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Sub-Saharan African Refugee Mother and Health Care Provider Experiences, Perceptions, and Needs

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To the Graduate Council:

I am submitting herewith a dissertation written by Jennifer Ward Ward entitled "Sub-Saharan African Refugee Mother and Health Care Provider Experiences, Perceptions, and Needs." I have examined the final electronic copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Child and Family Studies.

Hillary Fouts, Major Professor

We have read this dissertation and recommend its acceptance:

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(Original signatures are on file with official student records.)

Sub-Saharan African Refugee Mother and Health Care Provider Experiences, Perceptions, and
Needs

A Dissertation Presented for the
Doctor of Philosophy
Degree
The University of Tennessee, Knoxville

Jennifer Michelle Ward
August 2019

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Abstract

Refugees have resettled in the U.S. for decades and welcoming communities are charged with providing services to culturally and linguistically diverse groups of people. Women from Sub-Saharan Africa (SSA) have increasingly been resettled in the past decade and present specific challenges and opportunities to the health care system during pregnancy care. Pregnancy care in particular and maternal health care in general are of particular interest because they include services that have the potential to impact long-term health outcomes of families and because they are often a point of entry into the health care system. Through three studies, this dissertation examined the interactions between refugee women from SSA and their health providers in the context of maternity care through bioecological, socio-ecological, intersectional, and cultural competence theoretical frameworks. The first study used the PRISMA framework to systematically review what is known about the needs of women from SSA as they encounter the maternal health care system in the U.S. Results indicated that needs can be categorized as Clinical, Systemic, and Personal and recognized Strengths and Protective Factors. The second study is an in-depth case study that used interviews and observations to understand the experiences and perceptions of care received by two refugee women from the Democratic Republic of the Congo that were resettled in the southeastern U.S. Participants had different experiences of pregnancy care and these were related to the differences in personal characteristics between the participants. Personal characteristics influenced the participants' ability to access care and their subsequent experiences and perceptions of that care. The third study used key informant interviews with medical doctors, nurse practitioners, and nurse midwives to understand their perceptions of the needs of refugee patients from SSA and their needs as health providers interacting within their respective clinics and the larger U.S. health system. Together, the studies elucidate the importance of culture as a factor in health care interactions and opportunities for service providers and public health professionals to bolster services in a way that allows for more seamless service delivery in a culturally competent manner that ultimately improves health outcomes and reduces health disparities.

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Chapter I

Introduction

The purpose of this dissertation is to explore the ways in which refugee mothers and U.S. health providers mutually interact and how this impacts their experiences and perceptions.

Refugees are a growing part of the population in the U.S. with unique experiences and needs in healthcare (Carolan, 2010; Herrel et al., 2004). A significant portion of those refugees are from Sub-Saharan Africa (SSA), a population that has increased its presence in the last ten years of refugee resettlement in the U.S. Importantly, many refugees are of reproductive age and must interact with the health care system frequently especially when they become pregnant as pregnancy is a time when health care use is high (Gany & de Bocanegra, 1996). This time of frequent contact with the health care system and health providers comes with the potential to mediate health risks associated with refugee status (Ganann, Sword, Black & Carpio, 2012). For example, lack of social support and history of trauma common among refugee women results in higher rates of postnatal depression when compared to native-born populations (Collins, Zimmerman, & Howard, 2011).

By examining the dynamics between refugee mothers seeking prenatal and postpartum care and their health care providers, opportunities are identified to enhance services that benefit both health care providers and refugee mothers. Enhanced services should ultimately, lead to measurable improvements in health outcomes and a reduction in health disparities. To accomplish this, my dissertation is composed of three studies, each in the form of an independent manuscript. The first is a systematic literature review that identifies what is known about SSA

refugee women's maternal health care needs and their perception of health services in the context of resettlement in the U.S. The second is a case study documenting the experiences of two refugee mothers during pregnancy care in the U.S. This case study used observations and interviews to examine in depth, the experiences of two refugee women originally from the Democratic Republic of the Congo (DRC), and their interactions with the health care system as they sought prenatal, obstetric, and postpartum care. The third is a qualitative study using interviews of health care providers who serve refugees from SSA to understand their perceptions of cross-cultural health care provision, including lactation support, to their patients. Although principles of cross-cultural care provision by health providers can be applied to diverse populations, providers were asked questions specifically about SSA refugee patients to determine how cultural factors specific to this population are perceived by health providers and how/if health providers make accommodations for this population.

By studying refugee mothers and the health care system within which they receive care, this dissertation is positioned to inform service providers on how best to enhance services to refugee populations to meet their needs, improve maternal and infant health outcomes (e.g., positive health behavior, prevention, morbidity and mortality), and to bolster programs and protocols within the system to support health care providers. SSA refugees are not a monolithic group but may have some prevalent health needs specific to their histories as refugees as well as cultural factors unique to them. For example, refugee women from SSA experience disparities in health outcomes such as neonatal mortality and morbidity that cannot be explained exclusively by their differential exposure to diseases like malaria and HIV/AIDS (Carolan, 2010). Rather, those disparities persist in developed countries in which they have resettled and may be related to limited access to maternal health care (Carolan, 2010). Thus, this population is worth examining

as a specific entity to add to the existing literature on SSA women and to further delineate their health care needs from other refugee groups and from those of the majority population.

Theoretical Perspectives

The decision to examine the experiences of refugee mothers from SSA was guided by intersectionality theory as introduced and used by Kimberlé Crenshaw (1989). The descriptive or explanatory power of this theory allows the researcher to view results through the lens of power in explaining systems and the experiences of vulnerable populations with multiple oppressed identities. The work of Crenshaw (1989) informs the dissertation as her work views the intersectionality of gender, nationality, and race as important and mediating constructs influencing women's experiences. For refugee women from Sub-Saharan Africa, their experiences of health care in the U.S. are influenced by their race, gender, and country of origin (Collins, 1998).

The evolution of intersectionality as a theory is important to understand in this work and does not stand alone in informing this dissertation, but rather is the most salient perspective throughout the dissertation. Ideas about intersectionality were derived originally from feminist thought but feminist theory is insufficient to understand the experiences of women who are also racial minorities and immigrants (Carastathis, 2014). However, postcolonial feminism and the way that it has informed intersectionality is important to understand especially in work examining the lives of refugee women from SSA (Tyagi, 2014). Any researcher would be remiss not to point out the implications of refugee women's interactions with Western systems who are likely escaping economic and violent conditions caused by Western colonization. The dynamics present in a U.S. doctor's examination room are inherently and irrevocably tied to the historic dynamics between the U.S. and SSA.

Intersectionality posits that the experiences of refugee women can best be understood when considering their multiple identities as women, newcomers to the U.S., refugees, and in the case of African origin refugees, as racial minorities. This is in contrast to more traditional feminist theory that prioritizes their experiences as women, with less emphasis on multiple identities that could influence their experiences. Moreover, intersectionality theory has been proposed as a viable and necessary framework to study public health issues (Bowleg, 2012) and thus, is appropriate for use in studies that aim to have immediate public health value such as this dissertation. Specifically, intersectionality illuminates how multiple identities connect to each other on a personal level and reflect and create larger disparities that are the subject of public health research and intervention. In the case of women refugees from Sub-Saharan Africa, an intersectionality perspective would posit that they are more likely to experience disparities because of their blackness within the U.S. where whiteness is a privileged identity. In addition, they would have experiences informed by being a woman, in a patriarchal society where men are privileged, and their immigration status where the native-born population is privileged. Rather than these identities having separate and disconnected influences, they intersect in ways that result in experiences unique to them. In other words, they are unlikely to experience the healthcare system in ways that align with the way “most women” or “most racial minorities” experience the health system. The ways in which those experiences vary and are unique to them are best examined by using intersectionality because it is a framework for investigating populations with multiple oppressed identities (Bowleg, 2012).

The dissertation is also informed by the third phase of Bronfenbrenner’s (Bronfenbrenner & Morris, 2006) bioecological theory that focuses on proximal processes related to human development (Rosa & Tudge, 2013). The general ecological framework is an approach to family

studies and research that at its core, acknowledges the influence of varying systems that intersect and impact an individual's life (Bronfenbrenner, 1986). In contrast to the earlier iterations of the theory, the third phase is posited as that which urges researchers to structure studies to examine personal characteristics (including motivation and belief) in conjunction with proximal processes, context, and time (PPCT). Thus, in attempting to understand the experiences of refugee women in pregnancy and to make sense of health outcomes associated with those experiences, bioecological thinking guides researchers to examine and situate people within specific contexts of time and place, and interactions with other people and institutions (Bronfenbrenner & Morris, 2007). By approaching these experiences through this model, the resulting picture elucidates how mothers and healthcare providers interact in ways that may ultimately impact health outcomes.

To expand on Bronfenbrenner's work and to use a related theoretical perspective, the second manuscript uses the socio-ecological framework common in public health research and interventions (Richard, Gauvin, & Raine, 2011). Like the bioecological model, the socio-ecological framework allows for personal health behaviors, attitudes, and outcomes as related to a complex interaction between the person and their environment including people close to them, institutions, and the larger cultural context (CDC, 2017). The research presented in this dissertation addresses the personal experiences and reactions to refugee women's interactions with their health providers and the clinic within which they seek care.

Cultural competence, as applied in health care, is an additional framework used to inform the dissertation (Betancourt, Green, Carrillo & Ananeh-Firempong, 2003). The Office of Minority Health (n.d.) has outlined factors that make health services more accessible to diverse patient populations including appropriate language interpretation, effective communication, and

valuing cultural differences. Culturally competent health care services can improve patient health outcomes and impact the relationship between refugee women from SSA and their health care providers (Renzaho, Romios, Crock & Sonderlund, 2013). As research with applied aims, uncovering the extent to which clinicians provide services that are attuned to the needs of refugee women from SSA is critical in informing health care administration of opportunities to improve training and resources.

Key Terms

Key terms used throughout the dissertation are defined below.

Breastfeeding duration- The amount of time the infant is breastfed in terms of age of the child.

Breastfeeding initiation- A single attempt to breastfeed even if not successful.

Cultural competency- Behavior, attitudes, and policies that allow health care providers to effectively treat patients in cross-cultural situations including valuing diversity, the capacity for cultural self-assessment, being conscious of the dynamics inherent when cultures interact, having institutionalized cultural knowledge, and having developed adaptations to service delivery reflecting an understanding of cultural diversity (Cross et al., 1989).

Ever breastfed- A mother who has engaged in any breastfeeding even if supplements are used.

Exclusive breastfeeding- The act of breastfeeding without supplementation with milk substitutes (formula) or other food/water.

Federally Qualified Health Center- A community-based health center that provides primary and preventive care to underinsured and uninsured populations.

Lactation support- Information or advice provided to a person by a healthcare provider with the aim of helping the mother continue to breastfeed or make a choice about breastfeeding.

Maternal health care- Health care that is related to pregnancy, labor, delivery, and infant care.

Health provider- Any clinically trained medical professional who provides medical care including medical doctors, nurses, nurse practitioners, certified nurse midwives, International Board Certified Lactation Consultants (IBCLCs), and physician assistants.

Refugee- A person who has the legal status of refugee as defined by the United Nations High Council for Refugees (UNHCR) and has been granted documentation to that effect.

Sub-Saharan Africa- Those countries in Africa that are located fully or partially South of the Sahara Desert as categorized by the Library of Congress. However, priority is given to those populations most likely to have resettled in the United States including; The Democratic Republic of the Congo, Congo, Burundi, Somalia, Eritrea, Ethiopia, Liberia, South Sudan, and Rwanda.

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Chapter II

Maternal Health Care Needs and Services for Refugees from Sub-Saharan Africa: A Systematic Literature Review.

Abstract

As refugees move to the U.S. and seek healthcare, clinicians must find culturally appropriate ways to provide care. The cultures from which refugees come are vast and various and require medical practices that adapt to the changing needs, expectations, and values of diverse patient populations. Moreover, refugees often experience health disparities, thus presenting the U.S. health care system with an opportunity to improve health and wellbeing. The present study is a systematic literature review of studies (n = 18) published in the last twenty years (1997-2017) that have a focus on a broad range of maternal health issues and refugee women from Sub-Saharan Africa (SSA). Results from studies were qualitatively synthesized and findings indicate that there are three main categories of needs of SSA refugee women; Clinical, Systemic, and Personal and a fourth category illuminating Strengths and Protective factors. Recommendations for service providers and health professionals are discussed.

Introduction

The U.S. has been a partner in the United Nations refugee resettlement program resettling approximately 3 million refugees since 1975 (UNHCR, 2018). Although the number of refugees resettled annually changes, refugees must find housing, education, and health services in their receiving communities as they rebuild their lives (UNHCR, 2018). The health system in the U.S. is in many ways, different than the ones in countries from which refugees journey and often amplifies cultural values, expectations, and beliefs surrounding health. Providing competent health care to refugees includes understanding that people will understand and experience healthcare in a variety of ways depending on their cultural experiences, values, and beliefs. In this way, culturally competent health care and has the potential to impact short- and long-term health outcomes in a population that has experienced health disparities (Brach & Frasirector, 2000).

Refugees and Health Disparities

Racial and ethnic disparities are well documented in the health literature and are evident in prenatal care and health outcomes among minority mothers and their infants (Mayberry, Mili & Ofili, 2000). These disparities that are often reflected in refugee communities (Carolan, 2010) are complex and likely rooted in both biased treatment and discrimination (Edberg, Cleary & Vyas, 2011). In addition, less access to insurance and health care services that are complicated by language and transportation barriers may perpetuate disparities (Gagnon, Carnevale, Mehta, Rousseau & Stewart, 2013). Refugees often enter the U.S. with few resources and continue to occupy low socioeconomic categories, which makes them vulnerable to chronic disease related to the social determinants of health (George, 2010). Refugees have health needs relevant to their status as refugees and as newcomers in developed countries, which are often related to their

mental health and the trauma they have endured in war-torn homes and through persecution (Burnett & Peel, 2001; Carolan, 2010; Collins, Zimmerman & Howard, 2011).

Before resettling into a country like the U.S., many refugees spend their lives in limbo in unstable housing and conditions that do not meet their daily basic needs (UNHCR, 2017). Once resettled into a host country, those basic needs may be met by federally funded programs (ORR, 2015) but gaps remain. For instance, refugees are often among those who lack access to primary care health care services and are often under or uninsured (Mayberry, Mili & Ofili, 2000). This lack of access means health problems are likely to go undetected and untreated resulting in higher morbidity and mortality and higher healthcare costs through emergency services (Brach & Fraserirector, 2000).

Edberg and colleagues (2011) argued that health disparities set up refugees and immigrants for a trajectory of health and that these disparities are related to: access to health care including insurance, stress related to experiences as an immigrant, hardships in navigating community and social systems, beliefs about health and health behaviors, and bias from the health care system. These factors are areas in which those in power can intervene to improve circumstances and eventually health outcomes. For instance, health education can address health beliefs that are culturally rooted but not necessarily evidence based. For instance, some Sub-Saharan African (SSA) cultures may use herbal medicine that is unfamiliar to clinicians in the U.S. and may have implications for efficacy and interactions with prescriptions (Simmelink, Lightfood, Dube, Blevins & Lum, 2013). Policymakers can expand benefits and enrollment qualifications to capture the refugee population and provide insurance that adequately covers their health care needs including interpretation. Additionally, health care practitioners and the institutions within which they practice can improve their healthcare service delivery to address

issues of perceived discrimination and cultural barriers. Most importantly, these factors should not be understood independently, but as coexisting and related with an impact on each other. Given that the health needs of refugees are unique, those who are charged with improving the public's health must look for effective routes to intervention with high impact on refugees and their families. One such way is to focus programming and policies on maternal health care as it is a way into the health care system for many refugee families (Gany & de Bocanegra, 1996).

Maternal Health Among Refugees and Immigrants

Studying maternal health among diverse populations has the potential to inform best practices and positive healthcare interventions for families (Burnett & Peel, 2004). Moreover, enhanced cultural competency in healthcare may positively affect the health outcomes of mothers and their children. This potential impact on health and the desire to have greater cross-cultural understanding has driven research on the maternal health care needs of refugees in particular, across the globe and within the U.S. However, the current state of the literature is disparate and interdisciplinary. For example, some research focuses on refugees specifically and other research includes them as part of a larger immigrant sample without teasing out possible differences between the populations (Gagnon, et al., 2006; Gagnon, Black & Carpio, 2012). Some studies address only what clinical needs might be different among refugees without attention to social and structural needs and their potential impact on clinical presentations (Burnett & Peel, 2001). Moreover, many research studies take place in the context of various health care systems among many countries limiting the generalizability of findings in the U.S. (Gagnon, Zimbeck & Zeitlin, 2009).

Immigrants and refugees have specific health concerns that warrant distinct focus (Burnett & Peel, 2001). Health care that is sought during pregnancy is often an entry point to

health care access for refugees in the U.S. (Gany & de Bocanegra, 1996) with the potential to impact health outcomes for women themselves and their families. However, specific clinical outcomes associated with culturally competent healthcare in this area are not yet well established in the literature (Renzaho, Romios, Crock & Sonderlund, 2013). In the case of infant feeding, increasing exclusive breastfeeding for the recommended 6 months has the potential to improve health outcomes (AAP, 2012; Bartick & Reinhold, 2010) and potentially reduce health disparities experienced by refugees. Moreover, interventions that address emotional wellbeing in a culturally competent way may address the increased risk of postpartum depression that immigrants currently experience (Gannan, Sword, Black & Carpio, 2012) and reduce anxiety in refugee populations (Murray, Davidson & Schweitzer, 2010).

Women have specific health needs as refugees (Burnett & Peel, 2001) including access to robust maternal health services and those related to pregnancy. Given the limited access to health care for refugees in general, pregnancy related health care is a gateway to care for many families and is an opportunity for health providers to provide culturally competent care in a meaningful way that affects health outcomes in the long term (Gany & de Bocanegra, 1996). Previous research has identified needs related to specific disease profiles of countries of origin, access to systems and processes, and interpersonal needs between patients and providers (Betancourt, Green, Carillo & Ananeii-Firempong, 2003). Because of the various levels and types of needs, it is important to synthesize the literature examining their needs in order to make recommendations on how to overcome barriers. Moreover, it is important to focus on the U.S. healthcare system as it is distinct from other Western industrialized countries.

The Present Study

This systematic literature review synthesizes the findings of research published between 1997 and 2017 related to the pregnancy and maternity health care needs of refugees from SSA in the U.S. The past two decades (1997 - 2017) reflects a period in which refugees from SSA were resettled at relatively higher rates than in previous years to developed countries including the U.S., Australia, Great Britain, Canada, Sweden, and Finland (Hoas, 2007; Office of Refugee Resettlement, 2015; UNHCR, 2017). The increase does not reflect more refugees in Africa, as there had historically been high numbers of refugees originating from African countries, but a change in U.S. priorities for resettlement with a more humanitarian focus (Hoas, 2007). Thus, the impact of resettlement and experiences of refugees from this part of the world is reflected in the research that reacted to the increased presence of refugees from SSA during this time period, making it an important timeframe to examine. In bringing findings from the last twenty years together, this systematic review synthesizes articles that examine the maternal health needs of SSA refugee women in the U.S. health care system through qualitative, quantitative, and mixed method approaches. Articles on the maternal health needs of SSA refugees in the U.S. were reviewed using predetermined inclusion criteria detailed below and screening processes to identify and categorize the needs refugee women have during the range of maternal health care including: pregnancy care, labor and delivery, and postpartum support including infant feeding. The review elucidates the needs that refugee women have and the gaps that exist in healthcare services according to their perspectives and has resulted in an integrated model of what is known about maternal health care needs among SSA refugee women. This descriptive model clarifies and organizes past research and provides a framework for future research by identifying gaps in what is known about this population. Specifically, this review addresses the following question:

what are the pregnancy related health care needs of recently resettled (arrived within the last five years) refugees from SSA in the U.S. during prenatal care, labor and delivery, and immediate postpartum care (~6 weeks after birth)?

Methods

A systematic literature review surveying the research on pregnancy-related health needs of SSA refugees in the U.S. was conducted using the Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA) framework. The PRISMA framework is a well-established method of review (Moher, Liberati, Tetzlaff, & Altman, 2009; Smith, Devane, Begley, & Clarke, 2011). In this study, the following sections of articles were examined: title, summary, objectives, methods including eligibility criteria and databases used, results including a synthesis of results, and discussion as suggested by the PRISMA checklist (2009). Search terms were used to search for published peer-reviewed empirical articles in the following databases: Web of Science, PsycInfo, and PubMed. All results from combinations of search terms (see Table 1) were documented with yield results tracked in a spreadsheet. Search terms were combined from columns 1, 2, and 3 in Table 1 for each search. For example, the first search conducted in each database was “maternal health AND refugee AND U.S..” Studies that met the following criteria were included in the review: 1) published from January of 1997 to December of 2017 that included primary data or secondary analyses; 2) included participants who were refugees originally from SSA or with SSA refugees named as at least a portion of the population sample and that present results that specifically address refugees; 3) focused on prenatal care, labor and delivery, reproductive health, and/or postpartum care; 4) conducted in the U.S.; and 5) article was available in English.

Duplicates from database searches and other sources were removed. After that, an initial screening of abstracts took place removing articles that did not meet the basic criteria. For instance, many articles were removed because the abstracts indicated that the study took place in a country other than the U.S. The remaining articles were reviewed in full text for relevance. Any articles excluded after this stage were recorded in a spreadsheet with the reasons for exclusion noted. Those articles that remained were used for the qualitative synthesis of findings to: 1) identify the maternal health findings related to refugees during prenatal care, labor and delivery, and postpartum care, 2) categorize those findings, and to 3) integrate findings to identify needs of SSA refugee women. Articles included in the full text review (n = 27) were organized in an Excel spreadsheet. Relevant findings were noted and those articles that failed to meet inclusion criteria were excluded with reasons (n = 9; see Table 2). Each of the remaining articles (n = 18) were fully reviewed. The purpose of the study, methods including sample demographics, and findings were summarized and added to a table. Findings were then reviewed closely using thematic analysis in the first round of open coding. Findings were pulled from each study that were relevant to the SSA participants and to reproductive health. For example, the first round of coding in an article on Somali women's experiences of maternity care resulted in codes like "women don't want to continue practice of FGC but want respect for cultural beliefs" that closely followed the study author's language. After the first review of each article, the author did a round of secondary coding grouping codes into broader categories and connecting codes across articles. These codes came from the results sections of each paper to identify common themes among the particular findings. In the case of the code regarding Somali women and the practice of FGC the group of open codes related to that were grouped as a personal need for respect for culture. In addition, several studies cited health data indicating lower risk of preterm birth and

higher rates of postpartum care utilization. Open codes related to those findings were combined into a general theme entitled strengths and protective factors.

Results

Searches within the 3 databases yielded 487 results. The review process is outlined in Figure 1, leading to a final inclusion of 18 articles for qualitative synthesis (see Table 3). Some studies included a sample exclusively made up of refugees from SSA (n = 12) while others included refugees from SSA as a subset of a larger population sample (n = 6). Many studies named specific ethnic groups from SSA as the focus of the study such that the majority of studies were on Somali refugees exclusively (n = 9) or Congolese (n = 1) or Congolese and Somali refugees together (n = 1). Studies included in the review represented a mix of methodologies: quantitative (n = 5), qualitative (n = 8), and mixed methods (n = 5). In those studies where the location of the sample was named, they were geographically focused in northern states in the U.S.; New York (n = 3), Minnesota (n = 1), Massachusetts (n = 1) and Indiana (n = 1). Of those that reported descriptive statistics on age, two studies had women beyond reproductive age (McMorrow & Saksena, 2017; Chu & Akinsulure-Smith, 2016). Those that reported mean age of participants had participants ranging from 18 years old to over 67 years old. Several studies (n = 7) reported participants with a mean age between 24 years old and 40 years old. Some studies (n = 7) measured and reported the number of years refugee participants had been in the U.S. The means of years in U.S. ranged from 1 year to 6.8 years.

Although participants raised many issues and concerns within and across studies, three major types of needs of SSA refugee women were identified in the studies: 1) Clinical Risks, 2) Systemic Access Issues, and 3) Social Concerns. In addition to these identified needs, Strengths and Protective Factors were also identified; this included research that indicated promotive and

protective factors that related to a lower risk for some negative outcomes and experiences. These four categories (Clinical Risks, Systemic Access Issues, Social Concerns, and Strengths and Protective Factors) emerged through qualitative thematic analysis of the findings and include all findings discussed by articles reviewed. The major themes are illustrated in Figure 2.

Clinical Risks

Clinical risks were those medical issues that place refugee women and women from SSA at higher clinical risk than other population groups. The increased risk for certain diseases and complications related to reproductive health are important for doctors and other health care providers to be aware of so that appropriate screening and diagnostic tools can be used. Without this understanding, some symptoms may be overlooked or misdiagnosed. Moreover, refugee women from SSA accessed different types of care like preventive screenings and prenatal care at different rates than citizen or resident populations (Barnes & Harrison, 2004; Kentoffio, Berkowitz, Atlas, Oo, Percac-Lima, 2016; Saadi, Bond, Percac-Lima, 2015).

Several studies used quantitative methods, like retrospective chart reviews, to identify specific diseases or complications that had a higher prevalence rate in refugee populations (Barnes & Harrison, 2004; Blood, Beckwith, Baserman, Cu-Uvin & Mitty, 2008; Flynn, Foster & Brost, 2011). For example, Barnes and Harrison (2004) found that refugee women from a variety of countries including a small portion from SSA, had fewer screening tests for things like breast and cervical cancer and although 15% of the sample was pregnant, none were receiving prenatal care. Several studies found that refugees from SSA were at higher risk of severe maternal morbidity in general and specifically at higher risk of exposure to violence, HIV infection, low birth weight infants, emergency cesarean deliveries, female genital mutilation, anemia, and post-partum depression (Blood, Beckwith, Bazerman, Cu-Uvin & Mitty, 2008; Chu

& Akinsulure-Smith, 2016). These risks translate to the need for enhanced screening and treatment of refugee patients from SSA. Moreover, the finding that women from SSA were receiving less prenatal care than women from the U.S., could lead to higher clinical risk for adverse birth outcomes (Flynn, Foster & Brost, 2011). One case study on a single patient from Somalia expounded on the presence of genital tuberculosis as a reminder for doctors to consider the possibility of this diagnosis when treating women from this region and the outcome of infertility associated with the condition (Cookson, Brachman & Oladele, 2008). Quantitative studies that conducted chart reviews elucidated higher risk profiles of certain diseases (Barnes & Harrison, 2004; Blood et al., 2008; Flynn, Foster & Brost, 2011) recommending that physicians and other health care professionals pay attention to and screen this population appropriately (Barnes & Harrison, 2004).

Although refugee women from SSA had some noteworthy clinical risks in terms of morbidity and mortality, two prominent foci of clinically centered studies were HIV and female genital mutilation (FGM). This is likely because both HIV and FGM require modifications in clinical practices. Blood and colleagues (2008) found that refugee women from West Africa who were HIV positive had a high pregnancy rate despite counseling regarding the risks of pregnancy and transmission to their infants. FGM or female genital cutting (FGC), was a specific focus of two qualitative studies (Chu & Akinsulure-Smith, 2016; Johnson-Agbakwu, Helm, Killawi & Padela, 2014) that explored women and men's perception of the impact of FGM on their reproductive/maternal health care including pregnancy/labor and delivery. Although FGM is a common experience among refugees from certain parts of Africa, Chu and Akinsulure-Smith (2016) found among a West African sample that included refugees, in New York City (NYC) that participants were resistant to continuing the procedure in the U.S. This sample cited health

complications as the main reason behind discontinuing the practices of FGM rather than humanitarian focused reasons. Another study found that Somali refugee men in the U.S. were not supportive of continuing practices of FGC and were aware of negative health outcomes related to the practice (Johnson-Agbakwu, Helm, Killawi & Padela, 2014).

Systemic Access Barriers

Systemic access barriers are those components of the health system that relate to health care service delivery including access to interpreters, health insurance, strong relationships with health care providers, and education about birth practices and procedures (including cesarean deliveries) to improve health literacy (Gurnah, Khoshnood, Bradley & Yuan, 2011; McMorrow & Saksena, 2017; Pavlish, Noor & Brandt, 2010). These issues go beyond personal physiological needs and risks and relate to the broader health care system. The focus on systemic needs is particularly important, given that all articles reviewed were conducted in the U.S., which has a health care system distinct from other western countries that resettle refugees in that it does not have universal healthcare. Rather, the U.S. has a payor structure that uses a mix of government sponsored and for-profit insurance companies. Of particular importance for pregnant women, refugee populations encounter barriers in accessing prenatal care. For example, in a quantitative medical chart review study, Kentoffio and colleagues (2016) found that refugee women, including a large sample from Somalia, had fewer prenatal visits than U.S. born controls. On the other hand, they were more likely to have more postpartum care visits than U.S. born controls. It is worth noting that this study was conducted in the state of Massachusetts, which has near-universal health insurance coverage and where all pregnant women are eligible to be insured (Kentoffio et al., 2016).

In addition to access to clinical care appointments, language differences were often cited in qualitative studies as barriers to quality care. Often, participants in studies expressed a need for enhanced language interpretation (Gurnah, Khoshnood, Bradley & Yuan, 2011; Herrel et al, 2004). For instance, in a study of Somali Bantu women, participants had low faith in the competence of their language interpreters and cited that providers were unaware of dialects and differences in language. Participants explained that this lack of awareness and understanding led to the selection of the wrong interpreters for appointments (Gurnah, Khoshnood, Bradley & Yuan, 2011). Quality of interpreters and their impact on the quality of care were of paramount importance to Somali populations in several studies (Herrel et al., 2004; Gurnah, Khoshnood, Bradley & Yuan, 2011; Pavlish, Noor, & Brandt, 2010). Somali women's needs often went beyond strict language interpretation to broader and more complex communication issues. A study using focus groups found that there was a disconnect between the way Somali women were describing their symptoms and the way providers understood and acted upon those explanations. This pattern of miscommunication resulted in the generation of mistrust among patients (Pavlish, Noor & Brandt, 2010).

Access issues also encompass needs outside of a hospital or clinic and include the ability to get to appointments and to understand the way to make and follow up on appointments and insurance concerns. For example, McMorrow and Saksena (2017) found that Congolese refugees in Indiana were particularly concerned about access issues related to transportation to appointments, insurance/billing, and the structure of appointments. Transportation was cited as a barrier to getting to health care appointments. Participants expressed frustration over the insurance system including the various kinds of insurance for refugees and how insurance and billing worked. Some were confused about how to read bills and why they were getting bills

when they had insurance. Appointments were another source of frustration including the waiting time involved when they were experiencing an acute illness (McMorrow & Saksena, 2017). In addition to experiences at appointments, refugee participants desired appointment reminders so as not to miss important medical care (Saadi, Bond, & Percac-Lima, 2015). Medical infrastructure issues continued after appointments and extended to pharmacy processes. Interviews revealed that participants had issues with the pharmacy and getting medicines in a timely, seamless manner. In a study of Congolese women, participants were frustrated at the prescription and refill processes and asked to be educated on how to use a pharmacy and talk to a pharmacist (McMorrow & Saksena, 2017).

The processes and procedures in hospital birthing systems were also a source of concern for refugee women from SSA. For example, several studies that employed focus groups, found that women were particularly fearful of surgical delivery. Fear of cesarean delivery was a prominent theme in both Brown and colleague's (2010) study and Herrel and colleague's (2004) study with Somali women participants. As a solution to these concerns, participants expressed a desire for enhanced education provided by the health care system about surgical deliveries and interventions like chemical inductions and anesthesia (Herrel et al, 2004; Johnson-Agbakwu, Helm, Killawi & Padela, 2014). For example, Somali men expressed the desire to participate in hospital sanctioned education but felt that the class offerings were not culturally competent or accessible in that they were offered in mixed-sex groups, which was against their religious values and practices (Simmelink, Lightood, Dube, Blevins & Lum, 2013).

Moreover, participants in several studies (Herrel et al, 2004; Brown, Carroll, Fogarty & Holt, 2010) spoke positively about the enhanced health care system and competence of doctors in the U.S., yet they were still by and large opposed to interventions such as inductions because

they were associated with maternal mortality in their home country (Brown, Carroll, Fogarty & Holt, 2010). These past experiences made them scared and unsure about the use of obstetrical interventions in the U.S. Moreover, a study by Johnson-Agbakwu and colleagues (2014), found that participants were wary of doctors' competence to help a woman with FGM deliver vaginally.

Systemic barriers came up in several studies that examined participants' issues in accessing health care in a way congruent with their goals and their suggestions for improving health care (DeStephano, Flynn & Brost, 2010; Gurnah, Khoshnood, Bradley & Yuan, 2011; Herrel et al., 2004; McMorrow & Saksena, 2017; Saadi, Bond & Percac-Lima, 2015). This included access to appropriate and competent language interpretation, consideration of cultural values when implementing health education and communication programs, and increased resources to help with transportation, appointments, and cultural orientation needs (Herrel et al, 2004; Gurnah, Khoshnood, Bradley & Yuan, 2011; McMorrow & Saksena, 2017; Wojnar, 2015).

Social Concerns

Participants in several studies expressed needs for social support, equal treatment, and respect for their culture and values (Simmelink, Lightfoot, Dube, Blevins & Lum, 2013; Wojnar, 2015). Moreover, some groups expressed a fear of discrimination and the experience of discrimination from health providers that made them modify their healthcare utilization (Herrell, et al, 2004). Gender was a prominent theme in several qualitative studies where gender dynamics in the home and the healthcare system were emphasized (Johnson-Agbakwu, Helm, Killawi & Padela, 2014). In terms of pregnancy care, the gender of their provider was important to Somali patients who expressed concern over having male providers (Gurnah, Khoshnood, Bradley &

Yuan, 2011; Johnson-Agbakwu, Helm, Killawi & Padela, 2014). In addition, male interpreters for female patients were a concern for Somali women who valued female-centered care (Johnson-Agbakwu, Helm, Killawi & Padela, 2014). In terms of family dynamics, two studies with Somali men and women found that men were historically less comfortable being involved in childbirth and medical decision-making in their home countries and countries of refuge, but those gender roles and their coinciding beliefs were in flux in the U.S. (Gurnah, Khoshnood, Bradley & Yuan, 2011; Johnson-Agbakwu, Helm, Killawi & Padela, 2014). In one study, Somali men were more likely than the Somali women to prefer and anticipate being more closely involved in labor and delivery and to be involved in decision-making in general (Johnson-Agbakwu, Helm, Killawi & Padela, 2014).

A phenomenological study of Somali married couples found that values and beliefs informed their experiences of the healthcare system and revealed how participants perceived their experiences of healthcare (Wojnar, 2015). For instance, they were compelled to have large families by their religious beliefs and cultural values but expressed that the health care providers treating them did not show respect for those ideals. Moreover, participants reported feelings of vulnerability especially related to feeling misunderstood by providers and when they were uninformed of the things that were happening. For example, one couple explained that they were confused and saddened when their new infant was taken for routine vaccinations. Although this was a common procedure, the couple was unaware and did not know why the shots were being given and mistakenly assumed there was something wrong with their infant (Wojnar, 2015). Other studies made clear that communication issues and barriers also made talking about FGC and relevant complications and conditions more difficult (Gurnah, Khoshnood, Bradley & Yuan, 2011). Studies urged providers to have positive interactions talking about the “taboo” topic and

to engage in respectful conversations with Somali patients to make sensitive decisions about proceeding with reconstructive surgery (Gurnah, Khoshnood, Bradley & Yuan, 2011; Wojnar, 2015). These ideal conversations would be free of judgment and discrimination from the clinician and would provide patients with the full range of information that they need to make decisions about their bodies and their care (Wojnar, 2015).

In order to address the social concerns of refugee women and their families in the context of healthcare, many studies recommended enhanced cultural competency as a way to promote more positive health care experiences and outcomes for refugee women and their families. These studies (Gurnah, Khoshnood, Bradley & Yuan, 2011; Herrell et al., 2004) emphasized having appropriate language interpretation to facilitate conversations with patients that were sensitive to gender dynamics and cultural and religious beliefs common among patient populations.

Strengths and Protective Factors

Although women from SSA may have clinical risks and social experiences that negatively impact their health, several studies found strengths among this population that could contribute to positive health outcomes (McMorrow & Saksena, 2017; Kentoffio et al., 2016; Saadi, Bond & Percac-Lima, 2015; Miller, Robinson & Cibula, 2016; Wojnar, 2015). While not all research included in this review mentioned strengths or assets among their sample participants, those that did provide insight into characteristics and behaviors that can be supported by clinical team members to further improve service delivery. For instance, when compared to U.S. born women, one study that included SSA refugee women as part of a larger sample, found that refugees were less likely to experience preterm birth than U.S. born women (Miller, Robinson & Cibula, 2016). However, for Somali women in particular, the risk of

preterm birth increased as they became more acculturated, which was measured as length of time in the U.S. and degree of English language acquisition (Flynn, Foster & Brost, 2011).

Wojnar (2015) in interviews with Somali couples found that many experienced positive and supportive providers during clinical interactions. These experiences helped participants to feel heard and comfortable about the care they were receiving. Similarly, some studies showed that SSA women rated the quality of healthcare they received positively (Herrel et al, 2004; Saadi, Bond & Percac-Lima, 2015) or superior (Brown, Carroll, Fogarty & Holt, 2010) to that which they had previously experienced before living in the U.S.

Certain health behaviors were found to be positive among SSA refugee women. Physical activity and a positive view toward participating in exercise was found to be a strength among Congolese women (McMorrow & Saksena, 2017). Visiting the doctor during the postpartum period was higher among refugee women than U.S.-born women in a study by Kentoffio and colleagues (2016). This health behavior was in contrast to their lower rates of prenatal care utilization and the authors proposed that because this was found in a state with universal health care, that cultural differences impacted the way in which refugees sought healthcare. In other words, different rates of prenatal care utilization did not reflect lack of insurance or access to doctors as it might in other states without universal coverage. Rather, the authors reflect that utilization was impacted by cultural barriers to seeking healthcare.

Discussion

This review found four major themes related to the needs of SSA refugee women during their experiences in maternity health care; clinical risks, systemic access issues, social concerns, and strengths and protective factors. Findings in this review indicate that to provide quality

maternal health care to SSA refugee women and their families, clinicians must become culturally fluent and understand cultural values, norms, and related concerns. This range of needs and risks that refugee women from SSA encounter and experience relate to health behaviors. Focusing on these needs and addressing gaps in services has the potential to impact health outcomes and quality of life. Both clinicians providing direct care and public health professionals designing policy and protocol can use the findings in this review to inform their work.

Recommendation for Direct Care Providers

Health providers can use the results from this review to improve service delivery for their patients who are women from SSA and to inform interactions with various culture groups.

Providers must understand the clinical risks that are more prevalent among SSA refugee women to inform practice. Clinical needs can be unique among SSA refugee women as they experience higher rates of certain diseases like HIV and genital TB (Blood, Beckwith, Bazerman, Cu-Uvin & Mitty, 2008; Cookson, Brachman & Oladele, 2008) as well as clinical complications resulting from cultural practices of FGM (Johnson-Agbakwu, Helm, Killawi & Padela, 2014). While it is important to not over-generalize, being aware of these risks can inform screening practices and procedures, diagnosis, and treatment.

Although the clinical needs of refugee women from SSA include a higher risk of HIV, the solutions to these issues are not only clinical. In order to ensure that patients receive and comply with proper treatment, systemic access issues, such as transportation and help with appointments is essential (McMorrow & Saksena, 2017). When patients can access healthcare, including screenings (Barnes & Harrison, 2004), and understand their treatment protocols

through appropriate language interpretation, they are more likely to prevent the transmission of HIV (Blood, Beckwith, Bazerman, Cu-Uvin, & Mitty, 2008).

In terms of FGM, studies showed that support for the practice was changing in the U.S. but that ideas about gender, decision-making, and religion all play an important role in how patients wanted to address the needs and complications pursuant to FGM in the context of labor and delivery (Johnson-Agbakwu, Helm, Killawi & Padela, 2014). Not only should reproductive health providers understand the prevalence of patients with FGM, but also how to conduct patient health education and interpersonal communication in a respectful way (Wojnar, 2015).

Social concerns among refugee women and their families could be addressed with enhanced institutional knowledge of their needs. Not only should providers be aware that certain populations like Somali women are more likely to have FGM (Chu & Akinsulure-Smith, 2016), but how to address those clinical issues in a culturally competent and sensitive manner. Education for providers that covers information found in this review and the studies cited here could help them talk to patients in a respectful way to help them make decisions. Providers should not assume that refugee patients understand the services provided in the U.S. system (such as routine vaccination) and take time to use well-trained interpreters in the appropriate language to facilitate and empower patients to make decisions about their care. In the case of cesarean deliveries, enhanced health education and communication could help allay fears of surgical delivery often expressed by refugee women (Herrell et al, 2004; Brown, Carroll, Fogarty & Holt, 2010). In the case of vaccines or other procedures that require consent, providers should take the opportunity to help parents make informed decisions congruent with their cultural values and beliefs rather than assuming that routine vaccinations at birth are well understood by refugee

populations. These enhanced system-level solutions would address many of the personal needs expressed by refugee patients.

Recommendations for Public Health Professionals

Professionals in public health and healthcare administrators are charged with planning, developing, and implementing health care policies and protocols that impact the way patients receive care. For those who serve refugee women from SSA the findings in this review can inform those important job functions. Clinical protocols should be written with the understanding that refugee women from SSA have a higher risk of certain diseases like HIV and genital TB. In doing so, they can encourage or require physicians to address gaps in screening rates by being proactive in identifying patients with these conditions. FGM-specific delivery and treatment recommendations should be included in training for direct care providers. Moreover, healthcare facilities can dedicate financial and/or human resources to addressing the institutional barriers to care that refugees often experience including confusion with appointment expectations, pharmacy issues, and language interpretation. For instance, a clinic could invest in an appointment reminder system that is customizable in the preferred language of the client.

Limitations

There are several limitations to this study. Only one person conducted the literature review and thus there are no checks on possible human errors made during the search process and the review process. Individual authors of the identified studies were not consulted about the results of their studies and therefore, only the published findings were reviewed. No method outside of online database searching was used, such as asking authors for unpublished findings so there may be other data available to add to the findings in this review. Most articles included

had a focus on Somali patient populations and therefore the findings are most strongly applicable to that patient group.

Limitations of this study are also related to the limitations of the studies reviewed. Although this review required studies to name SSA refugee women as part of the study population, they were often still combined with various refugee groups representing great cultural diversity. Findings were not always presented in a ways that clearly delineated SSA refugee women. Moreover, while all of the studies reviewed included recommendations for improving care for patients it is unclear how culturally competent and accessible care will impact health outcomes.

Directions for Future Research

This review highlights a need for researchers to focus specifically on refugee women from SSA who have been resettled in the U.S. Only 18 studies conducted over a span of 20 years fit the criteria of this review. Over half of the studies reviewed focused on women from Somalia. Currently, The Democratic Republic of the Congo is one of the top 3 refugee producing countries (UNHCR, 2018). In addition, studies that focus on immigrants in general should take care to delineate among immigrant populations and specific refugee populations. If possible, studies should examine variables among SSA refugees as a distinct group given that their experiences are likely distinct than that of refugees from other regions of the world. To be included in this review, studies had to mention SSA refugees as part of their study sample, but it is likely other maternal health-focused studies on immigrants were missed because SSA refugees were not named.

Much of the research reviewed was qualitative in nature or a quantitative cross-sectional design. More information could be gleaned by dedicating research resources to examining the experiences and health outcomes of SSA refugee women longitudinally. Such research would provide insight into how culturally relevant healthcare practices influence short- and long-term health outcomes. It would also inform health policies and protocols that could be applied to various cultural groups. In addition, future research or systematic reviews should focus on how implementing culturally competent care impacts both the experience of health care by SSA refugee women and their families, and health outcomes associated with their care. This would move the research beyond perceptions and experiences toward causal relationships that can inform interventions.

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Appendix

Table 2.1 Search Terms

1	2	3
Refugee	Mother	Health care, healthcare
Migrant	Maternal	Healthcare needs
Immigrant	Maternity	Obstetric care
Displaced person, people, persons	Prenatal	Labor and delivery
Sub-Saharan, Africa, African	Postpartum	Hospital
Burundian, Cameroon, Congolese, Democratic Republic of the Congo, Ghanaian, Ethiopian, Eritrean, Liberian, Rwandan, South Sudanese, Ugandan	Intrapartum	Birth center
		Providers
		Perceptions
		Needs

Table 2.2 Articles Excluded After Full Text Review

Author(s)	Year	Reason for Exclusion
Glass, N., Ramazane, P., Tosha, M., Mpanano, M., Cinyabuguma, M.	2012	Not located in U.S.
Johnson, C.E., Ali, S.A., Shipp, M.P-L.	2009	Not maternal health related
Nyangoma, E.N. et al.	2017	Not located in U.S.
Okoro, O.N., Whitson, S.O.	2017	Did not specify refugees
Parve, J., Kaul, T.	2011	Not primary research
Pinder, L.F., Nelson, B.D., Eckardt, M., Goodman, A.	2016	Did not specify refugees
Piwowarczyk, L., Bishop, H., Yusuf, A., Mudymba, F., Raj, A.	2014	Not maternal health related
Vinesett, A.L., Price, M., Wilson, K.H.	2015	Not maternal health related
Wachter, K., Heffron, L.C., Snyder, S., Nsonwu, M.B., Busch-Armendariz, N.B.	2016	Not maternal health related

Table 2.3 Articles Included in Systematic Literature Review

Author (Year)	Method	Sample	Focus of Study
Barnes & Harrison (2004)	Retrospective medical chart review	Refugee women	Rates of preventive health screenings among refugees during early resettlement
Blood, Beckwith, Bazerman, Cu-Uvin & Mitty (2008)	Retrospective chart review	West African refugees	HIV transmission and counseling during pregnancy among refugee women
Brown, Carroll, Fogarty & Holt (2010)	Focus Groups	Somali Bantu refugees	Somali perceptions of healthcare in the U.S.
Chu, & Akinsulure-Smith (2016)	Mixed Methods	Guinea, Gambia, Mali, Sierra Leone, refugees and immigrants	Incidence of FGM and perception of FGM practices
Cookson, Brachman & Oladele (2008)	Case report	Somali refugees	Case study of Genital TB in refugee patient
DeStephano, Flynn, & Brost (2010)	Focus group, video evaluation	Somali refugees	Evaluation of health intervention using video
Flynn, Foster & Brost (2011)	Quantitative medical chart reviews	Somali refugees	Impact of maternal health behaviors and acculturation on birth weight and gestational age
Gurnah, Khoshnood, Bradley & Yuan (2011)	Interviews; focus group, survey	Somali Bantu refugees	Experiences of healthcare among Somali Bantu patients
Herrel et al. (2004)	Two focus groups	Somali refugees	Somali participants perceptions of healthcare and their needs
Johnson-Agbakwu, Helm, Killawi & Padela (2014)	Focus groups, individual interviews	Somali refugee men	Perceptions of maternal healthcare and expectations among Somali men
Kentoffio, Berkowitz, Atlas, Oo & Percac-Lima (2016)	Quantitative, health records	U.S citizen and refugees	Health care utilization among refugees
McMorrow & Saksena (2017)	Photovoice and interviews	Congolese refugees	Perceptions of health care system among Congolese refugees

Table 2.3. Continued

Author (Year)	Method	Sample	Focus of Study
Miller, Robinson & Cibula (2016)	Quantitative, health records	Refugees and immigrants	Preterm birth health outcomes among refugees
Pavlish, Noor & Brandt (2010)	Focus groups, and key informant interviews	Somali women	Somali refugee women's perspectives on healthcare system in the U.s.
Piwowarczyk, Bishop, Saia, Crosby, Mudymba, Hashi, & Raj (2013)	Program evaluation	Somali and Congolese refugees	Evaluation of DVD health intervention among refugees
Saadi, Bond & Percac-Lima (2015)	Interviews	Refugees	Health care needs among refugees
Simmelink, Lightfoot, Dube, Blevins & Lum (2013)	Two focus groups	Somali, Ethiopian, Eritrean refugees	Health behaviors and practices among refugees
Wojnar (2015)	Phenomenologic interviews	Somali couples	The experiences of Somali refugees and their interactions with the healthcare system

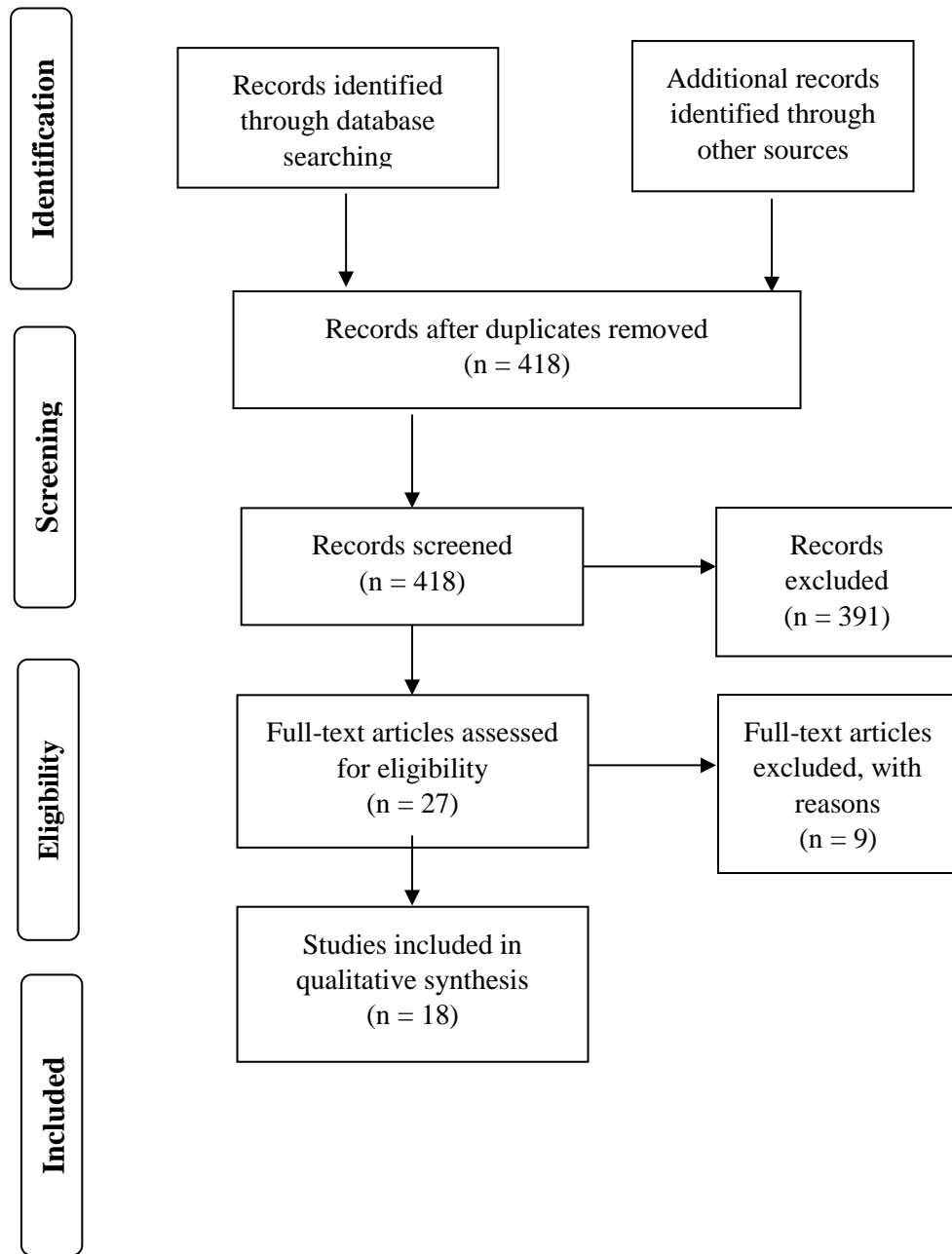


Figure 2.1 Prisma Flow Diagram (2009)

Clinical Risk	Systemic Barriers	Social Needs	Strengths and Protective Factors
<ul style="list-style-type: none"> • HIV • TB • FGM • PostPartum Depression • Lower rates - prenatal care • Lower rates - breast/cervical screening 	<ul style="list-style-type: none"> • Interpreters • Transportation • Appointments • Education about hospital protocols • Culturally relevant health education 	<ul style="list-style-type: none"> • Social support • Respect for cultural values and beliefs • Freedom from discrimination 	<ul style="list-style-type: none"> • Lower risk of preterm birth • Positive perception of healthcare in U.S. • Postpartum care utilization • Physical activity

Figure 2.2 Categories of Findings

Chapter III

Experiences in Maternity Care: A Refugee Case Study

Abstract

Refugee women who are resettled in the U.S. often enter the health care system through maternity care, giving the health care system an opportunity to provide care in a culturally accessible way. This qualitative study examines the experiences of pregnancy care of two women recently resettled in the U.S. as refugees with citizenship in the Democratic Republic of the Congo (DRC). Analysis of interviews, field notes, and an observation of a health care appointment revealed four themes related to the health care process: Personal Characteristics, Process of Accessing Healthcare, Medical Care, and Patient Perceptions and Needs. These themes reflect the process of accessing care and the lived experiences of the participants that can inform health care providers, administrators, and public health professionals on how to ensure services are delivered in a way that maximizes positive health behaviors and outcomes.

Introduction

Refugees have resettled in the United States for decades from various countries and conflicts, presenting receiving states and systems with dynamic challenges in service provision (UNHCR, 2018). In the past decade, refugees from Sub-Saharan Africa (SSA) have increased their presence in the United States (U.S. Department of States, 3/31/2017 admissions report) and thus, the demand for service providers to understand more about the ways in which culture and history impact the needs of this group. Part of the increase in refugee arrivals from SSA in general is an increase in recent years of refugees from the Democratic Republic of the Congo (DRC). The U.S. resettled nearly 8000 refugees from the DRC in the federal fiscal year 2015 up from the nearly 2000 refugees from the DRC resettled in the federal fiscal year 2012 (ORR, 2019). In recognition that refugees from SSA are not a monolith, but rather come from a variety of places, groups, and have diverse experiences, this paper focuses on the experiences of two Congolese women living in the southeastern U.S. while pregnant and delivering children.

Theoretical Framework

This study used Bronfenbrenner & Morris' (2006) bioecological model (also referred to as socio-ecological model) to guide the study design and to inform the understanding of two refugee women's experiences in pregnancy care. The bioecological model situates the individual, in this case pregnant refugee women from SSA, in the context of the systems with which they interact. Importantly, the study examines the individual's beliefs and experiences in conjunction with proximal processes, context, and time (PPCT). For this study, that means the experiences of the participants are examined in terms of the health care providers from whom they seek care, the larger health system, and the time in which they are experiencing this care. For this study, time is related both to their gestational age and the time since arriving in the U.S. In public health

related fields, this framework is more commonly referred as the socio-ecological model and has promoted the view that health outcomes are influenced by individual health behaviors, interpersonal relationships, institutions, communities, and social systems (CDC, 2017). Using the lens of social ecological theories can help research reveal and address health inequities and systems level variables in public health research (Krieger, 2001).

In addition to the bioecological framework, the study is informed by intersectionality theory (Crenshaw, 1989) because it is necessary to understand experiences through the lens of multiple overlapping and intersecting identities including gender, race, social class, and immigration status. The participants in the present study are SSA women of color who are low-resourced and who are newly arrived refugees. Bowleg (2012) posits that intersectionality can provide insights specifically within public health research regarding health disparities. In other words, to understand why health outcomes vary between groups across lines of identity, public health research should measure race, class, gender and other identity variables to elucidate how they impact outcomes of interest. Intersectionality lends itself to the examination of the concept cultural capital (Bourdieu, 1986) and the way in which gender, ethnicity, and class impact the experiences of refugee women. Cultural capital for the purposes of this paper is that which is embodied by an individual and represents long lasting characteristics and traits that are transmitted by family systems and other cultural groups. For example, knowledge of a health system and ways to navigate that system can be considered cultural capital. This concept has been used in migration studies that examine the lives of people who move between various cultural contexts (Erel, 2010) which makes it particularly relevant for the study of refugee women's experiences in maternity care in the U.S.

Refugee Women's Health Care Needs

Refugee women have specific health needs related to their status as women (Carolan, 2010) and as newcomers to the U.S (Burnett & Peel, 2001). Research in Canada, a country that resettles refugees, has found that immigrant women in general are more likely to have poor health outcomes and higher risk of postpartum depression when receiving obstetric care when compared to women born in Canada (Gannan, Sword, Black & Carpio, 2012). Carolan (2010) found that while there are certain clinical conditions that may be more widespread among refugee communities, access to care is a key problem because risk factors alone do not explain the health disparities among refugees. Moreover, while the qualitative literature on this topic is small, some research shows unmet needs among various refugee groups when encountering the U.S. healthcare system.

The need for appropriate language interpretation services appears paramount in the literature. For example, a focus group study (Herrel et al., 2004) with Somali refugee women in Minnesota found that the participants had unique experiences in accessing health care and they wanted changes to be made in the health care system to better accommodate them. Specifically, the participants were unsure of the quality of medical interpreters. Similarly, a case study of Somali women seeking health care in West London identified unequal access to maternity care related to interpreting services (Bulman & McCourt, 2002). A diverse group of refugee women living in Australia participated in focus groups and results were similar in that concerns about language interpretation were primary (Riggs, et al., 2012).

In addition to reliable interpretation services, refugee women want to know more about the how hospital processes work and more about the roles of certain health care professionals (Herrel et al., 2004; Riggs et al, 2012). In terms of birth services, women were concerned about

the need for cesarean sections in some births and wanted more information about why and how those births occur (Herrel et al., 2004). Refugee women have also expressed concern about diverse cultural values and racial stereotyping (Bulman & McCourt, 2002; Downs, Bernstein & Marchese, 1997). A case study conducted by a midwife of a Cambodian refugee indicates that mental health related to a history of trauma, cultural values, and practical barriers to care (e.g., needing transportation for appointments) were paramount to understanding the patient and providing adequate care (Downs, Bernstein & Marchese, 1997).

While these existing qualitative studies provide some insight into the perceptions of various groups of refugee women within diverse healthcare systems, the research is disparate and does not always address women from the DRC specifically or in depth. For instance, much of the literature focuses on refugees from Somalia, which is part of SSA, or on refugees as a monolithic group. Women from the DRC are likely to have experiences of seeking refuge and specific cultural values that make their experiences different from other refugee groups. In order to address this gap and provide information specifically about the experiences of women from the DRC within the U.S. health care system, this study combines interviews and observations of two refugee women. The case study format prioritizes their voices, resulting in an in-depth account of their beliefs, attitudes and behaviors related to pregnancy care. Case study research is useful for understanding phenomena, in this case the experiences of two refugee women from the DRC, within specific contexts. It is also particularly useful in health research with an applied focus and meaningful policy implications because the approach studies particular experiences in context where variables are not manipulated by the researcher. In this way, the case study allows a complex phenomenon to be seen and studied and in the case of healthcare, see how interactions between the provider and patient might influence the experiences and outcomes of the patient

(Baxter & Jack, 2008). Using both observations and interviews, this case study examines the experience of two local refugee mothers as they access pregnancy care, labor and delivery, and postpartum care within the local health system. To amplify the voices of two refugee women, this study is an intensive analysis of their experiences in pregnancy and in giving birth in the context of her resettlement. Two women with citizenship in the DRC and who have resettled in the U.S. as refugees within the last five years were included in this case study.

This case study answers the following questions about two refugee mothers from the DRC: 1) what are their perceptions related to their experiences with pregnancy care in the U.S. in terms of their needs and how well they are being met; 2) what are the patterns of interactions between them and their healthcare provider(s)?

Methods

Participants

After IRB approval and with the cooperation of the local resettlement office, the participants were recruited through word of mouth with a local interpreter. After identifying pregnant women through the help of other local English-speaking refugees, the researcher set up times to meet the potential participants and explain the study. After the study was explained, both identified women agreed to participate. The first participant was identified and included in the study approximately 3 months before the second participant was identified and included.

Both interested women were screened by the following inclusion criteria. Participants had to be pregnant with their first child that would be born in the U.S. (although they could have other children who were born in another country), had arrived in the U.S. within the last 5 years, and intended to use a hospital or birth center for prenatal care, delivery, and postpartum care to be included in the study. Including mothers for whom it was their first U.S. birth, allowed the

data collected to reflect an initial interaction with the maternal health care system, rather than using a mother with experience of pregnancy care in the U.S. health system and who may have adjusted her attitudes or behavior based on that previous experience. Moreover, refugee mothers who are relatively new to the U.S. also allowed for the data to avoid conflation with acculturation effects that may happen over time.

There were no language requirements. For the participant who did not speak English well enough to fully participate and express her thoughts in interviews, an interpreter was employed to conduct interviews in her preferred language of Swahili. Every interview with that participant conducted by the investigator utilized a volunteer interpreter who was also a refugee from the DRC but who spoke English and Swahili fluently. The interpreter helped both at the interviews and also served as a channel of communication to arrange the appointments themselves. The interpreter was highly regarded in the community and often helped as an interpreter in other venues. The researcher's past experience using interpreters professionally guided the decision to accept the services of this particular interpreter and trust her work.

Procedures

This case study used interviews and a health care appointment observation to produce an in-depth understanding of two people's experiences as refugees from the DRC seeking maternity care in the U.S.

The study design was guided by Yin's (1999) techniques for designing health case studies, which includes triangulating information from multiple sources to enhance the validity of the data. In this case, triangulation entailed using interviews with the participants, field notes including observations during the interviews, and observations during a health appointment. Although discovering two people's stories limit the generalizability of the conclusions (Yin,

1999), the experiences are both descriptive and explanatory in that results elucidate some of the needs of refugee mothers from the DRC and the way they experience healthcare in the U.S. Because the observations occurred in settings that were not designed or influenced by the researcher, the naturalistic nature of the case study lends itself to understanding experiences of the participant bound in context with multiple factors influencing the situation, rather than to effect changes in the experience or to determine causality between phenomena. In other words, understanding derived from the case study is holistic, illuminating phenomena not well understood, and providing practitioners with information from which to learn and modify practice (Abma & Stake, 2014).

Interview questions (see Appendix 1) were written to understand the participants' experiences of motherhood, perceptions of motherhood in the context of resettlement, experiences in the health care system, and infant care behaviors. Four semi-structured interviews were used: Background, Pregnancy, Labor & Delivery, and Postpartum. These four interviews included questions on demographics, experiences, needs, and hopes related to experiences with health care providers and the pregnancy in general. Their design was to allow for open-ended responses from the participants and some flexibility for the researcher to engage more deeply in topics of particular concern. After each interview was completed the participants were given a \$20 gift card as an incentive for continued participation. Each interview lasted approximately 45-60 minutes. Upon leaving each interview the researcher took field notes about the interview process, potential biases that came up from the researcher, and the mood and other unspoken characteristics of the participants that were analyzed in conjunction with the interview answers.

In addition to interviews, observations of the first participant at a follow-up general practice doctor appointment was conducted to add to the case study data. Initially, more

observations were sought and planned but concern from the participant about the doctor's knowledge of her participation in the study led to the change in observation plan. The second participant was not observed because she did not want her participation in the study to be known by her health care providers as the observation required the doctor's consent into the study. During the observation the researcher prepared extensive field notes that were descriptive in nature. These notes described the processes that the participant went through during the whole appointment including check-in, interactions with nurses, interactions with the doctor, and any prescribed tests and questions that are given to the participant (Bernard, 2006). Essential to this process was collecting continuous consent, a best practice in research with refugees (Lu & Gatua, 2014) as a participant might change her mind about the presence of the researcher (e.g., during the health history questionnaire or a sensitive ultrasound). During the approximately 90-minute health appointment observation, the researcher was aware of the participant's body language continuously assessing for discomfort or nonverbal cues that she was no longer comfortable with the researcher's presence. The observation was not interrupted, as the participant expressed no discomfort with the researcher. After the observation was conducted the researcher took field notes about the experience of observing and reflected on the possible influence of the presence of the researcher on what was observed (Bernard, 2006). The first participant was engaged in the research over the course of 8 weeks. The second participant was engaged in the research over 4 weeks.

Interpreter use. An interpreter was recruited from within the Congolese refugee community who had a prior relationship to the participant. The interpreter worked as a volunteer for the study and received no material benefit for assisting with the interviews. She was a similar age to the participant and had helped the participant with previous medical appointments

unrelated to the study. The author had 8 years of past professional experience with using interpreters and was able to navigate confusing or hard-to-translate parts of the interviews with the interpreter and the participant. For instance, at one interview the interpreter said the participant was “excited” about the upcoming induction. Given the context of the interview and the body language of the participant, the researcher asked for clarification and was able to understand that the participant was really using a word in Swahili that meant something closer to nervous or anxious in English.

Reflexivity. The researcher engaged in reflexive case noting throughout the study to minimize bias and improve the trustworthiness of the data collected through the case study. This included reflecting on the observer/interviewer’s place as a White woman who is native to the U.S. with cultural and social power. Moreover, the researcher’s past as an advocate for refugees and an employee of the local refugee resettlement office was recognized so that those experiences had a minimal effect on observations. For example, previous difficulties and negative experiences interacting with systems on behalf of refugees could have impacted observations and experiences in the study. However, after reflection on those experiences, the researcher was able to isolate those incidences and approach observations for the study with an open mind and receptiveness to the specific interactions observed with participants.

Analysis

Interviews were transcribed by the researcher and uploaded into NVivo12 software for coding. The researcher conducted a thematic analysis of the interviews and observation field notes. The first round of open coding was done by reading through the transcripts and identifying general themes in each individual interview, field notes, and the corresponding memos (Bernard, 2006; Corbin & Strauss, 2008). These initial codes were reviewed by a second researcher and

there was no disagreement. Open codes stayed close to the language of the participant or the researcher and reflected particular feelings and experiences. For instance, an open code from an interview with a participant was “doctors need to understand there are different kinds of Swahili.” The open codes were then reviewed and merged to create a smaller number of themes to reveal the core experiences and perceptions of the refugee mothers in regard to their interactions with the health care system surrounding her pregnancy. For example, the code regarding various dialects in Swahili was similar to other open codes about not understanding providers and grouped under a secondary code of “communication issues.” These secondary codes were reviewed with a second researcher and themes were re-categorized to better fit the emerging themes. A third round of coding revealed connections between themes to create an integrated model (Corbin & Strauss, 2008) of the participants’ experiences represented by Figure 1. These connections were discussed in consultation with a second researcher by looking at the experiences of the case study participants, the themes emerging from the data, and how they related to each other within the participant narratives.

Trustworthiness was achieved by several means including consulting with a second researcher as transcripts and field notes were coded and themes emerged. Two meetings took place to discuss themes and how they were related. Moreover, the use of several sources of data contribute to the trustworthiness of the results. Answers to interviews were corroborated by researcher observations and field notes.

Results

Demographics

Each participant is hereafter referred to using pseudonyms. Two women, Emma and Helen, were included in the study. Their demographic information is illustrated in Table 1.

Emma was a 30-year-old woman from DRC who had resettled in the U.S. after living for ten years in Uganda as a refugee. She had three children prior to this pregnancy, and they had all been born in the refugee camp prior to arriving in the U.S. She was first resettled in one southeastern state but then decided to move to another southeastern state during her pregnancy. This move meant that she saw a doctor in the first state for the pregnancy and then her care was interrupted until she found an obstetrician/gynecologist in her new community. At the time of the study, she was married to and lived with her husband who is also a refugee and who is employed full time. She was primarily responsible for childcare and was not formally employed. Emma was interviewed at approximately 38 weeks of gestation for the first time (although her exact gestational age was unclear) and was interviewed and observed until the newborn was six weeks old for about eight weeks total.

Helen was a 21-year-old woman who had resettled in the U.S. after living for 20 years in Uganda as a refugee from the DRC. She was a one-year-old child when her mother fled with her from the DRC to the refugee camp, therefore she lived the majority of her life in the camp environment until resettling in the southeastern U.S. in 2018. While growing up in the refugee camp she took English lessons and became both fluent conversationally and literate in English. At the time of the study she was just past the middle of her pregnancy with her second child; her first to be born in the U.S. Her first child was 3 years old and was born in the refugee camp at a government clinic. She was married to and lived with her husband who is also a refugee and who was employed full-time. She was also employed 32 hours per week as an interpreter. Helen was interviewed twice- once at five months gestational age and again at six months (exact weeks were not known).

The themes derived from analysis of the case study data reflected characteristics that had an impact on the process of accessing and receiving health care. The four themes were: Personal Characteristics, the Process of Accessing Healthcare, Medical Care, and Patient Perceptions and Needs.

Personal Characteristics

Personal characteristics were identified as individual level characteristics that varied among the participants such as the health of the pregnancy, social support, material/agency support, and cultural capital. These characteristics functioned as assets or barriers and worked in different ways to support or impede participants' access to healthcare.

Emma was at the end of her pregnancy when she participated in the study and although she spoke about being tired because she had three other children she reported that her pregnancy was normal in relation to her experiences. Although she revealed no diagnoses related to the pregnancy she did say that she “had a lot of scans” with this pregnancy because at one point the doctors were concerned the baby had water on the lungs. Emma spoke about her father-in-law and his presence in the U.S. She remarked that if she needed help with childcare for her older children while she was in labor or otherwise occupied, she could rely on him for help. It was also apparent in observing surroundings at the time of the interview, that refugee families living in the same apartment complex with Emma exchanged childcare and took a communal approach to supervising children. All interviews occurred in the evening when children from multiple families were playing together in common areas supervised by several local adults. This sharing of responsibilities was seemingly helpful especially when Emma was caring for the new infant. Both participants had their basic needs met in terms of housing but Emma was in a low-income housing apartment complex that was in disrepair and appeared to lack security as noted in the

researcher's field note observations. The two-bedroom apartment that Emma had for her family was furnished with donated appliances and furniture as is typical of recently arrived refugees. Emma was only able to communicate using a few words in English and thus, relied on an interpreter to access any services or to speak to anyone who was not fluent in Swahili – her preferred language. When she was given written instructions or information from her healthcare providers she needed to ask someone who was literate in English to read and explain the information to her. At the time when her obstetrician was urging her to be induced, she was confused by the information, the reason for the induction, and was unable to read the multitude of papers that she was given. During the Prenatal interview, the interpreter used for the research and who was also a friend of Emma, was able to read and relate some of the information about the induction and instructions from the medical provider.

Helen, when asked about how her pregnancy was going, she reported “I don't have any problems.” She expanded on this to say that everything was fine and all results from the labs and tests she had undergone so far indicated there were no problems. The lack of complications in her pregnancy meant that most of her experiences with her prenatal care were simple. Helen talked about an especially meaningful relationship with friends local to the receiving community who had provided them their current house as an alternative to a low-income apartment. It was not clarified if the house had been a gift or was a rental of some sort, but it was in good repair and provided ample space for the growing family. When speaking about them she said “they take good care of us and usually when I go to the hospital I do go with her. She is nice, like the husband and wife they are nice to us.” Helen spoke of having a negative experience with her family's case manager but said that because she spoke English and she had friends she was able to manage the perceived lack of formal help. Helen had access to a home in a middle-class

neighborhood and her house appeared to the researcher to be in good condition. Thus, they both had access to incomes that provided for the basic needs of their families. Helen spoke about the relationship between employment and the ability to live well in the U.S. by saying "...everything is okay. You can get food you can get whatever you want. If you have a job, then everything is easier to get. If you don't have a job then that's when it is hard. So you have to find a job to get what you want." Helen was herself an employed interpreter and was fluent and literate in English and was able to navigate medical appointments and daily life without the need for an interpreter. She even explained that medical jargon that she might not understand immediately, was not a problem to talk about and to eventually understand in English. She reported that she learned English at a school in the refugee camp and thus she came to the U.S. knowing English.

The health of the pregnancy was generally good for both participants. In terms of social support, both participants had support from their husbands in getting to appointments and in daily life. Participants had varying quality and access to material and agency support. Both participants had arrived through the U.S. refugee resettlement program and had access to formal support services through resettlement agencies and case managers. Emma and Helen had husbands who were employed full-time while only Helen was also employed. Both participants had various amounts of cultural capital. This was most notable in terms of English language ability.

Process of Accessing Healthcare

The second theme relates to responses and observations that reflect the process of accessing health care. Specifically, this reflects the logistics in getting to health appointments and understanding medical care.

Emma spoke about interpreters at length as she was not fluent in English and needed an interpreter for every interaction with medical staff and for every appointment. She expressed displeasure in the quality of the interpreters at times in terms of access to interpreters for all interactions with her health providers and the quality of the interpreters themselves. She also spoke about the difficulty of using an interpreter over the phone. She said “on the phone it is not really easy even the time [I] was going to deliver, [I] doesn’t really get it, so [I] had to tell them [I] didn’t hear. Some translators on the phone are difficult too.” At the time of labor and delivery and postnatal discharge, Emma indicated that she had access to an interpreter every time the doctor came to her but that when there were nurse checks or instructions, an interpreter was not always used. She explained this difficulty by saying “the doctors used the translators, but when the nurses came they didn’t use...so [her] husband tried he has a bit of English so some he would get and some not really.” The most common issue she mentioned to the researcher both during the interviews and in conversation was related to the dialects of Swahili and the difficulty in finding an interpreter that spoke Swahili in a way she understood. She expressed concern that doctors and those responsible for calling the phone-based interpreters did not understand that Swahili from the DRC was qualitatively different than Swahili from other countries and that she would not understand an interpreter that did not speak Swahili from the DRC. The use of the interpreter during the healthcare observation seemed to be of good quality and was used throughout the appointment as Emma interacted with her doctor. At one point a question about the baby’s mild birth injury to her clavicle was the subject of some confusion between Emma, the translator and the doctor. Emma wanted to know if she needed to continue pinning the baby’s arm to immobilize it. At first, the doctor thought she was asking if it would heal to which she responded in the affirmative. After some confusion and clarification with the help of the

interpreter the physician understood that Emma wanted more specific information on how long to continue immobilizing the baby's arm.

There were a few interactions with nurses or other staff when Emma had negative experiences. She said about her stay in the hospital during labor and delivery that "everyone was okay, and everyone took good care except for the last person. After delivery everything was okay but the last nurse that attended to [me] was a bit rude." She also indicated that during appointments that the people who "receive" her (the front desk staff) were not what she expected but when she got back to the doctor she felt "back to normal" because the "doctor is always happy." During the observation of the health appointment with Emma, the researcher noted that there was some confusion between the participant and the front desk staff at the beginning of her appointment. Although Emma seemed to understand what was needed of her after some prolonged interaction with the staff, it was not apparent that an interpreter was used for that initial part of the appointment. This could have resulted in feelings of frustration similar to what she expressed when talking about difficult interactions with staff but more positive interactions with the doctor. Emma did not mention her formal insurance as an issue and it is not known what type of insurance, if any, she had.

Emma was taken to appointments by her husband because he worked night shifts and therefore was able to accompany her to appointments during the day. However, there was some complexity with the induction appointment for Emma as she was told to report to the hospital at a certain time in the morning to be induced. When she got there, she was turned away because an unexpected number of laboring mothers were at the hospital.

"When [I] was told to go back [I] wasn't happy about it. [I] was angry or sad but [I] had no choice but to go back because she was the one in pain and who needed the doctor.

And also since the doctor said there was a lot of people she understood there was nothing that could be done and [I] had to go back to the doctor.”

Because Emma was not contacted prior to her arrival at the hospital to tell her that she could not be induced at the expected time, she had gotten childcare for her other children and had been dropped off at the hospital by her husband unnecessarily. Because the children had other appointments, her husband had left and then was called to return to get her. She then returned to the hospital mid-day to be induced and had the baby later that evening.

Helen expressed similar positive feelings about interacting with the staff during her prenatal appointments at both the health clinic where she received general care and at the hospital where she saw a specialist for certain diagnostic ultrasounds and other procedures. Navigating the insurance system was a prominent subtheme for Helen as she had recently received a letter that she perceived to be telling her that she would be dropped from the state Medicaid program. Although the content of the letter was not reviewed by the researcher, she said “they were saying I’m not qualified. And I was really scared. Like they were saying that me and my husband we have like high income so I’m not qualified. And I was like oh my god this is so bad. How can this happen and I’m pregnant and I know very soon I may stop working.” Helen had little trouble navigating appointments, language, and health therefore, this seemed to be the most pressing concern that she had. She wanted to ensure that her family would have insurance and be able to see doctors.

Emma and Helen both had generally positive things to say about their providers but Emma expressed more difficulty in accessing healthcare as it related to language, transportation and understanding providers. Interpersonal interactions with staff emerged as a subtheme as it was an integral part of appointments. Both participants reported feeling like their health care

providers were competent and that the people that worked in the offices were kind and helpful. Appointments seemed to be navigable by both participants in that they had reliable transportation to them either by friends or personal car (Helen) or riding with her husband (Emma). Insurance became an issue for Helen as she might have become ineligible for Medicaid but as pregnant women, both participants qualified for Medicaid at the time of the study.

Medical Care

The third theme is the medical care that each participant received as there were many questions dedicated to their experiences of both clinical care and health education. Clinical care was the services that were directly related to the provision of diagnostic services and health treatment. Emma said that when she goes to the doctor, she says “this is how I’m feeling and then the doctor touches and examines and the pain is because of this, that’s why you are feeling so.” During her induction Emma did not know what medicine she was given when asked, but she said that she was told “they were going to increase the pain. [I] agreed and [I] was told if the pain was too much that they can give [me] a shot to try and reduce and [I] said no.”

During the observation of a pediatric visit with Emma, the researcher noticed that the doctor asked a lot of questions about how Emma was doing with breastfeeding and provided extra instruction on how to care for the newborn’s injured clavicle. After Emma asked about umbilical cord care, the doctor also spent time explaining how to clean and care for the remaining cord. It was noted that Emma was confused about the care and had questions because the doctor’s advice differed from that which she had received with her previous children born in Uganda. The advice was to get some hydrogen peroxide and to clean with cotton provided by the doctor. Emma spent a lot of time asking about how to get the hydrogen peroxide from the store and the doctor explained that she could go to a store with a pharmacy and ask the pharmacist

how to get it. Given that the participant did not drive herself to the appointment, she needed to make plans to get it later when she had transportation and the means to buy the hydrogen peroxide.

Emma reported receiving instructions on infant care, such as safe infant sleep practices, in the hospital from the nurses. Helen had only yet received prenatal care and thus, had not yet received information on infant feeding or infant care that she reported. Both participants reported that they intended to breastfeed. Emma reported that she would breastfeed for a few months and then add formula/bottle feeding so she could look for a job and become employed. Emma's comfort with asking questions of her provider was evident during the observation of the doctor visit after Emma gave birth. The infant had a clavicle injury and Emma had some questions about how and when to continue pinning her clothes in a way that immobilized the infant's arm. The doctor was able to address those questions and then before the appointment ended Emma had questions about umbilical cord care. She not only asked how to provide care but asked clarifying questions and including how to obtain the products she needed to continue with the doctor's advice at home.

Helen spent a lot of time talking about how medical care in the U.S. was superior to that which she received in the country in which she took refuge. She also talked about "here they test for everything" in the U.S. and that when she had her daughter in the refugee camp, that they only tested for HIV and there was little prenatal testing otherwise. Furthermore, she explained that she preferred and trusted the tests in the U.S. and that she opted in to the ones that were not required. When asked about her plans for birth Helen did not seem to understand some of the processes or common practices in the U.S. delivery system such as the use of epidurals for pain management. It was unclear if she had received any education about those procedures or if that

would come later in her pregnancy. She did not express concern or worry about the birthing process but trusted that the U.S. healthcare system was superior than what she had experienced previously in the refugee camp.

Both participants talked about trusting in the competence of their medical providers and of medical care in the U.S. in general. Similarly, when asked if they felt like when they had an issue or question that their concerns were addressed, both participants replied in the affirmative. Another important aspect of medical care in general was the health education that each participant received from the doctors and nurses. Both participants received explanations about clinical care but also about infant feeding and infant care. Neither participant reported receiving infant feeding support or education but did report that they were supported by their doctors in their choices. They both had breastfed previous children and did not anticipate needing help with breastfeeding. Importantly, both participants reported that they were comfortable asking questions to their providers.

Patient Perceptions and Needs

The fourth theme of Patient Perceptions and Needs reflects the specific experiential responses that the participants had to the range of health care experiences from pre-appointment logistics to the care they received in the office. Both participants had a lot of positive things to say about their healthcare and their providers. Helen, when talking about the increased quantity of prenatal testing said “It’s good because when they give you tests that’s how you know how you are how the baby is doing. You know if anything is in your body.” She appreciated knowing that there was testing being done even though she reported to the researcher that she didn’t always understand exactly what they were testing for. She also made many references to the care

“back in Africa” noting that “many people are dying there because of bad health care. It’s hard there. I don’t know how much I can explain but it’s hard there.”

Not all reactions to the health care process were positive. Emma seemed more flustered and confused about the reason for her induction, expressing her desire to wait to have labor come on naturally. There had been confusion about Emma’s due date between the doctors and ultrasounds with several different health care providers giving her different expected delivery days. Once she conceded to be induced, she was then “angry or sad” when the appointment had to be moved back and she had to wait. She also explained that during delivery she was in so much pain that she begged for a surgical delivery, which the doctor denied. After the birth she had mostly positive things to say about the doctors that took care of her and she attributed a safe delivery to their care.

Interaction Between Themes

Figure 3.1 shows a heuristic model of the themes and how they interact with each other. Each circle represents one of the four main themes and how they influence each other. The first circle is Personal Characteristics that interact with Process Accessing Healthcare to influence the nature of and access to Medical Care. The lines connect the circles to indicate that the themes do not interact in a linear fashion but are mutually interactive. Such that the experiences of medical care and understanding of health education could influence the health of the pregnancy or how the participants were able to access the care itself. The experiences the participants had were then influenced by their clinical care and health education that they received and thus, their perceptions about their experiences and their needs.

Personal Characteristics of the participants seemed to affect their ability to handle the logistics associated with health care. Perhaps most obvious was the way in which Helen was able

to easily make appointments and communicate about insurance with providers because of her fluency in English. Her cultural capital aided her in understanding the various interactions with health care providers and the services they were providing. In contrast, Emma had more barriers to understanding all staff members even when interpreters were employed. This may have been most evident in her confusion about the reason for the doctor's insistence in her being induced and the concern she felt regarding the process. During the observation of Emma's follow-up health appointment after her delivery, the lack of English made the check-in process more difficult when there was a question from the front desk staff about the newborn and her insurance.

While personal characteristics and logistics were influenced by each other, they both were connected to the ability of the clinical care and health education during appointments to proceed. For example, transportation was essential in getting to the appointment in a timely manner. Both participants had access to reliable transportation that was essential to their participation in appointments. The availability and quality of interpreters impacted the length of appointments and the ability for doctors and nurses to convey important clinical and health education information. Their ability to communicate and the participants' ability to understand instructions for health behavior and care beyond the doctor's office. Although not measured in this study, the quality of medical care and the ability of the patients to comply with medical advice seems related to their ability to be at appointments and to understand what was being said. During the obstetric health observation with Emma, she had questions about umbilical cord care. She was adept at asking clarifying questions and when the physician advised her to buy an over the counter antiseptic, she asked exactly what it looked like and where she could get it at the pharmacy. Even without a prescription, Emma anticipated the difficulty of finding the correct

item in a store without the ability to read labels. These seemingly minor activities are a much larger hurdle for a refugee who does not have familiarity with medical products and the language with which to learn about them.

Lastly, the clinical care and health education received by participants influenced their perceptions, both positive and negative about their experiences. Both participants were active and engaged in their healthcare and reported asking questions of their medical providers. Asking questions was observed by the researcher with Emma when she had to ask about several medical issues related to her newborn. Both participants perceived some of their providers to be competent and kind. However, Emma had experiences with certain staff members and a nurse that she perceived as rude and confusing. These interactions were likely influenced by the ability to communicate and could have had an impact on Emma's perception of the advice coming from those staff members. Perhaps most concerning was Emma's interactions with nurses in the hospital after delivery who had not engaged interpreters at all points and provided infant care instructions in English without the use of an interpreter. Emma was concerned that she did not understand everything that the nurse said and therefore an opportunity for adequate health education was missed.

Discussion

This research provides a unique perspective into the experiences of two refugee women originally from the DRC who resettled as refugees in the U.S. as they interacted with the health care system to obtain pregnancy care. Because the participants had limited prior exposure to pregnancy care in the U.S., the study illuminates the ways in which the culture of the participants and the competencies of the system address their needs. In other words, the participants had various ideas and knowledge about health care systems and their previous pregnancy experiences

that resulted in different degrees of cultural capital between participants. The knowledge of the healthcare system and the way in which they were able to navigate it in the U.S. was related to their experiences as refugees in migration and living in refugee camps where access to basic needs resources was limited. The results of this study show how various individual level characteristics impacted the process and experiences of pregnancy care in the U.S. and the opportunities the health system has to better address their needs. Although previous research has indicated that language is a barrier for refugees in general in accessing services, for the woman in this study that did not speak English, access to an interpreter was not always consistent or of consistent quality. This impacted her ability to understand important things such as discharge instructions from the hospital and safe infant care practices. In contrast, the participant who was fluent in English reported little trouble in understanding the medical advice and care she was given and understood how to navigate the system. The two varied in their English ability despite being refugees from the DRC taking refuge in Uganda which could be a result of the age at which they fled. Helen was a child and educated in the refugee camps where English was available and Emma was an adult when she fled the DRC and likely did not have the opportunity to take English classes. Thus, Helen had cultural capital in the form of language that was transmitted via the institutional resources and groups in the refugee camp. The difference in language between two women with similar backgrounds underscores the importance for helping professionals to avoid treating refugees as a monolithic group.

The logistical hurdles faced by the participants including insurance and transportation relates to previous research with similar findings. A review of research conducted after 1996 indicated that immigrants were less likely to have health insurance and regular provider care resulting in undetected health issues and infrequent provider interaction (Pitkin Derose, Bahney,

Lurie, & Escarce, 2009). McLafferty and Grady (2005) found similar results in Brooklyn where reproductive health care was less geographically accessible for immigrants. While these studies do not concern refugees specifically, Helen's experiences with Medicaid issues suggest that access to insurance is a difficult process to navigate.

In addition to these access issues the study is situated within an intersectionality framework and elucidates the impact that race and ethnicity have on experiences of pregnancy care. Racial and ethnic disparities are well documented in the health literature (Mayberry, Mili & Ofili, 2000). These disparities are complex and likely rooted in systemic oppression and discrimination (Edberg, Cleary & Vyas, 2011) that are difficult to target through health interventions. Emma was concerned about her treatment by certain health staff members and although she didn't attribute rude or dismissive behavior to her status as an immigrant woman of color, it is possible that it was an influential factor in the interaction.

The provision of clinical care and diagnostics along with health education were the two main parts of the health care experiences for the participants. Both Helen and Emma had received health education about various topics including infant care practices particularly for Emma who delivered her baby during the study. Although Emma seemed to understand the instructions given to her by her provider such that she was able to repeat the general recommendations for things like feeding and infant sleep; it is unknown the extent to which she complied with that medical advice. Her newborn did have a clavicle injury that was observed by the researcher and during the interviews and observations she did have the arm pinned as instructed by the doctor and healing was evident during the health observation. Aversion to medical intervention has been demonstrated in some research of African origin mothers (Brown, Carroll, Fogarty & Holt, 2010) and this was evident in Emma's reaction to her provider's advice

to be induced. She had previous births without intervention but the doctor was adamant, according to Emma, that induction was important and medically necessary and even brought in another provider to explain it. Emma finally agreed to the induction but did not have positive things to say about it during the postnatal delivery interview. There might have been an opportunity for the provider to explore more about Emma's beliefs and experiences with her prior births in order to talk about induction and the reasons for it in order to come to a mutually beneficial and consensual conclusion.

Implications for Practice

The goal of the study was to inform health care practitioners and others who interface with refugee mothers on the specific needs and concerns of refugee women from the DRC and the extent to which existing services meet their needs. Professionals in the health care field should understand that a primary concern for those patients with limited English proficiency is the need for an interpreter in their preferred language, which may have various regional dialects. Matching an interpreter with the most similar dialect to a patient will enhance communication. It might not be widely known that there are various dialects in Swahili and that without having a mechanism to request that dialect specifically, valuable patient care time is lost to logistical communication issues. Beyond language barriers, refugee mothers are also faced with other barriers to accessing care including transportation and insurance. In Emma's case, a normal reschedule of an induction was a major inconvenience given her limited transportation options and her lack of cultural capital including knowledge about health institutions and practices.

Other professionals including refugee resettlement workers who are charged with connecting refugee mothers to health resources including appointments for health care can prioritize those clients for whom the barriers to accessing care are higher. For instance, non-

English speaking refugees with little social support and cultural capital would likely have better experiences in pregnancy care with additional support from a case manager or volunteer who can help. This assistance could be providing long term logistical support in arranging alternative transportation options within the community and teaching refugees how to access this transportation reliably. The importance of this support was clear in Helen's case, where U.S. citizen volunteers turned friends were essential to her ability to get to appointments. At the systems level, bolstering local transportation by local governments or from independent agencies and health care centers could also address this issue. Increasing access to health care provision for mothers in the prenatal and perinatal periods is an opportunity for providers and policymakers to affect change in health disparities for women and their families.

Limitations

The case study design of this study provides a depth of information about two participants. The nature of the small sample means that generalizations should be avoided about all refugees or all refugee women or even all refugee women from the DRC who have resettled in the U.S. These lived experiences are important to consider in the context of the existing qualitative and quantitative research, which reflects the needs and experiences of refugee women in terms of their health and the health care system.

The use of a volunteer interpreter is also a limitation of the study. She was not formally employed nor was the researcher able to assess her skills in Swahili. However, the researcher had little concern about the quality of interpretation as Emma had a good rapport with the interpreter and seemed comfortable during research interactions. The interpreter for the study had also been used by the hospital at which Emma delivered as an ad hoc interpreter during labor and delivery thus, she had established credibility and experience as an interpreter. The researcher's past

experience working with refugees who needed interpreters informed the way interpretation was used. When it was clear that certain words were difficult to translate, there was more conversation and probing to understand more precisely the thoughts and feelings of the participant.

At the time of the study, the researcher had ten years of experience working with refugee populations including refugees from various countries in Africa and had developed skills in cross-cultural work essential to carrying out this research. However, it is important to recognize that as a White woman who presents as middle class and is from a local university and a citizen of the U.S., that there are inherent power dynamics at play in any interactions between the participants and the researcher. It is possible that the participants answered some questions in ways that reflected those power differences. However, both participants were openly critical of the health system and some resettlement experiences implying that they felt comfortable expressing concerns and being honest about their experiences.

In addition, Emma's careful questioning of the way in which the information would be used and disseminated during the consent and during the labor and delivery interview indicates that she was thinking about how to form her answers and when she was satisfied and reassured that her identity would be confidential, she proceeded to describe the nuances of her birth experience that included criticisms of some health care provider interactions.

Directions for Future Research

This case study and the heuristic model presented provide a foundation upon which future quantitative research can examine the relationships between themes and subthemes. For instance, a study could examine to what extent cultural capital influences refugee women's ability to get to health appointments and their subsequent experiences during those appointments.

Health research could also build upon the perceptions and experiences of refugee women and examine how variables such as social support, English language ability, and access to care influence things not measured in this study such as health outcomes and compliance with medical advice.

Conclusion

Several themes derived from this case study interact to inform the perceptions and needs of refugee women's experiences of pregnancy care in the U.S. By viewing these experiences through intersectionality and bioecological/socio-ecological frameworks, it is apparent that individual characteristics and experiences are influenced by the dynamics inherent in interactions between a refugee mother patient and the larger system from which she seeks care. While these two participants were similar in that they were both in the U.S. as refugees, their experiences navigating the health system diverged especially when it came to language ability and social support. Moreover, the health of the pregnancy and the complications experienced by Emma illuminated gaps and opportunities in health care provision that had not been experienced by Helen who had an uneventful pregnancy at the time of the interviews. Health care providers must take culture, individual backgrounds, and access to social support into consideration when providing care. Moreover, larger social systems and providers can influence policies and programs to better support those characteristics that support positive experiences of health care and meeting the needs of refugee patients.

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Appendix

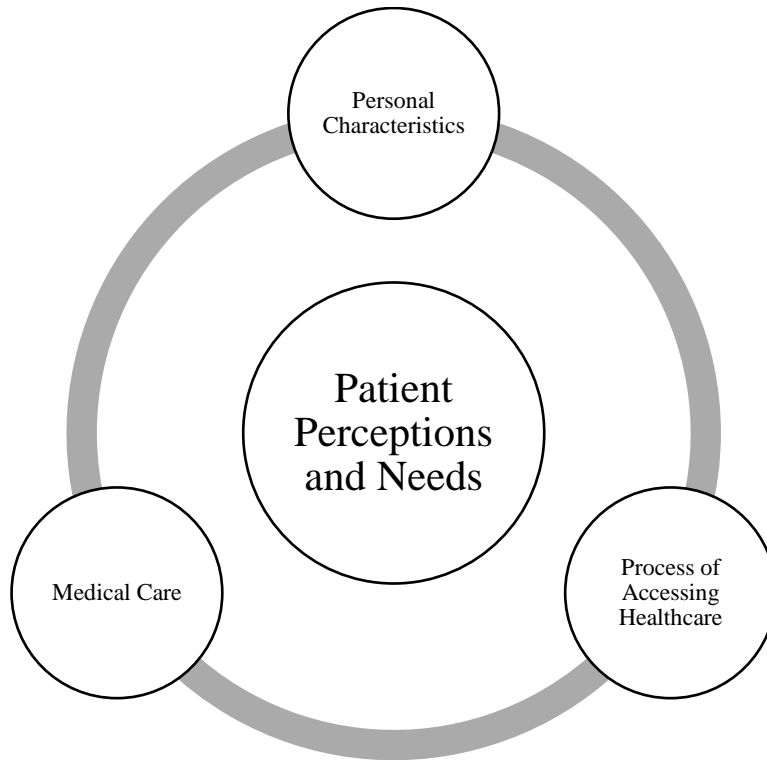


Figure 3.1 Case Study Themes

Table 3.1 Case Study Participant Demographics

Pseudonym	Emma	Helen
Country of Citizenship	DRC	DRC
Age	30	21
Marital Status	Married	Married
Employment Status	Unemployed	Employed Part-Time
Years in Refugee Camp	10	20
Years in U.S.	3	2
English Ability	Beginning	Fluent and Literate

Case Study Interview Instruments

Interview 1: Background

1. Please tell me about your family.
2. How many children have you given birth to?
 - a. What are their ages?
 - b. Are they boys/girls?
3. Who lives in your house?
4. When did you come to the U.S.?
5. Can you tell me about your life before you moved here? Where did you live? What kind of work did you do?
6. How would you say you are adjusting to life in the U.S.?
7. What kinds of things are helping you live well here? (ask about friends, family, agencies, neighbors, etc. if needed)
8. What kinds of things are hard about living here?
9. How is your pregnancy going? How do you feel?
10. Is there anything we haven't talked about that you feel is important for me to know?

Interview 2: Prenatal

1. How far are you in this pregnancy according to your doctor?
2. What kind of doctor or birth health practice are you seeing for care?
3. How do you feel when you go to an appointment?
4. How do you get to your appointment?
5. When you go to your health provider, what is your preferred language?
6. Do you have access to an interpreter? In what language?
7. What kinds of things does your health provider do that you like? Follow up: tell me why you like this.
8. What kinds of things does your health provider do that you don't like? Follow up: tell me why you don't like this.
9. Do you feel like you get to ask questions and have them answered by your health provider?
10. Is there anything else about your pregnancy care that you want to tell me?
11. Do you have plans or preferences for your upcoming birth (c-section, medication, etc.)?
12. Do you feel supported in your plans by your doctor, nurses, or midwives?
13. What do you wish for in your upcoming birth experience?
14. How do you plan to feed your baby?
15. What kind of help do you want or need to help you as you deliver your baby? After you have the baby?

Interview 3: Labor and Delivery

1. How are you feeling?
2. How is the baby?
3. Can you tell me about your experience giving birth to [use baby's name]?
4. What things went well during labor and delivery?
5. What things do you wish were different during labor and delivery?

6. How did you feel you were treated while you were in labor?
7. Do you feel like your wishes were respected during labor/delivery?
8. Did you ask your health provider questions during labor? Do you feel like your questions were answered?
9. Did you have access to language interpretation? For how long during labor and delivery?
10. Did you understand any instructions or advice that came from your health provider?
11. Has any health provider talked to you about infant care? Feeding? Bathing? Sleep? If so, what have they told you?
12. Is there anything you need more support for or more information about?
13. Is there anything else about your labor and delivery experience that you would like to add?

Interview 4: Postpartum

1. How are you feeling? How is the baby?
2. What health providers have you seen since the baby was born?
3. When you see a health provider, what is your general experience? How do you feel when you go to your appointment?
4. Does the health provider answer your questions?
5. What kind of information or support does the health provider give you?
6. Does the health provider help you with infant care? Feeding? Sleeping? Other? If so, what do they say?
7. Do you feel like you can ask questions?
8. Do you feel like your questions are answered?
9. Do you have access to language interpretation? In what language?
10. What kind of things does your health provider do well?
11. What kind of things do you wish your health provider would do or do better?

Chapter IV

Health Provider Perceptions of Cross-Cultural Maternal Health Care Services for Patients from Sub-Saharan Africa

Abstract

Refugee women from Sub Saharan Africa (SSA) have increased their presence in the U.S. in the past decade and interact with health care providers and systems to receive vital maternal health care services. Little research has focused on the needs of health care providers as they interact with patients from diverse backgrounds especially refugee women from SSA who are likely to have suffered trauma and resettlement stress (Stewart, 2015). The present study used open-ended interviews with health care providers (n = 10) who regularly serve refugee women from SSA. Thematic coding of interviews revealed providers' Perceptions of Interactions with Refugee Patients, Perceptions of Refugee Populations Needs, Ideas about Cultural Competency in health care provision, and descriptions of Infant Feeding support and professional recommendations. While providers employ various strategies to manage patient care interactions and to support optimal health outcomes, many mentioned that bolstering resources including improved language interpretation and diversity training could benefit their services. Results elucidate opportunities for health care administrators to support providers in their interactions with diverse patient loads that include SSA refugee women.

Introduction

Maternal health care is often an entry point to the U.S. health care system for refugees (Gany & de Bocanegra, 1996). Given that refugees from Sub Saharan Africa (SSA) have increased their presence in the U.S. in the last decade (ORR, 2015) it is important to understand how health providers and the systems within which they work interact with these patients. The literature provides some insight into the needs of SSA refugee women as they seek health care and maternal health care in particular in the countries in which they resettle (Carolan, 2010; Gagnon, Carnevale, Mehta, Rousseau & Stewart, 2013). However, few studies have examined the experiences and perceptions of the health care providers who serve them. This qualitative study used interviews with doctors, nurses, and midwives who serve refugee patients from SSA in a range of maternal health care services including pregnancy care, labor and delivery, and postpartum care.

Racial and Ethnic Disparities in Health Care

The demographic landscape of the United States is changing such that healthcare professionals must often serve members of communities different from their own (OMH, 2017). Racial and ethnic disparities in health are well-established (Mayberry, Mili & Ofili, 2000) and the need to use culturally competent approaches to redress this situation is evident (Betancourt et al., 2003) and are evident in prenatal care and health outcomes among minority mothers and their infants (Mayberry, Mili & Ofili, 2000). Racial health disparities that are often reflected in refugee communities (Carolan, 2010) are complex and likely rooted in both biased treatment and discrimination (Edberg, Cleary & Vyas, 2011). In addition, less access to insurance and health care services that are complicated by language and transportation barriers may perpetuate disparities (Gagnon, Carnevale, Mehta, Rousseau & Stewart, 2013). Refugees often enter the

U.S. with few resources and continue to occupy low socioeconomic categories, which makes them vulnerable to chronic disease related to the social determinants of health (George, 2010). Refugees have health needs relevant to their status as refugees and as newcomers in developed countries, which are often related to their mental health and the trauma they have often endured in war-torn homes and through persecution (Burnett & Peel, 2001; Carolan, 2010; Collins, Zimmerman & Howard, 2011).

Before resettling into a country like the U.S., many refugees spend their lives in limbo in unstable housing and conditions that do not meet their daily basic needs (UNHCR, 2017). Once resettled into a host country, those basic needs may be met by federally funded programs (ORR, 2015) but gaps remain. For instance, refugees are often among those who lack access to primary care health care services and are often under or uninsured (Mayberry, Mili & Ofili, 2000). This lack of access means health problems are likely to go undetected and untreated resulting in higher morbidity and mortality and higher healthcare costs through emergency services (Brach & Fraserirector, 2000).

Health Services and Infant Feeding Support

Breastfeeding is known to have significant health benefits for mothers and children (AAP, 2012; Lessen & Kavanagh, 2015). Breastfeeding support is often a supplementary service in pediatric offices (Sikorski, Renfrew, Pindoria & Wade, 2003) and therefore may not be perceived as necessary for patients for whom delivering care is more difficult. In other words, refugee mothers who receive pediatric care for their infants may not be perceived to need lactation support because of their cultural tendency to breastfeed and may not receive support when they do need it because of language or other obstacles.

Although some immigrants may be healthier than the general population (Markides & Rote, 2015), immigrants in general may suffer a decline in their positive health status over time. For instance, immigrant mothers are generally more likely to breastfeed than native-born populations in several Western countries (Neault et al, 2007) but this propensity declines over time resulting in suboptimal infant feeding according to WHO guidelines (Gibson-Davis & Brooks-Gunn, 2006). A study revealed that the availability of clean water, formula vouchers, discomfort breastfeeding in a Western culture, and the demands of daily life are obstacles to breastfeeding to minimum standards (Schmied et al., 2012; Hohl, Thompson, Escareno & Duggan, 2016).

One key to solving the problem of declining rates of breastfeeding among immigrant mothers, is understanding the dynamics in health care delivery that support or fail to support breastfeeding mothers in a way that allows them to translate their cultural values of and propensity toward breastfeeding in a new culture. In addition to lactation support, the gamut of prenatal and obstetric services are essential in promoting positive health outcomes among refugee women.

Culturally Competent Health Services

Stewart and colleagues (2015) outline challenges and barriers perceived by African refugees in Canada that include stress, marital discord, past trauma, poorly coordinated services, and discrimination. Moreover, the refugee experience is characterized by stress and persecution, with a significant impact on health outcomes including depression, pain, and poor health (Bates, Burman, Ejike-King & Rufyiri, 2012; Yun, Mohamad, Kiss, Annamalai & Zimmerman, 2016). It is within this context that any health care services must operate.

Health care providers have moved toward practice that recognizes and appreciates the diversity of their patients. The cultural competence (CC) perspective is one that specifically addresses the needs of culturally and linguistically diverse (CALD) patients (Betancourt, Green, Carrillo & Ananeh-Firempong, 2003). Research shows the need for culturally competent health care to ensure effective service delivery and positive health outcomes including benefits to the patient-provider relationship (Renzaho, Romios, Crock & Sonderlund, 2013). In the case of refugee populations, culturally competent health care would include appropriate language interpretation, effective communication including listening, valuing cultural differences, and services that address their needs (Office of Minority Health, n.d.). In terms of infant feeding, culturally competent care from pediatric health providers is likely essential to encourage and support breastfeeding among African origin refugee mothers.

Cultural competence among health providers has received a lot of attention because some cultural knowledge and appropriate use of language interpretation among other skills, is known to have a positive impact on the experiences of patients with a culture different from that of their provider. There has been significant attention and research on cultural competence, its impact on patients, and cultural competence intervention efficacy in changing provider knowledge (Gany & de Bocanegra, 1996). However, there is scant information on the perceptions of health providers and their provision of pregnancy care specifically to SSA refugee patients. Using cultural competence in health care as a guiding framework, this study will address the perceptions of health providers who provide a range of health care services to refugee mothers originally from SSA.

The present study used key informant interviews to examine the perceptions of health providers in terms of their experiences in serving refugee mothers from SSA with respect to pregnancy care and lactation support. This study will answer the following questions: 1) How do health providers perceive their interactions with refugee mothers from SSA during the postpartum period especially in terms of lactation support, 2) What do health providers consider to be priority health needs of refugees from SSA?, and 3) How do health providers conceptualize culturally competent healthcare and what do they think they need to improve their services?

This study analyzed how various health providers perceived the maternal health care and infant feeding support they provide to refugee women from SSA in light of commonly accepted principles of culturally competent care, and what support they might need to better serve their patients. The results reveal opportunities that health administration can use to enhance service provision to refugee mothers and their families to support healthy outcomes and behaviors.

Method

Participants

Health providers were recruited as participants from medical practices that serve refugee patients. Providers were eligible if they provided clinical services to refugee women or children as part of their practice. Clinical providers included medical doctors, nurses, nurse-midwives and nurse practitioners. These practices were identified by consulting with a case manager from a local refugee resettlement agency in the Southeastern U.S. After practices were identified, the researcher sent an email to all clinic administrators informing them of the study, the purpose, and asked them to respond with their willingness to participate and availability for contact. Those interested participants were contacted via phone or email by the researcher to set up a time for an interview. Professional participants did not receive a financial incentive to participate. The

sample was obtained by convenience and using snowball sampling. After each 30-60-minute interview the participant was asked if they knew any other providers who might participate and were asked for an appropriate way to contact that potential participant. Interviews were analyzed on an ongoing basis and recruitment of participants ended once saturation was reached, that is, when no new themes were identified from interviews as confirmed through collaboration with a second researcher.

Procedure

Semi-structured interviews were conducted to determine the health practitioners' experiences with patients who are refugees from SSA. Questions also addressed perceived challenges and barriers, personal conceptions of cultural competency in health care practice, and the institutional support desired by providers to better serve their patients. These interviews took place individually, in a mutually agreed upon place (e.g., the doctor's office, a coffee shop) or over the phone, and were recorded using a handheld audio recorder. Immediately following the interview, the researcher took field notes to describe the interview, note nonverbal behavior by the participant, and any extenuating circumstances that might have affected the interview. Interviews were then be transcribed verbatim by trained undergraduate research assistants and uploaded into NVivo12 software for coding.

Analysis

The analysis of key informant interviews was guided by a thematic analysis approach. A first round of open coding identified general themes in each individual interview and the field notes or jottings (Bernard, 2006) associated with those interviews (Corbin & Strauss, 2008). These codes reflected ideas and concepts using the language in the interviews. For instance, a provider who was talking about having difficulty using an interpreter for complex medical issues

was coded as “trouble using interpreter.” Codes were then reviewed and merged to create a smaller number of themes to reveal the core perceptions of clinicians about their interactions with refugee. After several providers had talked about the difficulties and benefits of interpreter services, those open codes were synthesized as “interpreter use.” A second round of coding used the initial themes to compare interviews and begin to synthesize the data. A third round of coding revealed relationships between themes creating a descriptive model (Corbin & Strauss, 2008) of healthcare providers’ perceptions of intercultural health care provision to refugee mothers and children. These interactions and connections emerged by reading the context of the codes and connecting them in the narrative to the outcomes and perceptions coded close to them in the interview. For instance, when a provider talked about having trouble with interpretation and the difficulty that caused in a patient’s understanding of their blood pressure medicine a line was drawn between “interpreter use” and “clinical needs.”

Coding was conducted on an iterative basis. Interviews were transcribed during data collection and coded while participants were still being recruited. This allowed the researcher to identify new themes. Once interviews revealed no new themes, saturation was assumed to have been reached. Participant recruitment lasted for approximately 9 months. A second researcher was consulted at each stage of coding to enhance trustworthiness. When there was disagreement about the classification of a theme the researchers discussed and came to an agreement. Although not a health care professional, the researcher has engaged with health care professionals on behalf of refugee patients in the past. To minimize bias, the researcher engaged in reflexive thinking prior to partaking in the study and made reflexive memos after interviews about the process and personal observations. In addition, the second researcher was consulted and engaged

in reflexive discussions during the process of conducting interviews to discuss preliminary results and saturation.

Results

Results are organized into demographics and themes that emerged from the interviews from analysis. Table 1. summarizes the characteristics of the participants, including professional title, years practicing, size of practice, and nature of interactions with refugee patients. Themes that emerged from the interviews are represented in Figure 4.2 include 1) Interactions with Refugee Patients with subthemes: (a) Culturally rooted misunderstandings, (b) Strategies to manage interactions, (c) Needed support; 2) Perceptions of population needs with subthemes: (a) Access, (b) Clinical, (c) Social determinants of health; 3) Ideas about cultural competency; and 4) Infant feeding support.

Demographics

Table 4.1 provides a summary of the study participants' characteristics. Health care providers (n = 10) were interviewed and included pediatricians (n = 2), obstetrician/gynecologists (n = 2), family nurse practitioners (n = 2), and certified nurse midwives (n = 4). Four providers worked at a federally qualified community health center (FQHC). Four providers worked at a university hospital system in various departments, one provider was retired from direct clinical care but had worked in a stand-alone birth center, and one provider was at a nonprofit clinic for the uninsured population. Participants had been practicing for an average of 18 years (SD = 13.9) with a range of 3 to 42 years. All but one actively practicing provider worked within a smaller practice of 2 to 6 individuals. One provider was part of a larger groups managing residents in a training hospital clinic.

Interactions with Refugee Patients

Health providers were asked about their experiences interacting and providing services to refugee patients from SSA. Because the providers had different specialties, they encountered patients in different circumstances and had different aims. For example, the women's health clinic providers, both nurses and doctors at the FQHC saw women when they were pregnant and during the postpartum period. Because the FQHC did not have a labor and delivery unit, patients were referred to the university hospital for various tests and for labor and delivery. The obstetricians at the referring university hospital saw pregnant patients for ultrasounds and during labor and delivery in addition to seeing high risk patients. Providers had many positive things to say about their general experiences serving SSA refugee women patients. The nurse practitioner that saw refugees for their initial health screening as outlined by the federal resettlement requirements and then later saw them as primary care patients said "I love working with this population...it's just really refreshing to have people who have insight from all different parts of the world." A certified nurse midwife said "they're beautiful people." A different nurse midwife said "[they] have so many gifts to share. They're creative, smart, they're relaxed, they're fun-loving."

Culturally rooted misunderstandings. Despite these positive general comments, providers spoke about challenges interacting with their patients especially when cultural background variables were at play. For instance, a nurse practitioner who did family practice spoke about some issues with refugee children being brought into the office for care by people other than their legal guardians. She understood that children were often raised by their biological parents but also "aunties" and those "aunties" felt like they could seek care on behalf of the children but "legally a provider cannot touch a child who is under 18 if their legal guardian

isn't in the room with them." This issue then delayed care for some children and required extra explanation to the affected families.

Both an obstetrician and a nurse-midwife noted that they had difficulty treating SSA refugee women patients with hypertension. There was a disconnect between explaining the disease which is often asymptomatic and encouraging compliance with long-term medication. In one instance, a nurse practitioner described a patient whom she thought understood to take her medication on a daily basis but the patient did not understand that her dosage had been changed and had been taking an old prescription. "She never went to pick up the medication" and had untreated high blood pressure with serious potential health consequences.

Providers also often talked about interpreters and their ability to communicate complicated medical information to patients. One obstetrician noted that her patients "don't ask a lot of questions...[I] wonder if they even understand...I've had to talk to them about age related risk and there was one time we had an interpreter tell us 'I can't translate that, that doesn't translate.'" Two nurse practitioners talked about frequent somatization of mental health issues among refugee women from SSA that often physical complaints would have a mental health root. Only after running a battery of diagnostic tests did one provider understand that a patient was actually depressed and then was able to refer her to an appropriate provider. Trouble communicating continued in the delivery room in serious circumstances. An obstetrician noted that she had two cases where women from SSA refused cesarean sections despite evidence on monitoring devices that their babies were not doing well. She said "[I] can't force them into a c-section. But you also wonder if they are understanding me and if they are understanding, do they not trust me?" In both cases the obstetrician said the babies were delivered safely but that she wasn't sure of the long-term outcomes for the children.

Strategies to manage interactions. Given the challenging nature of some interactions between health providers and their SSA refugee patients, the providers spoke during interviews about the strategies they used to manage misunderstandings to achieve their goals. In terms of language and communication, a pediatrician spoke about specific ways to check for understanding among patients. He said “compliance questions are best asked by going way back and using the what, how, why, when, where kind of questions. ‘What do you remember from your last visit?’ ‘How do you remember what we talked about?’” An obstetrician in the FQHC when talking about noncompliance with hypertension medicine spoke about a patient that wanted a long acting form of birth control. His strategy was to refuse the birth control until the patient obtained and took her medication for high blood pressure. He said, “it actually worked, she went to the ER and got her medication because she wanted the contraception.” An obstetrician in the high risk practice said that “in the more complicated medical world” you “try to figure out a way to break that down and make it more simple. And then sometimes you take the paternalistic approach to medicine and say ‘I’m going to pick what’s best for you.’”

Providers also talked about taking time with patients both in terms of building rapport and in extending allocated time for appointments. A nurse practitioner said “it takes a lot of time. We automatically have longer visits for these patients in our schedule. So we automatically have 30 minutes in the schedule for them whereas as normally we have 15 minutes.” A certified nurse-midwife said, “I think more effort has to go into creating and building therapeutic relationships.” The high risk obstetrician noted that in gaining a history of child birth and loss she often had trouble getting the reason for a previous child loss from her patients and even though she would ask questions about nutrition and disease, eventually she would just accept that they don’t know and “move on.”

Needed support. When asked what support providers needed to further manage their interactions with refugee patients from SSA, language and education were paramount. Bolstering in-person language interpretation was a desire of several providers at the community health center. Although providers at the FQHC used in-person interpreters for most patient appointments, they recently had their female interpreter leave her job and thus, they only had one male interpreter for all women’s health appointments. A certified nurse-midwife said “I know it’s near impossible to have in person interpreters available all the time. I just think that makes such a huge difference. I wish we had more resources for that. On so many levels I think it would make a big difference.” Another nurse said she would want “someone that could come with them and translate.”

Beyond language interpretation resources, providers wanted to know more about the culture and past experiences of their patients. A nurse midwife explained that she would like to understand “what kind of care do women get in pregnancy and childbirth [in Africa]. And what’s her experience? I would like to know if [my patient] had a gynecological exam before or not, so I know how much to explain.” A family nurse practitioner mentioned that it would be helpful if her health center administration provided diversity and inclusion training for the staff of the health center. A nurse midwife wanted to know more about patients’ ideas about childbirth and their values surrounding women’s health and reproduction in general. She also said “I want to understand where they are coming from, and what their concerns might be. Because I know what my concerns are but that may not be what their concerns are.”

Perceptions of Population Needs

In addition to questions asking about their experiences serving refugee women from SSA, participants were also asked what they viewed as the most pressing needs of their patients.

Themes derived from those answers included access to health care concerns, clinical needs and priorities, and social needs.

Access. Providers noted that getting to appointments for many of their patients was difficult. The pediatrician who worked at the clinic for the uninsured said “there’s the challenge of getting them to appointments because a lot of time they don’t have transportation.” While this logistical hurdle was noted, an obstetrician was particularly concerned about the barriers that lack of insurance and low incomes presented this patient population. An obstetrician noted that there were delays for certain Medicaid insurance applications which prevented patients from receiving timely prenatal care. Moreover, the ability to serve the patient population as it is growing was noted. An obstetrician said “we are already having trouble getting some people in. the obstetrical care in the country is kind of getting to a breaking point. Because all these places are closing. There’s not enough money.”

Clinical. Aside from getting to appointments and having the funds or insurance mechanism to pay for that medical care, providers mentioned some specific clinical concerns they had for refugee women from SSA. Hypertension was noted and emerged as a prominent theme. High blood pressure, according to the participants, was a common chronic disease among the population that was particularly problematic because of its tendency to be asymptomatic. A nurse practitioner noted “it’s a lot of not being diagnosed or not understanding what a chronic condition is...So acute things... if a child is having a high fever or if they’re not eating or something that’s really visual.” She also mentioned that diabetes occurred in this population but was not as well managed. Two providers said that they noticed more obesity among SSA refugee women, and one even cited that 40-50% of the adults became obese or overweight within a few years of arriving in the U.S. with elevated blood sugar. A nurse midwife talked more about the

somatic complaints like abdominal pain and explained that many cases were mental health related issues.

Social Determinants of Health. Providers spoke about the social needs of refugee women from SSA as being a pressing issue but also one that was outside of their control. A pediatrician noted that they tend to have more food insecurity and more transportation difficulty related to their personal resources and their environmental resources. Although participants noted these needs, a nurse practitioner said she had to find balance in communicating to her patients that she could help with medical issues but not as a “case manager” by saying “I can’t take care of you to make sure you have food on your table.”

Ideas about Cultural Competency

Participants were asked how they defined the term cultural competency and to what extent they felt their services were culturally competent. In defining cultural competence, providers talked about being aware of diverse cultures and experiences, and also of being aware of and acting against biases. For one nurse-midwife cultural competency meant “you have to understand they are coming from a completely different frame of concept of healthcare...and to go into that with humility and try to understand each other as well as you can.” Another nurse practitioner said that it was “really just being aware on a very basic level that all patients enter care with culture influencing their beliefs and understanding what health is.” Providers talked about understanding these cultural ideas about healthcare and then applying that to their understanding of their interactions, health behaviors, and traditions that might have an impact on the way they receive health care.

Awareness of bias was mentioned less frequently but came up in interviews. A nurse midwife explained that understanding culture was important, but it was also important to

“acknowledge their beliefs without deriding them.” A nurse midwife said that “just the awareness of these biases helps you to be a more inclusive provider.”

Infant Feeding Support

All participants were asked about their professional recommendations in terms of infant feeding and the support that they or their practice provides to patients to learn to feed their babies. Every provider responded that they support breastfeeding as an optimal way to feed a baby in comparison to using milk substitutes. A nurse practitioner said “I would always recommend breastfeeding.” One nurse practitioner noted the possible contraindication to breastfeeding that HIV would present and that it could be an issue among SSA refugee women patients. Answers varied slightly as to the specifics of the recommendation but most cited recent professional recommendations that included breastfeeding exclusively for four to six months and then adding complementary food.

Although all providers recommended breastfeeding, few perceived refugee women from SSA as needing help with breastfeeding and therefore had little experience providing clinical help or education. A nurse practitioner said “I’ve so far been really impressed with how well our families from SSA take up breastfeeding and continue breastfeeding for at least a year.” Given that this was perceived as a cultural strength, providers mostly talked about their support in terms of referrals to breastfeeding classes during the prenatal period although it was not known whether their SSA refugee patients attended those classes or if they were accessible in a language other than English. The nurse midwives talked more about providing intensive prenatal education about breastfeeding and then mentioned the support in hospitals that any patient could get from an internationally board-certified lactation consultant (IBCLC) after delivery. One obstetrician said that breastfeeding education was beyond their mission and the time resources

they had to serve their patients. Providers did not expound greatly on their conceptualizations of cultural competency and infant feeding and thus these themes are considered more minor than the previous ones.

Discussion

Given their diverse professional backgrounds and positions, the similarity of answers and saturation in themes suggests that there are common challenges in serving this population across a range of services in pregnancy care. Interviews revealed both challenges and opportunities for health care providers to best serve their patients. Many providers had positive views of their refugee patient population but recounted specific instances where culturally rooted misunderstandings and miscommunications could have or did result in negative health outcomes. This was most pronounced in relation to the incidence of hypertension in the population and difficulties in managing compliance with medication. Several possible reasons were perceived by providers as explanation for this noncompliance including misunderstanding the nature of chronic disease management (e.g., taking medicine indefinitely), and the processes involved in obtaining medicine such as going to the pharmacy and getting refills. Although providers were frustrated with the challenges they encountered with their refugee patients from SSA, they seemed to understand the root of those challenges as cultural rather than as personal failings. This is important in terms of culturally competent health care because understanding cultural differences is a key component (Office of Minority Health, n.d.). In addition, several of the nurse midwives spoke in depth about establishing relationships and getting to know their patient's ideas of birth and experiences. This approach to pregnancy care, where the whole person is a priority, is also consistent with culturally competent health care (Renzaho, Romios, Crock & Sonderlund, 2013).

Health care providers were asked about their infant feeding support both in terms of their professional recommendations and the actual support they provide in the office. Participants mostly responded that their support was minimal in terms of their particular practice but that there were infant feeding nutrition classes to which they referred patients and that there were lactation consultants available particularly in the hospital after delivery. The nurse midwives who had previously worked in a birthing center spoke more in depth about their breastfeeding support initiatives. Most participants did not view SSA refugee women as particularly in need of or interested in breastfeeding support but they all said that if they were asked they would be able to provide it. This is an important finding in light of the evidence that breastfeeding wanes as refugees spend more time in the U.S. (Gibson-Davis & Brooks-Gunn, 2006). Although patients might not need support in the short-term with breastfeeding (Neault, 2007), it is likely still important to provide education about the benefits of breastfeeding in addition to assisting patients in accessing resources that allow them to breastfeed when it is their desire. This would include accessing breast pumps through insurance programs for those mothers who engage in paid employment outside of the home. Findings suggest that providers are less aware that refugee women are likely to discontinue breastfeeding and that there is an opportunity to provide support even when it is not explicitly requested.

Participants in the study did not frame their perceptions of the needs of refugee patients in the context of racial and ethnic health disparities, but they were aware that cultural ideas of health, previous experiences of trauma, and living in low resource environments had an impact on the interactions between providers and patients. This is consistent with the literature that suggests refugees are likely to suffer health inequities related to the social determinants of health (Mayberry, Mili & Ofili, 2000). Providers talked in particular about the impact of trauma on the

wellness of their patients and the way that presented clinically as somatic complaints. While providers did not express concerns about racial discrimination and bias in service provision, they did mention that biases in general could impact services. This has been shown in studies especially when refugees are asked how they perceive the services they receive (Carolan, 2010; Edberg, Cleary & Vyas, 2011).

It is evident that health care providers are working hard and often under difficult circumstances to provide care to low resource individuals and to individuals who need accommodations such as language interpretation. These strategies included taking more time to understand the cultural background of their patients, allocating more time into appointments, and using communication techniques to illicit understanding and compliance. In fact, language barriers and use of interpreters was a common issue among all participants. Providers weren't always sure that complicated medical information was truly interpreted and understood by their patients. The FQHC staff had access to in-person interpreters for women's health appointments but a recent employment change meant that the only interpreter for women's health was a male. Providers noted that this was not ideal but that the interpretation quality was superior than that provided through the phone service. Providers at the university hospital system used the "language line" consistently for appointments and although that resource was readily available there were still difficulties in communication. These strategies are consistent with best practices in culturally competent health care provision (Betancourt, Green, Carrillo & Ananeh-Firemong, 2003).

The awareness of cultural differences and how they inform patients' health beliefs and behaviors particularly surrounding pregnancy was evident among health providers. Although they largely valued these cultural differences, they were still often concerned about addressing

clinical issues, such as hypertension, in a meaningful way to prevent morbidity and mortality among their patients. Participants provided ideas about things that could help them such as a wider variety of translated materials that include pictures and robust language interpretation services.

Limitations

With a smaller sample of 10 health care providers the results are limited in their generalizability. All providers were from the same region of the U.S. and had exposure to refugee patients from SSA.

Another limitation is the reliance on self-report information. Some providers could have provided more socially desirable answers to the interviewer. However, the multitude of stories about challenges with patients lends the researcher to believe that important information about health care interactions were conveyed in the interviews.

Directions for Future Research

This study provides groundwork for larger quantitative studies that could assess the ubiquity of certain experiences of health care providers. The themes discussed in this paper could provide direction for survey questions for a larger sample of care providers. Further research could also explore the ways that the strategies used by doctors and nurses to manage their interactions with patients influence health behaviors and outcomes. This could be done by using an observational design and triangulating information from interviews with providers, patients, and health data. Moreover, all providers included in this study had previous experience with refugee patients and worked in clinical offices that served low resource patients from diverse backgrounds. Future research could focus on providers with less experience with refugees to assess their ideas about cultural competency if their practice were to serve refugee patients from

SSA. This could be particularly important in tertiary medical clinics where specialized care is provided but is accessed less often than general care practices.

Conclusion

Refugees and receiving health care systems encounter challenges related to health care provision that are culturally rooted. Policy makers and health care administrators can support clinical staff by providing resources for competent and appropriate language interpretation and training on cultural competency. Providers are aware of different needs among their patients from SSA and are interested in learning more about their cultural backgrounds, thus hospital administrators could bolster their diversity training to include information on this population specifically surrounding cultural experiences and ideas about pregnancy and birth. Moreover, practical resources such as extended case management, in-person interpretation services, and transportation support would address some of the needs of refugee patients and their providers in accessing health care. Health care providers are addressing important issues to manage the clinical needs of refugee patients in a context where their social and economic needs are high. Their perspectives are important for public health professionals to consider when planning interventions and policies aimed at reducing racial and ethnic health disparities.

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Appendix

Table 4.1. Health Provider Participant Demographics

Professional Type	Years Practicing	Type of Practice	Nature of Refugee Patient Interactions
Family Nurse Practitioner	3	FQHC	Initial health screenings upon arrival; family practice
Nurse-Midwife	17	Hospital- Labor & Delivery	Pregnancy and delivery care
Nurse-Midwife and PhD in Nursing	23	Not currently practicing, previously practiced at birth center	Pregnancy and delivery care
Nurse-Midwife	34	FQHC	Women's health
Pediatrician	32	Faith based safety net clinic	Initial health screenings upon arrival, primary care for uninsured
Pediatrician	11	University safety net clinic	Primary care
Nurse Practitioner	7	FQHC	Family practice
Nurse-Midwife and Family Nurse Practitioner	5	Hospital- Labor & Delivery	Pregnancy and delivery care
OB/GYN	42	FQHC	Women's health
OB/GYN	7	High risk OB in hospital	High risk pregnancy and delivery care

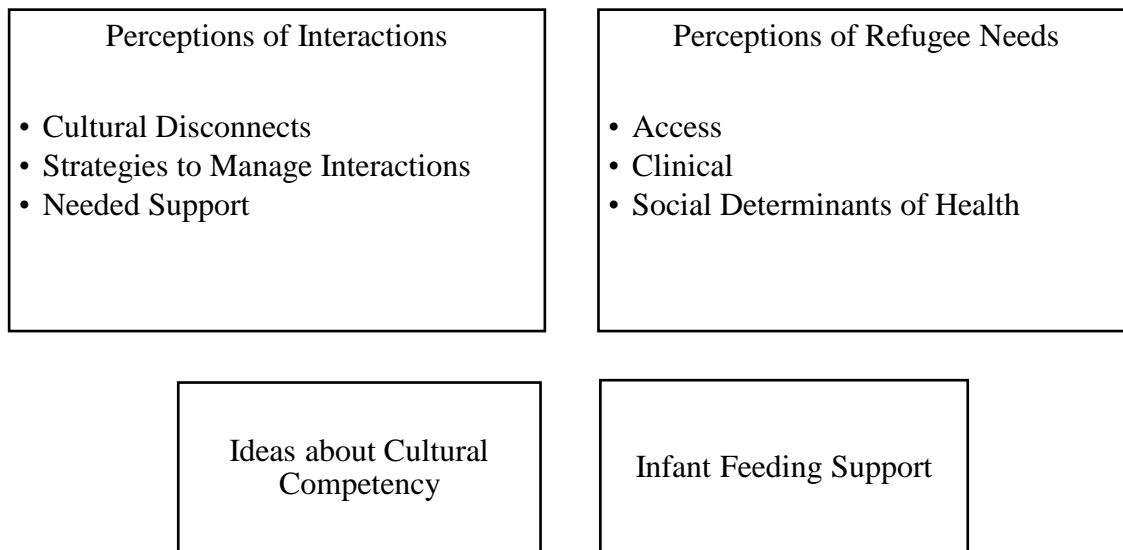


Figure 4.1. Interview Themes

Chapter V

Conclusion

Refugees have been resettling formally in Western countries for decades as part of the refugee resettlement program managed by the United Nations. The U.S. has historically welcomed refugees from all over the globe as part of the U.S. federal resettlement program and thus, in the past decade, refugees from Sub-Saharan Africa (SSA) have increased their presence as a resettlement population (ORR, 2015). Given that refugees come from various cultures and have experienced life events particular to their status as refugees, welcoming communities are charged with providing culturally competent service provision to meet their needs. Although federally funded resettlement agencies assist refugees in the transition to living in the U.S., their services and scope are limited. Schools, government agencies, and health systems all interface with refugees as students, clients, and patients. Supporting health services in their work with refugees is vital because this population has health needs and challenges in accessing health care. Research on the gamut of health care services and perspectives within the system can elucidate the health needs of refugees specifically and ways to improve health outcomes. Because maternal health care is often an entry point to the health system for refugee women, this area of service provision is of particular interest and was the focus of this dissertation.

Chapter two provided a systematic review of the literature related to the needs of refugee women across the range of maternal and reproductive healthcare in the U.S. This systematic review focused only on research conducted in the U.S. and 18 articles were identified and analyzed qualitatively using the PRISMA framework (Moher, 2009). Results indicated that there

were various categorical needs of refugee women from SSA including Clinical, Systemic, and Personal needs. A fourth category was identified and that emphasized the Strengths and Protective factors that refugee women from SSA bring with them to health care interactions. These results are important in that they recognize the clinical needs of this population in addition to issues that are cultural and systemic in nature. In other words, although it might be obvious to clinicians that refugee women from SSA have differential exposure to disease, it is less obvious that social factors that contribute to their experiences of health care. Factors such as insurance, transportation, social support, and culturally relevant education impacted refugee women and their health. This study is important in recognizing the strengths that SSA refugee women had including a lower risk for preterm birth and a positive view of the U.S. health care system overall. Health care providers and public health professionals can recognize the needs and opportunities serving SSA refugee women presents while also capitalizing on their assets in strengths-based approaches to intervention. By doing so, providers would be utilizing cultural competence frameworks (OMH, n.d.) to address the needs of this population. Moreover, they would be recognizing that their patients' experiences are informed by their past as refugees (Stewart, 2015), and their identities in the U.S. as racial minority immigrant women.

The systematic literature review revealed a small amount of studies dedicated the needs of refugee women from SSA during maternity care in the U.S. To expand what is known about the experiences of a particular group, chapter three was a qualitative case study that closely examined the experiences of two refugee women from the Democratic Republic of the Congo (DRC). Although resettled in a similar time period and pregnant within the same year, results elucidated how experiences of pregnancy care were influenced by personal characteristics including language ability and health status. The participant who spoke English fluently and had

a healthy pregnancy had fewer concerns and difficulties than did the participant who relied on language interpretation services and had some pregnancy/delivery complications. These personal characteristics including language ability and health, influenced the process of accessing health care including making and attending appointments. Their access to appointments then influenced their experiences of both clinical care and health education, thus resulting in their perceptions and needs related to pregnancy care. This study underscores the importance of understanding the individual background of patients and the opportunity to tailor social and health services to support the particular needs of patients. Beyond the practical implications, the findings from the case study reveal that the experiences of health care are rooted in the interactions between a patient, their relationships, and the systems within which they interact as described in the socio-ecological model (CDC, 2017). One of the participants had difficulty with her insurance applications and thus was worried about her continued access to health care. Her health care experiences could not be understood adequately without addressing the issues of payor structures in the U.S. health system. Moreover, intersectionality (Crenshaw, 1989) theory is applicable as difficulties and bias were described by one participant as she interacted with various clinical staff. Her status as a patient who needed language accommodation had an impact on the way she was treated.

To provide a holistic view of the interactions between refugee patients and their providers, the study in chapter four was an answer to a dearth of literature on the perspectives of health providers in serving patients from diverse backgrounds. Although cultural competency standards exist (OMH, n.d.), the perspective of clinicians in providing care in a culturally competent manner specifically to refugee women from SSA is scarce. Analysis of key informant interviews revealed a variety of perspectives on cultural competency and experiences serving

refugee women from SSA in a range of health services directly related to pregnancy care and care that is supportive to maternal health in general. Providers were generally positive regarding their experiences serving refugee women from SSA and emphasized the need for robust language interpretation services and enhanced translation services for written materials. Clinicians viewed challenges with cross-cultural service provision as rooted in communication barriers and various cultural ideas about health and wellness consistent with the literature on cultural competence in health care. Chronic high blood pressure was often cited as an example of misunderstandings and pharmaceutical noncompliance with potentially severe health consequences. The most salient clinical priority among the practitioners interviewed was related to high blood pressure, which wasn't a finding in the systematic literature review in Chapter 2. These concerns demonstrated the providers' confirmation of the health disparities and vulnerabilities experienced by refugee patients (Mayberry, Mili, & Ofili, 2000).

Despite their positive outlook and willingness to provide high quality care, health care providers expressed a need for more support in terms of diversity training and practical resources to provide competent language services to patients. It is notable that despite the fact that all providers had access to language interpretation services in some form, they all found them insufficient in some way. Although cultural competence standards (OMH, n.d.) had been technically met by the presence of competent interpreters by phone or in-person, the communication needs and trustworthiness of the process was still lacking. When asked about their ideas about cultural competency several participants spoke about being aware of cultural ideas and traditions of their patients in addition to being aware of their own biases. One provider talked about taking a paternalistic approach to health care when serving some patients from SSA when the communication barriers were too great. Others spoke about building intentional

relationships with patients to understand their cultural ideas surrounding birth and to address those in the context of their health service goals. Enhancing institutional supports and training could improve the ability of health providers to provide care in a way that is less cumbersome (Gany & de Bocanegra, 1996).

The qualitative research featured in this dissertation provides in-depth information about the experiences of two refugees and ten health providers in a particular geographic location. Findings are consistent with previous qualitative research on the needs and experiences of refugee women of various nationalities including the need to be treated with respect with understanding for the culture from which they come (Wojnar, 2015). For example, experiences of trauma were discussed by health providers as influencing the way they approached obstetric exams and reflects the reality that many refugees have experienced persecution and violence in the past (Burnett & Peel, 2001). Providers were aware that transportation and other logistical issues are barriers to accessing care for their patients and refugees in general (Gagnon, Carnevale, Mehta, Rousseau & Stewart, 2013) and this was confirmed by the case study participants. Although they both had access to cars, their transportation depended on their spouse's ability to drive and friends in the community. Some research suggests that postpartum depression risk is increased among immigrants (Collins, Zimmerman & Howard, 2011; Gannan, Sword, Black, & Carpio, 2012) and this was not mentioned by health providers suggesting that perhaps other health needs were a more salient priority.

New findings in this research suggest that although infant feeding is strongly supported by providers, it is not seen as a priority need among refugee women from SSA. The previous literature demonstrates a decline in the practice over time and is an unrecognized opportunity by health providers who assume it is a cultural strength. Promoting breastfeeding and finding

culturally relevant ways to support the practice could impact long term health outcomes for both mothers and infants. Moreover, hypertension was a primary clinical concern of patient needs from provider perspectives as discussed in Chapter 4. This was not a finding in the systematic literature review and presents a new direction for research into the reasons why high blood pressure is a chronic and hard to treat disease among SSA refugee women. Moreover, the systematic literature review findings that FGM were a prevalent issue was never mentioned in health provider interviews in the third study. This underscores the importance of understanding local refugee groups that are resettling in the area and the cultural differences among them.

Future research that is quantitative in nature could reveal larger trends within and between refugee groups as it relates to health care needs. Moreover, interventions that are designed in response to the findings presented in research on refugees and health care could evaluate the relationships between factors such as social support and quality interpretation services and actual health outcomes. The ultimate goal should be to situate the variables revealed in this research to be important to both SSA refugee women patients and the health providers that serve them to actionable intervention strategies. By investing in and evaluating intervention strategies, health disparities that persist among refugees can be addressed by the public health system.

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Vita

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