriefed with AMF regularly. RN also formally memoed after each interaction, a process that allowed for reflections on emergent themes and concepts as well as the participant-researcher-interpreter interaction. The memoing process also allowed RN to establish thematic saturation for the in-depth interviews [33].

With the permission of the participants, we audio-recorded all but one of the interviews and discussions. We used *NVivo 11.4.3* to manage our data, which included transcripts, notes, and memos, and we analyzed these data for content and themes [33,34]. We employed an iterative analytic approach and began data analysis during the data collection phase. We developed an initial codebook containing a priori codes based on the study aims and research questions; as we familiarized ourselves with the data, we added emergent codes and categories. RN coded the data and then worked to identify themes. We initially worked with each component of the study separately; in the final analytic phase we reviewed all components and explored areas of agreement and disagreement. Regular meetings between RN and AMF guided this process and the overall interpretation of the findings. Presentation of these results at several international meetings and global webinars yielded valuable feedback that shaped our final recommendations.

This project received ethical approval from the Social Sciences and Humanities Research Ethics Board at the University of Ottawa, Canada (File #: 04-17-15), the School of Medicine Research Ethics Committee at Makerere University, Uganda (File #: 2017-073), and the Uganda National Council of Science and Technology (File #: SS-4321). Additionally, given the nature of this project and the participants, we also obtained clearance from the Office of the Prime Minister in Uganda to conduct our study at the Nakivale Refugee Settlement. In this paper, we use illustrative quotes to showcase themes and ideas and narrative vignettes to provide a more robust picture of individual women's experiences. We have removed and/or masked all personally identifying information and used pseudonyms throughout.

Results

Participant characteristics

The key informants we spoke with included policy makers, health service providers, and non-governmental organization (NGO) representatives working in the humanitarian sector or with refugees in the Nakivale Refugee Settlement (n= 4) and in Kampala (n=7). We had a total of 36 married and unmarried Congolese women participate in our four FGDs. Focus group discussion participants ranged from 15 to 48 years old and were divided by marital status across both study locations as we have detailed elsewhere (Nara et al., 2018a). We conducted 21 in-depth interviews with Congolese women in the Nakivale Refugee Settlement (n=10) and Kampala (n=11). Of our Nakivale Refugee Settlement participants, 40% were between the ages of 45 and 49, 50% were widowed, 40% had some high school education, and 40% originated from North Kivu. The majority of our Kampala participants were between the ages of 26 and 35, over half (56%) were married, 36% were high school graduates, and 36% were from South Kivu.

Vignette #1: Marien's story

Marien is an unmarried 24-year-old Congolese refugee from South Kivu. She has been living with her aunt since she was young and fled the DRC with her aunt and uncle as they were being pursued by the government. She has been living Kampala for the last 10 years. She was using condoms as contraception and realized she was pregnant when she didn't get her period for two months in a row. She did not take a pregnancy test as she could not afford one. Because she was not married, Marien decided to seek an [unsafe] abortion. For Marien, not having a husband was the deciding factor.

Marien went to the pharmacy and used the little money she had to buy some medicine. She did not know what medication she bought as the pharmacist did not provide her with any information. She went home and took the pills. After about two days, she passed a large blood clot and continued to bleed. She also began to experience significant abdominal pain.

After three days of heavy bleeding and severe abdominal pain, Marien went to a hospital with a friend; healthcare staff asked her why she did "it" by herself. Although she was bleeding, Marien believes that the doctors delayed treating. She felt as though they were punishing her. Her friend advocated for her and implored the staff to do something. In the end, Marien waited for 5 hours; she ultimately received a manual vacuum aspiration procedure and antibiotics, as well as counselling on contraception. Although she received treatment, Marien reported that it was not easy to get care when she needed it.

Congolese refugees in Uganda are engaging in unsafe abortion practices

Here you will find a young girl of 15 years is pregnant, and then because she fears giving birth, she ends up doing an abortion.

– Unmarried FGD Participant, Nakivale Refugee Settlement

Unlike Marien, most of our FGD and interview participants did not share personal abortion stories. However, almost all of the refugee women in our study discussed the [unsafe] abortion experiences of women in their communities. Women described a range of practices including

using detergents, crushed bottles, herbs and teas, pain medications such as paracetamol, and large doses of oral contraceptive pills

Consistent with the reports of Congolese women, key informants who were health service providers repeatedly discussed seeing unsafe abortion and treating abortion-related complications. As a health service professional working in the Nakivale Refugee Settlement explained: “You cannot go a month without receiving an [unsafe] abortion case.” Like women, key informants reported that refugee women use a range of objects to instrument the uterus, detergents and vaginal douches, and non-abortifacient medications, such as antimalarials and pain medications, to induce an abortion. Key informants were clear that the abortion practices of refugee women were similar to those of host country nationals. As one key informant from the Nakivale Refugee Settlement explained: “[Abortions] happen, we treat them. But I can say the prevalence, or the abortion ratio [for Congolese refugees] is not far from the national.”

The legal restrictions on abortion directly contribute to unsafe practices

The [legal] environment is not that friendly for people to go and seek a safe abortion. Even the service providers themselves are hesitant to provide safe abortions since they can be persecuted.”

– Key informant, Kampala

Key informants in our study recognized that the legal restrictions on abortion and the lack of clarity regarding the interpretation of the exceptions contribute to the occurrence of unsafe abortion. Almost all of the key informants reported that due to the laws surrounding abortion, women fear the legal consequences of attempting to have an abortion at a healthcare facility. At the same time, health service providers fear that there will be professional repercussions if they provide an abortion to a patient. As one key informant from Kampala stated:

Abortion - it is actually a big problem because it's illegal. First of all, [safe abortion] is not that available. And people who provide it, it's expensive. You find that it's rare that you can do it in a recognized health centre or government health centre. So, you have to go to a private [clandestine] clinic, because no one wants to be known as [having performed an] abortion.

Anne's story

Anne is a 32-year-old married Congolese refugee living at the Nakivale Refugee Settlement. She has been at the camp for three years and is married with four children. She fled North Kivu when militants stormed their village. Anne and her children left in a hurry, leaving her husband behind because he was out on an errand. At the time of the interview, she still did not know his whereabouts.

Anne had been in Uganda for two months when she realized that she was pregnant. She had not had relations with anyone other than her husband. She did not know what to do; she was in a new country and did not want to have another child but was also struggled with her faith.

One day, she shared her ambivalence toward the pregnancy with a friend in the camp. Her friend put Anne in contact with a “medicine woman” who gave her an herbal mixture to terminate the pregnancy. Anne decided that adding an extra mouth to feed would be selfish so she drank the mixture at her home in the camp. After a couple of hours, Anne started bleeding and cramping. She used rag cloths to absorb the blood and took paracetamol for pain.

The bleeding continued over two weeks and then stopped. Anne thought that the herb worked and her pregnancy was terminated. However, about three and a half weeks after drinking the broth, Anne felt a sharp abdominal pain and collapsed. Fortunately, one of her daughters was there to help her to a cot. Anne started bleeding again. She again used cloths to absorb the blood and paracetamol for pain. Anne knew that abortion was illegal, but she also did not want others in the Congolese community to know what she had done. She continued bleeding for several days, but then felt very weak and decided to go to the doctor. She told the doctor that she had miscarried and she was provided with post-abortion care.

The legal restrictions on induced abortion impact post-abortion care

[When] we have cases of abortion [most of the women] will not really come out clearly, in case it’s induced. Nobody will come out and say, “Ah, this is induced.” They will say, “Oh I got a fever and then all of a sudden, I started seeing bleeding.”

– Key informant, Nakivale Refugee Settlement

The legal restrictions on induced abortion appear to be having a chilling effect on post-abortion care. Consistent with global standards, refugee women in Uganda are entitled to receive post-abortion care, as Anne’s story shows. As one key informant in Kampala explained, “We have the [post-abortion care] services. We have skilled personnel who provide those services to [refugees].”

However, the fears that both women and providers have about the legality of induced abortion appears to influence post-abortion care. Participants in the interviews and FGDs repeatedly explained that Congolese women will not present to a health facility after attempting to induce an abortion because of concerns about prosecution and imprisonment. Indeed, we heard several stories about women who postponed seeking post-abortion care until it was too late. This was echoed by a key informant from Kampala who shared the following story:

There are those [refugee women] who induce abortions, and yet they are not well treated after. And this has so many consequences for them. I know one lady who did it [an unsafe abortion], and she did not get adequate medical treatment. Unfortunately, challenges in obtaining post-abortion care result in dire consequences such as infection and even death.

Several of our key informants also reported being unclear as to the legal status of post-abortion care and were unsure what could be provided if a woman presented with complications from a pregnancy loss.

Discussion

The relationship between the legal status of abortion and the safety of abortion provision is clear: restrictive abortion laws directly impact access to safe abortion and contribute to the prevalence of unsafe or clandestine abortions [35,36]. Indeed, highly restrictive abortion laws do not reduce abortion rates – prohibitive laws only serve to increase the likelihood of unsafe abortions [5]. The complications associated with unsafe abortion result in morbidity and mortality include gynecological injury, hemorrhage, infections, uterine scarring, and death [37].

Unsafe abortion contributes to a large proportion of global maternal mortality [10]. Despite the global acknowledgement of the impact of unsafe abortion on maternal health outcomes, there are still many countries, largely concentrated in the Global South, with highly restrictive abortion laws [5]. Data suggest that 97% of unsafe abortions occurred in low-income countries in Africa, Asia, and Latin America [37]. Coincidentally, developing countries, characterized by weak health systems and poverty, host the overwhelming majority of displaced populations [1]. Although reliable data on abortion in refugee, crisis, and conflict settings is limited, humanitarian stakeholders and agencies recognize the value of abortion as a life-saving procedure [10] and unintended pregnancy is a significant public health issue in humanitarian settings [9,38]. Therefore, efforts to ensure access to safe abortion care for all women, including refugees and displaced populations, must continue [39]. Indeed, the 2018 Interagency Field Manual for Reproductive Health in Humanitarian Settings now provides greater clarity on the need to provide safe abortion care, to the full extent of the law, in humanitarian settings [38]. This is an important step in increasing access to safe abortion care at all phases of an emergency.

However, the legal restrictions surrounding abortion in Uganda continue to present challenges to Ugandan and refugee women alike. Unintended pregnancy is quite prevalent in Uganda [40] and unsafe abortion remains a major problem for Ugandan women despite the decline in the abortion rate, from 54 abortions per 1,000 women age 15 to 45 in 2003 to 39 in 2013 [22]. Our study suggests that the laws in Uganda affect the provision of safe abortion care as both women and providers fear the consequences of obtaining and providing an abortion [17]. Reasons for the apprehension include the lack of clarity on legal exceptions and inconsistent interpretation of the legislative and criminal provisions; these dynamics create confusion for both women and provider [19]. As is consistent in other humanitarian settings [31,32], our study reveals that safe abortion care not routinely in camp and urban settings.

Moreover, our study suggests that Congolese refugees engage in unsafe abortion practices, a dynamic that is consistent with other areas where safe abortion care is not available [11]. As in other humanitarian settings [14,15], establishing safe referral systems that link eligible refugee women to Ugandan health facilities could expand access to safe and legal abortion care. Educational efforts to increase awareness regarding the eligibility for referrals should be coordinated with the implementation of this type of referral system.

Our study also suggests that there is a need to engage in efforts to reduce harm from unsafe abortion. Recent projects in both northern Thailand and Nepal suggest that community-based

distribution of misoprostol can be an effective strategy in low-resource and conflict-affected settings [41,42]. Implementing a similar strategy could prove to be feasible in Uganda as misoprostol is currently registered to treat post-partum hemorrhage and is on the essential medicines list [43]. Further, some civil society organizations in Uganda already encourage the off-label use of misoprostol to induce labour or abortion [44]. In camp-based settings, misoprostol is made available through the Inter-agency Reproductive Health Kits [45]. Thus both Ugandan and refugee women have access to drugs that could significantly reduce harm from unsafe abortion.

Although abortion is legally restricted in Uganda, post-abortion care (PAC) is not; a range of health facilities can treat and manage post-abortion complications [43]. Findings from our study show that the legal status of abortion in Uganda not only affects access to safe abortion services but also access to post-abortion care, which is consistent with previous research [43]. In consultation with experts and consistent with global standards of care [47], the Ministry of Health in Uganda has adopted guidelines for comprehensive abortion care that aim to address and respond to unsafe abortion through the improvement of services related to unintended and unwanted pregnancy [46]. Thus ensuring women are fully aware that PAC is legally permissible, as well as when and how to access services, is crucial for reducing poor reproductive health outcome.

Limitations

As is true of qualitative studies, the findings presented in this article are not representative or generalizable [48]. Nonetheless, we are confident that the themes we have identified are transferable to other Congolese refugee populations in Uganda. It is worth noting that we recruited participants only in Kampala and at the Nakivale Refugee Settlement through NGOs, therefore, our data is not reflective of other perspectives. Finally, this study was a cross-language qualitative study which included focus group discussions and in-depth interviews with refugee women in French, Lingala and/or Swahili. Consequently, the use of interpreters may have impacted our findings as complex concepts, phrases, and words may be difficult and or impossible to translate verbatim.

We also recognize that RN's positionality as a young Congolese-Canadian woman and with more formal education, influenced interactions with both refugee participants and Ugandan stakeholders. We tried to minimize this limitation by working with local NGOs and research assistants from the community. Through regular memoing, debriefings, and team meetings with local research assistants, we were better able to understand these influences, and how to navigate these complex dynamics, thereby increasing the credibility and trustworthiness of this study.

Conclusion

Our study shows that legal restrictions, inconsistent interpretation of laws and policies, and fear of legal consequences influence access to safe abortion and post-abortion care for refugees living in Uganda. While clarification of the current legal status of abortion is required, strategies to overcome legal and policy barriers are also warranted. Harm reduction efforts that increase

access to safe abortion care and campaigns to increase awareness of PAC services to refugee and Ugandan women could save lives and improve reproductive health outcomes.

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Chapter 6: Discussion

Integration of results

Neglect and a lack of prioritization of reproductive health services for displaced populations has long plagued humanitarian agencies (McGinn, 2000). After the recognition of the failure to provide said services, there have been concerted efforts over the last 20 years to improve the availability and accessibility of reproductive health services (Austin et al., 2008). Yet, our results demonstrate that significant challenges to the provision of sexual and reproductive health services to displaced populations continue to exist. Our findings suggest that the reproductive health needs of Congolese refugees are significantly unmet in Uganda. Specifically, our study highlights that there are significant unmet SRH needs with regards to the provision of maternal and delivery care services, comprehensive family planning services, including emergency contraception, and safe abortion and post-abortion care.

Results presented in the first article outline the service delivery and service utilization challenges in the provision of and access to maternal health and delivery care services. The second article focuses on emergency contraception and highlights that availability of EC in camp-based humanitarian settings is inconsistent due to supply chain management challenges and theft of product by staff. Also, our study suggests that amongst urban refugees, the cost of EC is a concern. In regards to contraception in general, our study highlights that the lack of contraception knowledge and counselling shapes use. Finally, our third article demonstrates that the legal status of abortion affects access to safe abortion, but also post-abortion care.

The integration of these findings paints a bleak picture regarding the reproductive health of this population in Uganda. Refugee women from the DRC have witnessed

considerable violence and many have experienced sexual violence as a result of this highly complex and protracted conflict. Though Uganda is labelled as a hospitable refugee hosting nation, recently some news articles have suggested that this label is potentially dangerous and misleading as the policies may not necessarily reflect what occurs in practice (Kigozi, 2017; Schiltz & Titeca, 2017). Our study suggests that this is the case with respect to reproductive health care. The lack of consistent access to comprehensive SRH services has profound health implications for a population of women that are already at heightened risk of sexual violence and unintended pregnancy.

Despite several efforts at health systems reform, Uganda's health system remains characterized by structural underdevelopment and inequity (Okech, 2014). The 2011 Uganda Health System Assessment Report found challenges in governance, health financing, human resources, and service delivery (Ministry of Health, Health Systems 20/20, & Makerere University School of Public Health, 2011). Kiguli and colleagues found that these same impediments affected the perceived quality of care among poorer Ugandans (Kiguli et al., 2009). Our study aligns with the conclusions of the report and the 2009 study suggests Congolese refugees' access to health services, particularly those in urban areas, are influenced by the same dynamics.

The UNHCR reports that displaced populations are increasingly settling in high population density areas (UNHCR & Government of Uganda, 2018). This is also the case in Uganda; an estimated 103, 694 refugees currently reside Kampala (UNHCR, 2018d). These settlement patterns add a layer of complexity to service delivery and a diverse approach will be required to ensure that the varied reproductive needs of urban refugees in Uganda are met

accordingly. A 2013 report by the Women's Refugee Committee found that urban refugees in Kampala have challenges accessing health services (Women's Refugee Commission, 2011a) even though approximately 70% of all physicians practice in urban areas of Uganda (World Health Organization, 2011). Our study suggests that Congolese refugee women experience significant barriers to accessing quality reproductive health care in both camp and urban settings and recognizing the needs of both populations is imperative.

Dissemination of the findings

Multiple stakeholders have identified understanding the reproductive health needs of conflict-affected populations in low-income host countries as a priority. Uganda, with its progressive policies but limited resources, serves as an interesting case study. Our findings offer insight into the realities of refugee life in Uganda. This information can be used to inform strategies to improve program planning and service delivery for sexual and reproductive health. Thus I have prioritized disseminating the results of the study to multiple audiences.

In 2017—2018 I gave both poster and oral presentations at a number of international meetings and conferences. This included the 17th annual meeting of the Inter-agency Working Group on Reproductive Health in Crises (Athens, Greece), the 23rd Canadian Conference on Global Health (Ottawa, ON), and the 2017 EC Jamboree hosted by the International Consortium for Emergency Contraception (ICEC) (Washington, DC). I also had the opportunity to present the EC-related findings at a global webinar hosted by the ICEC and the maternal health-related findings at a seminar hosted by IDRC. Feedback from participants and stakeholders at all of these events has informed my recommendations. In addition to contributing three articles to

the peer-reviewed literature, an important avenue for disseminating findings to researchers, I will be preparing a report for local stakeholders. My aim is to distribute the report to government and NGO representatives, local service providers, and study participants.

Recommendations

In order to truly make Uganda a “refugee’s paradise,” the infrastructure, systems, and practices on the ground must align with policies and regulations. Below I offer several recommendations, generated from the study, that aims to improve the delivery of sexual and reproductive health services to Congolese refugees in Uganda.

The health system infrastructure in Uganda is insufficient to meet the needs of refugees. Our study shows that there is a great need for trained healthcare professionals in both urban and camp-based facilities. The inadequate number of healthcare staff delays access to quality care; efforts to reduce “brain drain” through appropriate incentives and retention strategies is crucial to improving maternal health outcomes. Further, the lack of drug availability is a direct barrier to care; better management of supply chains, particularly in refugee camps, should be encouraged. Facility condition assessments should also be conducted to identify priorities for repair and procurement.

Women are less likely to use services if they are treated disrespectfully or if the quality of care is poor. To this end, it is important to acknowledge that bribery is a problem. Only by acknowledging this reality will it be possible to explore drivers of the practice. Implementing and ensuring adherence to anti-bribery and anti-corruption policies would also be an important initial step. Engaging healthcare professionals in cultural sensitivity training could help address

discrimination. Identifying creative strategies to address the evident language barriers would also help build trust between patients and providers. Finally, efforts to create private spaces for women who are delivering and ensure that women experiencing complications are promptly transferred to appropriate facilities are warranted.

Emergency contraception is a crucial component of the humanitarian response. Although Uganda has favourable policies, in general, toward refugees and emergency contraceptive pills are available, our study suggests that there are still gaps. Notably, our study reveals that there is a significant need to ensure the consistent availability of EC in rural/camp settings by fortifying the supply chain. Acknowledging that theft of product by providers and staff is a problem and developing measures and organizational protocols to discourage theft is key. It would also be worthwhile to explore why it is that providers and staff are taking EC and think through strategies for making the medication available to those working for implementing agencies.

Cost has been shown to be a barrier to SRH service accessibility. In humanitarian contexts, urban refugees often incur costs for services and supplies that are offered free-of-charge for camp-based refugees. In our study, urban women recognize that some women are unable to purchase EC because they cannot afford it. Exploring ways to subsidize the cost of all contraceptives, including EC, appears warranted. This type of effort will be for naught if women do not have medically-accurate information about EC thus efforts to raise awareness of this critical pregnancy prevention option are important as well.

Although abortion is legally restricted in Uganda, its occurrence is no less prevalent among refugee populations residing in the country. In the absence of legal reform and the

expansion of safe and legal abortion services, it is critical to reduce harm from unsafe abortion. Provision of information to and support for women seeking post-abortion care is imperative. Further, implementing safe referral systems could help refugee women who do meet the eligibility requirement access legal services. Finally, the distribution of misoprostol, a medication that is used for a number of obstetric and gynecological indications and is a safe and effective method for early induced abortion, could reduce harm from unsafe abortion.

Limitations

As is true with qualitative studies, our findings are not meant to be generalizable or representative (Crouch & McKenzie, 2006). Rather, this multi-methods qualitative study sought to provide “a rich, contextualized understanding of human experience through the intensive study of particular cases” (Polit & Beck, 2010). Thus, our aim was to reach thematic saturation, the point at which the addition of participants does not yield additional information (Glaser & Strauss, 1967). We are confident that we reached thematic saturation with respect to both the FGDs and the in-depth interviews; for key informants, we were aiming for a range of perspective which we also achieved. Thus, we are confident that the results of our study are transferrable and relevant beyond the bounds of the immediate study population. However, we are unable to assess the degree to which these experiences represent broader patterns.

We recruited women through two local refugee-focused organizations. Although these organizations have significant reach, women who are not familiar with these organizations were unlikely to hear about our study. Further, it is always a challenge to work in multiple languages. Indeed, this study included components in English, French, Lingala, and Swahili. As I

am not proficient in Swahili I worked with interpreters and translators for this part of the project. Of course, there is a possibility that some nuance or subtlety was lost in translation. However, there was also tremendous value to working with an interpreter who was a refugee woman from the same community as our participants.

Positionality and reflexivity

In qualitative research, acknowledging that the experiences of the researcher influence and affect the research and the interpretation of the data is imperative (England, 1994). Reflexivity is process by which the researcher actively becomes aware of how her positionalities (including characteristics, experiences, and values) impact the project throughout its life-cycle (Macbeth, 2001). Reflexivity ultimately gives us the opportunity to understand better the research process (Nencel, 2014).

I was well positioned to undertake this study. As a Congolese immigrant, I am well-versed in the native language, Lingala, which facilitated my relationship with Congolese participants. It encouraged organic dialogue and helped in creating a comfortable and safe space for disclosure. Furthermore, I possess cultural competency as I maintain certain traditional and cultural practices that are specific to the Congolese people. This facilitates my understanding of nuances, which helped significantly in both data collection and analysis.

However, I recognize that I am also a Canadian and have resided in Canada for most of my life. This identity sets me apart from the Congolese women who participated in the study, but also, from local Ugandans stakeholders both those who were participants in the study and those who reviewed study materials and protocols. Being cognizant that my status as a

foreigner may have affected my interactions, my local research assistant helped me understand and navigate these dynamics as she was born, raised, and currently resides in Uganda.

As part of the research process, I engaged in note-taking during interviews and debriefing sessions and memoing after the interviews and focus group discussions. This was especially useful as I was able to identify the recurrent themes and establish thematic saturation. But these exercises were also part of the reflexive process. Through memoing in particular, I was also able to flag ideas and concepts, to my research assistant and translators that required clarity and further discussion, as well as identify my own subjectivities and how to mitigate them.

Conclusions

Despite all the positive media surrounding Uganda's progressive policy on refugees, our study suggests that Congolese refugee women experience significant challenges accessing quality reproductive health services in both camps and urban settings. In order to truly make Uganda a "refugee's paradise", the infrastructure, systems, and practices on the ground must align with policies and regulations. Only by identifying and acknowledging the needs and challenges experienced by refugees and asylum-seekers will we be able to identify entry points for appropriate and sustainable solutions to the challenges faced by displaced populations globally.

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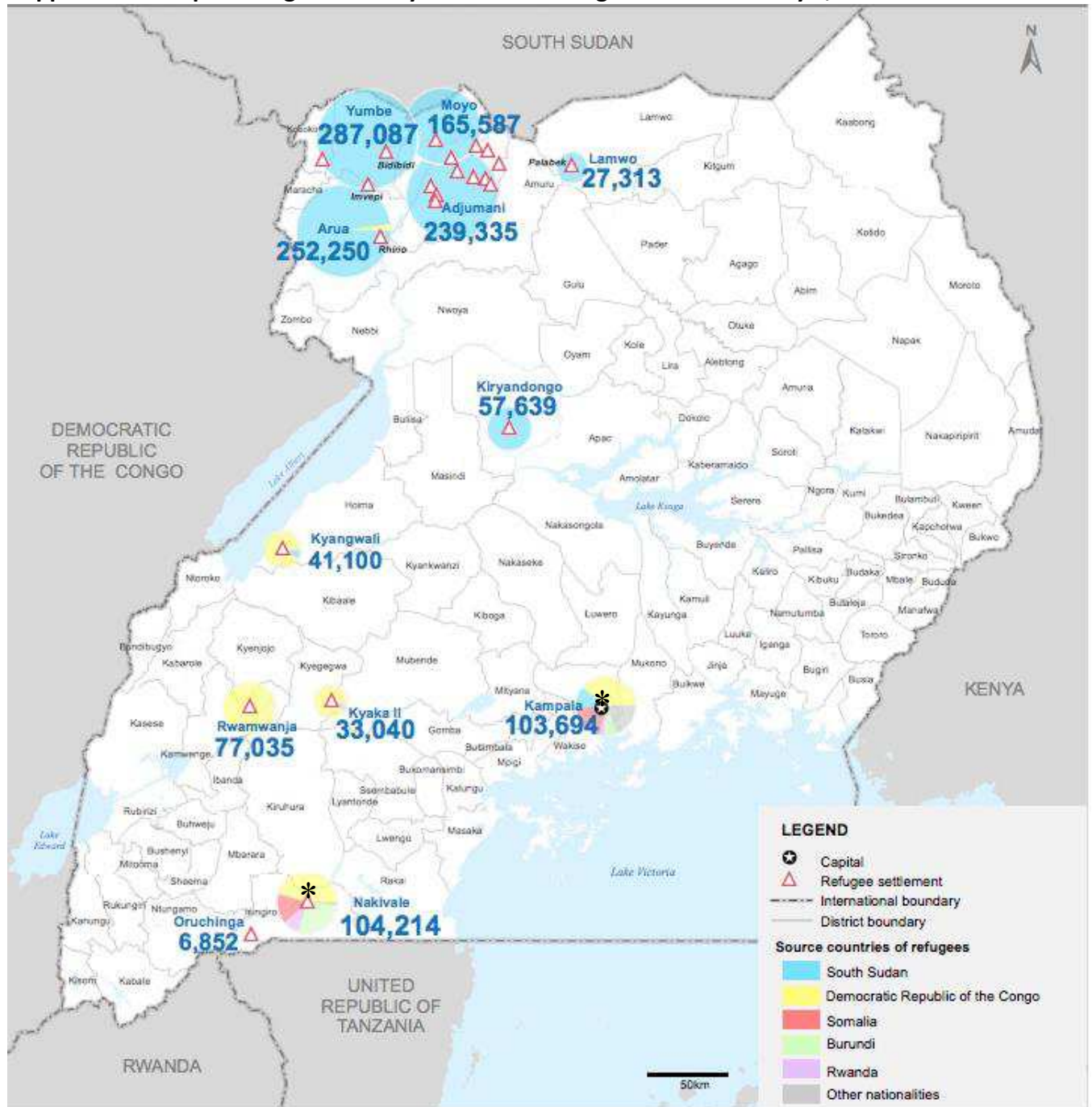
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Appendix A: Map of refugees and asylum seekers in Uganda as of January 1, 2018



Study sites are indicated by an asterisk (*). Geodata Sources: UNHCR, UNCS, UBOS Statistics: Provided by Government – Office of the Prime Minister, Refugee Department.
Author: UNHCR Representation in Uganda

Appendix B: University of Ottawa Ethics Approval Letter

File Number: 04-17-15

Date (mm/dd/yyyy): 07/28/2017



Université d'Ottawa **University of Ottawa**
Bureau d'éthique et d'intégrité de la recherche Office of Research Ethics and Integrity

Ethics Approval Notice **Social Science and Humanities REB**

Principal Investigator / Supervisor / Co-investigator(s) / Student(s)

<u>First Name</u>	<u>Last Name</u>	<u>Affiliation</u>	<u>Role</u>
Angel	Foster	Health Sciences / Others	Supervisor
Ruth	Nara	Health Sciences / Others	Student Researcher
Marie-Gloriose	Ingabire	IDRC	Other Collaborator

File Number: 04-17-15

Type of Project: Master's Thesis

Title: Understanding the reproductive health needs of displaced Congolese women in Uganda

Approval Date (mm/dd/yyyy)	Expiry Date (mm/dd/yyyy)	Approval Type
07/28/2017	07/27/2018	Approval

Special Conditions / Comments:
N/A

Appendix C: Makerere University Ethics Approval Letter

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**COLLEGE OF HEALTH SCIENCES
SCHOOL OF MEDICINE**

RESEARCH ETHICS COMMITTEE

June 12, 2017

Dr. Ruth Nara, Interdisciplinary School of Health Sciences
University of Ottawa
C/O Dr Rhona Mijumbi-Deve
MakCHS

Category of Review
☒ Initial review
☐ Continuing review
☐ Amendment
☐ Termination of study
☐ SAEs

Dear Dr. Nara,

Re: Approval of proposal #REC REF 2017-073

"Understanding the reproductive health needs of displaced Congolese women in Uganda"

Thank you for submitting an application for approval of the above – referenced proposal. The committee reviewed it and granted approval for one year, effective June 12th, 2017. Approval will expire on June 11th, 2018.

Continuing Review

In order to continue work on this study (including data analysis) beyond the expiration date, the School of Medicine Research and Ethics Committee must reapprove the protocol after conducting a substantive, meaningful, continuing review. This means that you must submit a continuing report form as a request for continuing review. To best avoid a lapse, you should submit the request six (6) to eight (8) weeks before the lapse date. Please use the forms supplied by our office.

Amendments

During the approval period, if you propose any change to the protocol such as its funding source, recruiting materials, or consent documents, you must seek School of Medicine Research and Ethics Committee approval before implementing it.

Please summarize the proposed change and the rationale for it in a letter to the School of Medicine Research and Ethics Committee. In addition, submit three (3) copies of an updated version of your original protocol application- one showing all proposed changes in bold or 'track changes,' and the other without bold or track changes.

Page 1 of 2

Reporting

Other events which must be reported promptly in writing to the School of Medicine Research and Ethics Committee include:

Suspension or termination of the protocol by you or the grantor
Unexpected problems involving risk to participants or others

Adverse events, including unanticipated or anticipated but severe physical harm to participants.

Do not hesitate to contact us if you have any questions. Thank you for your cooperation and commitment to the protection of human subjects in research.

Final approval is to be granted by Uganda National Council for Science and Technology.

Documents approved for use along with protocol:

- English informed consent forms

Yours sincerely,



Assoc. Prof

Chairperson School of Medicine Research and Ethics Committee

Appendix D: Uganda National Council for Science and Technology Ethics Approval Letter



Uganda National Council for Science and Technology

(Established by Act of Parliament of the Republic of Uganda)

Our Ref: SS 4321

24th July 2017

Nara Ruth Geena Mimbo
Principal Investigator
C/o Uganda Youth Alliance for Family Planning and Adolescent Health
Kampala

Re: Research Approval: Understanding the Reproductive Health Needs of Disabled Congolese Women in Uganda

I am pleased to inform you that on 19/06/2017, the Uganda National Council for Science and Technology (UNCST) approved the above referenced research project. The Approval of the research project is for the period 19/06/2017 to 19/06/2019.

Your research registration number with the UNCST is SS 4321. Please, cite this number in all your future correspondences with UNCST in respect of the above research project.

As Principal Investigator of the research project, you are responsible for fulfilling the following requirements of approval:

1. All co-investigators must be kept informed of the status of the research.
2. Changes, amendments, and addenda to the research protocol or the consent form (where applicable) must be submitted to the designated Research Ethics Committee (REC) or Lead Agency for re-review and approval **prior** to the activation of the changes. UNCST must be notified of the approved changes within five working days.
3. For clinical trials, all serious adverse events must be reported promptly to the designated local REC for review with copies to the National Drug Authority.
4. Unexpected events involving risks to research subjects/participants must be reported promptly to the UNCST. New information that becomes available which alters the risk/benefit ratio must be submitted promptly for UNCST review.
5. Only approved study procedures are to be implemented. The UNCST may conduct impromptu audits of all study records.
6. A progress report must be submitted electronically to UNCST within four weeks after every 12 months. Failure to do so may result in termination of the research project.

Below is a list of documents approved with this application:

	Document Title	Language	Version	Version Date
1.	Research proposal	English	N/A	December 2016
2.	Consent to participate in research and dissemination of results	English	N/A	December 2016
3.	Key informant interview guide	English	N/A	December 2016
4.	In - depth interview guide	English	N/A	December 2016
5.	Focus group discussion guide	English	N/A	December 2016

Yours sincerely,

for: Executive Secretary
UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

Copied to: Chair, Makerere University School of Medicine, Research Ethics Committee

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