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Maternal mortality is a global public health concern. At present, the US reports the highest number of maternal deaths among all Global North countries. Research shows disparities in maternal care access and outcomes by race, ethnicity, and country of origin. Refugee women are one of the most vulnerable groups who are disproportionately disadvantaged due to their social positioning. Their disposition in the global world is quickly emerging to be a major global public health crisis. They are also 20 times more likely to die from pregnancy related factors compared to their native counterparts. However, maternal research on refugee women is limited. Study aimed to examine Bhutanese refugee women's maternal care process and experience when receiving perinatal care in the US and explored provider's perspectives on providing care to various groups of refugee women. Care process was examined using a constructivist grounded theory model through an inductive constant comparative analysis using semi-structured interviews with Bhutanese refugee women (n=15), field observation notes from a larger CBPR study (n=28), and semi-structured interviews with providers (n=11) such as healthcare practitioners (n=6), medical interpreters (n=4), and resettlement official (n=1). Two major thematic findings that impacted refugee women's care interaction process were care continuity and health history. These findings were grounded in the experiences of Bhutanese refugee women and various providers who shared their experiences giving care to refugee women. These thematic findings highlight the need for a cultural understanding of refugee women's pre-resettlement experience that is unique to each refugee subgroup and addressing structural challenges to adequate care giving through a culturally responsive approach.

EXAMINING PERINATAL HEALTHCARE PROCESS AMONG REFUGEE WOMEN
RESETTLED IN THE US

by

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CHAPTER I: INTRODUCTION

Statement of the Problem

Maternal health is a global public health issue. In 2017, approximately 810 women died every day from pregnancy related issues that were easily preventable (WHO, 2019). The United States in particular, reports to have the worst maternal mortality rate among all Global North countries. The US accounts for 29 deaths per 100,000 compared to Canada with only 7 per 100,000 (WHO, 2019). In 2015, the maternal mortality rate in the US was 14 deaths per 100,000 which almost doubled by 2019. Despite the worsening maternal mortality rate, research on maternal health is limited in the US. Additionally, there are disparities in maternal health outcomes by maternal age, race, ethnicity, country or origin, and sociodemographic factors. Across Global North countries, the US has one of the highest numbers of resettled refugee populations. Among refugees, women and children make up more than 50% of the total refugee population (UNHCR, 2017). Refugee women from Global South countries to the US are an underserved population in public health research. They are 20 times more likely to die from pregnancy related factors which are easily preventable (Urquia et al, 2017). However, little is known about factors contributing to this disparity in health outcomes.

Even among refugee populations, there are disparities in maternal health outcomes by ethnicity and country of origin. Reports show refugee women from Sub-Saharan Africa, Eastern Africa, and Southeast Asia to have a higher risk for severe maternal morbidities putting them at a higher risk for pregnancy related deaths compared to other immigrant populations. One of the steadily growing refugee populations in North Carolina are ethnic-Nepali speaking Bhutanese refugees from Southeast Asia. They are also one of the fairly new refugee resettlement groups, and as such, maternal health research on this population is almost non-existent. Current research

reports a high prevalence of mental health disorders and poor health literacy among this refugee population in the US.

Purpose of the Study

Research on refugee women is sparse as is, and the field of maternal health research in Global North countries continues to under-represent refugee women's maternal health practices, access to care, and the quality of care women receive from the resettled healthcare system. Understanding the context in which refugee women navigate the US healthcare system and receive care from their providers is essential in examining factors contributing to refugee women's maternal health status. To do this, it is important to explore the care continuum processes influencing refugee women's prenatal and postpartum care experiences which in turn, affects their maternal health practices, and essentially has implications for health outcomes. Additionally, exploring the provider perspective within the spectrum of refugee women's healthcare experience adds important insight to the health interactions between the women and providers within a healthcare setting. This process of women's navigation within the healthcare system and their interactions with the providers will shed light on the overall process that contributes to Bhutanese refugee women's maternal health throughout pregnancy, childbirth, and postpartum. Therefore, the purpose of this study was to examine the maternal caregiving and care receiving process throughout pregnancy and postpartum between Bhutanese refugee women and providers.

Research Questions

Overall research question: What is the process for giving and receiving pregnancy-related healthcare services for Bhutanese refugee women who have resettled in the US?

1. How do women perceive receiving maternal care at a healthcare facility in the US?

- a. How do they perceive their interactions with the healthcare providers?
 - b. How do they navigate the US healthcare system?
 - c. What are their birthing experiences?
 - d. For the women who are seeking care during Covid-19, how has the pandemic affected their care receiving experience?
2. How do providers perceive giving maternal care to refugee women?
 - a. How do providers perceive their interactions with refugee women?
 - b. What are their perceptions on providing care services to refugee women?
 - c. What challenges are providers identifying in providing adequate services to refugee women?

How has the pandemic affected the provider's care giving experience?

CHAPTER II: REVIEW OF THE LITERATURE

Maternal health status in the US

Maternal morbidity that leads to maternal mortality is a global public health concern. Death of women during pregnancy or childbirth as a result of maternal complications is termed as maternal mortality. Such complications during pregnancy are known as maternal morbidities that may be mild or severe, and put pregnant women at risk for maternal deaths. At present, there is no global standardized definition for maternal morbidities in the maternal health literature (Creanga et al., 2014). This is due to the complexity in health systems around the world compounded by inaccuracy in vital records as a result of inadequate health information systems (Firoz et al., 2013). Additionally, studies utilize various methods to assess maternal morbidities which include self-reported morbidity reports, clinic/hospital-reported patient morbidity reports, or specific morbidity assessment measures. These variations in assessment result in the risk of the health issues being over- or under-diagnosed. Therefore, the magnitude of these issues that vary across regions and cultures are uncertain in research and practice, thereby, leading to lack of standardized morbidity assessment.

Some of the common morbidities experienced by pregnant women in the US include chronic health conditions such as hypertension, diabetes, and chronic heart disease (CDC, 2020). Other risk factors for pregnancy-related deaths include eclampsia, hemorrhage, sepsis, hysterectomy, etc. (Say et al., 2009) that is more common among refugee and immigrant women. Morbidities such as gestational diabetes and hypertension can be managed with early detection and treatment during women's pregnancy. However, severe morbidities such as eclampsia and maternal sepsis require extensive and quality care since these risk factors put both the mother and infant's life at risk and are a major contributor to the annual maternal death. In addition to

morbidities, certain maternal health behaviors also contribute towards maternal care during pregnancy which may have adverse outcomes if not detected and controlled during early stages of pregnancy. Pregestational body mass index (BMI) and gestational weight gain (GWG) are the two prime indicators of maternal health behaviors during pregnancy that are easily manageable and low-cost procedures. They also serve as important measures for maternal nutritional status before and after pregnancy (Rodriguez et al., 2009).

Reports show nearly 1.2 million women have obstetric complication caused by pregnancy or a preexisting morbidity aggravated by pregnancy (Danel et al., 2003). The US particularly, reports a steady rise in maternal deaths where 658 women died in 2018 due to pregnancy or childbirth related health complications (CDC, 2019) compared to 396 deaths in 2000 (MacDorman et al., 2016), and two-thirds of these maternal deaths were due to preventable morbidities. The rate of maternal morbidities in the US increased 200% between 1993-2014 (CDC, 2020). As such, the US currently has one of the worst mortality rates among all industrialized countries where refugee and immigrant women are 20 times more likely to die from pregnancy related factors compared to their US native counterparts after adjusting for age (Urquia et al, 2017). Adequate maternal care throughout pregnancy, childbirth, and postpartum is, therefore, crucial to women's health. There are myriad factors that contribute towards maternal health, and research is consistently progressing towards our understanding of the psychosocial factors that contribute to maternal morbidity and mortality (Gadson, Akpovi, & Mehta, 2017). Although this process is still evolving, researchers and healthcare providers prioritize the process of prenatal care to be a crucial indicator for women's health throughout pregnancy and childbirth.

Prenatal care as a determinant of adverse outcomes

The World Health Organization (WHO) prioritizes prenatal care for promoting the global Sustainable Development Goal (SDG) in reducing global maternal deaths to 70 per 100,000 live births by 2030 (WHO, 2017). Prenatal care, an essential preventative care service provided to women throughout their pregnancy by medical professionals trained in maternal care, is a major determinant of maternal morbidity. The purpose of prenatal care is to deliver a healthy newborn without jeopardizing the health of the mother (Ashraf-Ganjoei, Mirzaei, & Anari-Dokht, 2011). As such, the process includes frequent check-ins with providers to track women's health status throughout the course of the pregnancy, and also provide women with healthcare information and recommendations of care for healthy pregnancy behaviors beyond the visits. In the U.S., women with access to good health care have as many as ten prenatal care visits across a single pregnancy which includes a monthly check-up until 28 weeks of pregnancy, biweekly from 28 to 36 weeks, and weekly starting at 36 weeks (Rosen et al., 1991)¹. A standard prenatal care visit assesses maternal health profile such as maternal age, weight, self-reported health status that inquire about any pre-existing conditions or family history of any chronic health disease, and maternal behaviors such as smoking, alcohol consumption, and dietary needs/restrictions. All the information that healthcare professionals obtain from the women are entirely self-reported and care measures are adapted according to the patient report.

¹ This standard remained the same pre-Covid-19. The in-person visit requirement has changed in response to COVID-19

Factors impacting prenatal care

Disparities in prenatal care utilization exist among women in terms of access to care and quality of care. The primary indicators used to assess maternal care access and utilization are sociodemographic and economic factors. The assessment for these factors include maternal age, marital status, education, race, and maternal body mass index (BMI) (Sharma et al., 1994; Orr et al., 2007). Minority women, specifically African American women and refugee/immigrant women are disproportionately disadvantaged in receiving adequate prenatal visits and experience delay in initial prenatal care appointment (Danel et al., 2003). Undocumented migrant women often experience barriers in access to prenatal care due to lack of insurance and their ineligibility to utilize support and care resources (Pasick & Burke, 2003). However, there is no standard measure that assesses the quality of prenatal care women receive in the clinics. Historically, research has focused on the number of prenatal visits throughout the course of pregnancy (Alibekova et al., 2013) to assess the effect of prenatal care on maternal health outcome. This measure assumes higher number of visits leads to better care. However, a quantitative assessment of the number of prenatal care visits does not accurately account for disparities in healthcare access and utilization that vary across maternal age, race, ethnicity, socio-economic status, and prior morbidity histories (Phillippi, 2009). Heaman and colleagues (2014) have developed a quality of prenatal care assessment instrument that inquire about patient information sharing, availability, support and respect (the complete table can be found under figure 1). However, the validity of the assessment instrument has not yet been established.

Additionally, the assessment is not transferable to immigrant and refugee populations due to the population's barriers of language, culture, immigration status, and acculturative factors (Beiser, 2005). In fact, culture as a context is not at all present in Heaman and colleague's (2014)

quality of prenatal care assessment. Therefore, there is a need to examine maternal care disparities among refugee and immigrant populations that are impacted not only by their sociodemographic and economic factors, but also through sociopolitical factors and their social positioning in the country of resettlement. Additionally, the majority of studies on maternal health focus on birth outcomes as indicators for maternal health. It is important that we shift our focus to women centered maternal health outcomes in order to adequately assess maternal health. This becomes more necessary for studies examining postpartum maternal care.

Postpartum maternal care

One of the important factors that affect the continuum of maternal care is postpartum. The postpartum period is a crucial transition time for women physically, socially, and psychologically (Shaw et al., 2006). This phase of care occurs after childbirth and is often the most overlooked phase of maternal care where the care is more compromised for the women. Research shows that postpartum stays in the hospital have significantly decreased over the years and the consequences of inadequate postpartum care has been well documented (Katz & Gagnon, 2002). Despite the evidence on the effectiveness of postpartum interventions on women's health, implementation of such care is disproportionate in North America (Katz & Gagnon, 2002). In the US, women who are provided access to prenatal care through government funded Medicaid are not covered for postpartum care. Most refugee women especially, newly arrived refugee women seeking maternal care do not receive postpartum care in the clinics since they rely on the government-funded Medicaid program for access to maternity care. As such, they are at a higher risk of adverse postpartum outcomes within the continuum of maternal care. However, early detection of maternal morbidity minimizes this risk of adverse postpartum outcomes. Therefore,

appropriate and adequate prenatal care mitigates the risk of adverse maternal health outcomes postpartum through prevention, early detection, and treatment.

Refugee journey from displacement to resettlement

The United Nations High Commissioner for Refugees (UNHCR) defines refugees as “someone who has been forced to flee his or her country because of persecution, war or violence. A refugee has a well-founded fear of persecution for reasons of race, religion, nationality, political opinion or membership in a particular social group. Most likely, they cannot return home or are afraid to do so. War and ethnic, tribal and religious violence are leading causes of refugees fleeing their countries”. Refugees are a vulnerable group of population and their disposition in the global world is quickly emerging to be a major global public health crisis. Consistent to UNHCR’s definition, refugees often flee from violent situations as a result of war, genocide, or life threats due to political affiliation or sexual orientation (Mehta et al., 2017). Majority of the refugee populations are displaced in Global South countries for a significant amount of time until they are resettled in Global North countries (Malebranche et al., 2019).

From 2008 to 2017, the U.S. resettled, on average, 67,100 refugees per year and is responsible for negotiating terms for legal and physical protections of refugees equal to those guaranteed to U.S. citizens (Ajjarapu, Story, & Haugsdal, 2020). Refugees post resettlement in the US are documented as permanent resident aliens and often categorized into the immigrant subgroup. Therefore, it is important to recognize and include all persons of refugee origin when studying refugee health even though they may be considered citizens at the time of data collection. Additionally, the mass categorization of refugees into the immigrant sub-group can adversely affect the population’s access to community and health resources due to two major misconceptions. One of the historically popular misconceptions is the immigrant health paradox

or the ‘healthy immigrant effect’. The healthy immigrant effect (Urquia et al., 2012) refers to the concept that immigrants usually experience similar or better health outcomes than their native counterparts. However, this concept does not take into regard the diversity in immigrant population and their varying social positioning in the country of resettlement.

Furthermore, immigrants who voluntarily migrate to the US have higher education status and greater access to health resources. Refugees on the other hand, have limited education and are positioned at the bottom of the social scale (Cubbin & Braveman, 2010). Thus, an important distinction is to be made between immigrants who voluntarily migrated and refugees or persons of refugee origin who suffered forced migration as key differences that shape the population’s health status and experiences. The overlooking of these migration conditions adversely affects research and the population’s opportunities for adequate health needs, and essentially results in mis-appropriate reporting of their health statuses by grouping them with the comparatively ‘healthier’ immigrant subgroups who have greater access to resources.

Concurrent to this mis-categorization is the disregard for ethnicity and region-specific categorization. For example, all Asian immigrants and refugees are often grouped together even though their economic and health profiles differ drastically. Similarly, African refugees are often grouped into the ‘black’ race categorization post resettlement which creates room for mis-informed research findings. Within the context of these misconceptions and incorrect categorizations, refugee women’s health in particular, is influenced by various factors unique to them compared to native born women. These unique factors comprise cultural measures such as ethnicity-based beliefs and practices, their health history in the country of origin, system of healthcare in the country of origin, health conditions and experiences during displacement, and

acculturative factors such as years in the US, access to healthcare, social affiliations post resettlement (Paton et al., 2013).

Refugee women's health status in the US

Refugee women particularly, are at a greater disadvantage due to their social positioning and make up 50% of the refugee population (UNHCR.org, 2017). Although refugee women represent a heterogeneous group from diverse ethnic, religious and economic backgrounds, they are a distinctly vulnerable group who experience refugee status differently than men (Malebranche et al., 2017). Sex and gender-based violence is common among their country of origin and throughout displacement (WHO, 2019), and the women are subjected to domestic or physical abuse, rape, and trauma in addition to the structural discrimination throughout displacement (Mehta et al., 2017). As such, it is important to consider crucial mental health factors that impact the women's physical health status and needs for care. Again, this becomes more necessary for postpartum maternal health.

In the US, most refugee women (subject to their household income level) are eligible for government-funded Medicaid insurance that provides them access to prenatal care. However, the disparity lies in care initiation time, quality of care during the visits, and higher prevalence of comorbidities compared to native born women (Ajjarapu et al., 2020). As such, there is little evidence on refugee maternal health status. However, research is slowly evolving in examining region and ethnicity- specific maternal health experiences among refugee women. These studies show that refugee women have varied risk factors that may be inherent or acquired and differ by maternal country of origin (Cripe et al., 2010) and acculturation (Fuentes-Afflick et al., 2014). Prior to resettlement, refugee women may have never received obstetric care such as mammogram or cancer screenings (Samari, 2017). They are also less likely to seek gynecologic

care due to lack of information and experience with preventative gynecologic care (Mehta et al., 2017) or preference to only be seen by a female obstetrician (Samari, 2017). They also report a higher rate of cesarean births compared to native women (Ajjarapu et al., 2020). However, there is not enough information on the care process through which these disparities are experienced by the women.

Bhutanese refugee women's health status in the US

There is little to no existing literature on Bhutanese refugee women's maternal health. Bhutanese refugees are ethnically Nepalese and spent a significant amount of time in the displacement camps in Nepal with restricted healthcare facilities. The access to hospital care and the quality of care they received in the camps were more compromised than the care received by native born women of Nepal. Therefore, we anticipate Bhutanese refugees to have poorer health outcomes compared to native born Nepali women. However, due to non-existent research data on Bhutanese women's maternal health status, we can look at Nepal's maternal health research reports to examine potential health needs of Bhutanese refugee women during displacement at the Nepal camps. According to the 1996 Nepali Family Health Survey, 539 per 100,000 Nepali-speaking women die from pregnancy related outcomes which could constitute Bhutanese refugee women as well. Gender roles also play a major role in Nepalese cultural norms which has a vital impact on maternal care access and practices of care. A study by Henjum and colleagues (2015) found that Nepalese women may be at risk for adverse postnatal outcomes due to factors such as lack of dietary diversity and poor micronutrient uptake.

According to CDC (2014) health profile for Bhutanese women, most Bhutanese women had never received a mammogram or a Pap smear prior to arriving in the United States. Within the post-resettlement US environment, the most common health concerns among Bhutanese

women include reproductive and gynecologic care (Maxym, 2010). As such, there is a need to explore Bhutanese refugee women's maternal care needs and maternal status post resettlement.

Differences in the quality of prenatal care experienced by native women and refugee women

With the growing need for adequate quality of care, research is evolving to help providers optimize prenatal care effects by encouraging care that is patient-centered (Nicoloso-Santa Barbara et al., 2017). A patient-centered care assures adequate quality healthcare by catering to individual patient needs that are unique to each patient. This quality of care is encouraged with an expectation of improving patient-provider relationship through increased communication, effective relaying of health information, and facilitating women in their own care (Epstein et al., 2005). This process is assessed through patient satisfaction questionnaires that inquire about women's satisfaction with the care they received from their providers. However, this patient-centered satisfaction focused care may not be optimum for refugee women due to barriers of language and culture. Perceptions of quality of care can differ between native and refugee women because of culture and previous life experiences. These differences in perception can affect satisfaction ratings. While native women expressed their frustrations with their appointment wait times (Novick, 2009), refugee women expressed the appointment system to be a strength of US hospitals. A procedure such as an ultrasound is standard care for native women but refugee women's experience with ultrasound is associated with high quality care where they are able to view/know about the growth of the baby (Novick, 2009). A study comparing native Norwegian women and Somali refugees report native women to have a positive relationship with the nurses whereas, refugee women reported concerns about not receiving assistance during their hospital experience (Pavlish et al., 2010). Overall, they also reported obstacles in communication

with providers. It is also important to consider the impact of race-based health consequences because the U.S. has a long-standing history of racial discrimination against persons of color, and similar trends can be observed in obstetric care (Ajjarapu et al., 2020). Reduced access to quality healthcare, greater number of comorbidities complicating pregnancy, increased susceptibility to generational discrimination, and implicit bias have been recognized as factors contributing to worse obstetric outcomes among women of color (Creanga et al., 2014; Hall et al., 2015).

Maternal health status and quality of care services significantly differs across ethnic refugee/immigrant communities where women from Southeast Asia, Sub-Saharan Africa, and Eastern Africa report poor maternal health statuses with a higher risk for severe maternal morbidities (Ahmed et al., 2016). Sub-Saharan Africa and South Asia account for 86 per cent of maternal deaths worldwide (unicef.org, 2019). Most refugee women are resettled in the US with a greater risk of morbidity and mortality due to issues from their country of origin as well as the journey of displacement. Therefore, they are higher risk as is, but in addition, post resettlement, they are interacting with US systems that have a history of race-based discrimination. As such, they are at most risk to negative maternal outcomes compared to native born women in the US.

Provider perspectives on refugee maternal care

Language is a crucial and primary barrier for providers in their ability to provide optimum care for refugee and immigrant women. Ng and Newbold (2011) examined provider's perspective on the provision of prenatal care to immigrants and found that the providers struggle communicating with the women and making sure they understand the information being relayed. They also expressed poor quality of interpreters who either deliberately do not interpret the entire information, or themselves do not fully understand the information. An expectation of providers

to have cultural awareness of the women's background is another barrier that providers experience. McKeary and Newbold (2010) found that immigrant women often expect their providers to be females and the interactions with male providers are limited due to cultural conflicts. This factor further asserts the need for culturally responsive framework of care that prepares providers to appropriately serve refugee communities.

Pregnancy and pregnancy related events are intricately tied to the ways different societies define and practice culture. Healthcare providers, therefore, may be unaware about certain cultural understanding, attitudes, and practices of refugee women that may significantly differ from the US healthcare. They may also be unaware about the women's complicated health accounts prior to resettlement which may be crucial in order to provide appropriate care respective to their health status needs. It is crucial that research explores the interaction process of healthcare providers and patients in order to rigorously understand the crucial gaps in care practice.

Theoretical Framework

Historically, the field of public health operated without a culturally inclusive framework of practice and hence, its theories are historically structured around a standard conceptualization of human behaviors and their health needs (Bowleg, 2012). As the United States expands in its diversity and the steadily increasing immigrant and refugee population, disparities in healthcare access and needs continue to widen. However, research in the United States continues to under-represent refugee and immigrant women in maternal health research. In order to develop a comprehensive understanding of refugee maternal health, it is essential to establish a strong theoretical foundation centered around third-world women (women from the Global South) with a decolonial conceptualization of feminist theories. These factors should specifically cater to

women of the Global South who fled from violent environments and were displaced with limited access to healthcare. De-colonial feminism refers to the acknowledgement of multiple marginalization of black and brown bodies (Aizura, 2014), and deterring from the western conceptualization and terms that imply hierarchy and power. Terms such as ‘minority’ serve an implicit bias towards Global North citizens who are perceived as the majority authorities in the global world although they only make up 11.8% of the global population (UNCHR, 2020).

Examining refugee women’s health in particular, requires a comprehensive yet holistic understanding of their health histories and experiences that are not only marginalized through race, gender, sexual orientation, and SES, but also disabled through colonization and multiple displacement. My social positioning, therefore, as an immigrant woman and as a public health researcher possessing an immigrant lens pushes me to centralize refugee women’s experience as the core of my conceptual framework within refugee women’s health research. Additionally, my paradigmatic approach to research practice as a social constructivist is in line with my social positioning in research.

There is a need to understand social, historical, cultural, and environmental dimensions of an individual’s health status that builds the foundation for refugee/immigrant maternal healthcare. I believe that utilizing a feminist lens is crucial in maternal health research especially among vulnerable populations such as the refugees since they are placed at the bottom of the social scale and experience greater disparity in healthcare access, use, and their overall health status. They are also multi-marginalized through gendered issues as well as their socio-economic status post resettlement in addition to the sociopolitical climate they were displaced from. As such, immigration specific social determinants of health with a decolonial third world-focused

feminist lens was used to develop a conceptual framework in understanding and examining refugee maternal health.

Aspects of intersectionality and its use in refugee maternal research was also explored to contextualize the multidimensionality of health impacts on refugee women. A deeper exploration of intersectionality in minority health research is crucial regardless of the arguments around its limitation (King, 2015). This is because intersectionality is one of the very few theoretical frameworks that conceptualizes marginalization beyond the gender dichotomy. White feminism mostly functioned on gender dichotomy as their major argument of oppression, and their experiences do not echo the multi-faceted discrimination that minority women experience in the US. While no framework is complete because they are consistent iterations of people's experiences through time and serve as a signifier of growth and movement over time; however, inclusion of intersectionality within refugee women's research becomes more important as we further our knowledge and understanding of non-white experiences in Global North scholarship. The concept of intersectionality is significant to public health theories because it removes the burden of individual behaviors as a predictor of individual health outcomes. Through intersectionality, we are also able to dissect measures that shape refugee maternal health status as a consequence of the socio-political and environmental dimensions.

Additionally, cultural humility may be pivotal in approaching refugee maternal health research because every ethnicity perceives and experiences motherhood and care of infants differently. Their beliefs and practices of care are heavily influenced by their cultural understanding and workings in their community, and therefore, may be impactful towards their health status post migration. Moreover, the women's default need to assimilate or acculturate post-resettlement, may create a lag between their cultural understanding of maternal health care

and the United States health-system protocols of maternal care. Inclusivity-based research then becomes crucial in adequately assessing their health needs and strategizing ways that are most appropriate to specific communities.

Conclusion

Refugee women are at a high risk for adverse maternal health outcomes due to their violent displacement histories caused by forced migration from their country of origin, and disparities in access to healthcare and quality of care received post resettlement. Research is limited in its understanding of the healthcare processes in which refugee women receive care, and the factors impacting the care provided to them by the healthcare professionals. Bhutanese refugees are one of the newly resettled refugees in the United States with no significant research conducted around their maternal health. Consequently, the study explored prenatal care giving and care receiving experiences of refugee women by exploring the perspectives of both women and providers.

CHAPTER III: METHODOLOGY

Study Overview

The goal of this qualitative study was to better understand the continuum of maternal care processes that Bhutanese refugee women experience in the US post resettlement. In order to examine this context of maternal care interactions between the women and the providers, we explored the perspectives and experiences of both the women and the providers. A constructivist grounded theory approach was utilized to develop a comprehensive care interaction model of women's maternal cycle and the influence/impact of provider care services within the US healthcare system. The study included secondary analysis of ethnographic data consisting of participant observation field notes and key informant interviews. Primary data was collected among Bhutanese refugee women through key informant interviews within Guilford County of North Carolina. Interviews were conducted among providers who had ever provided services to refugee women. Data analysis was approached using a decolonial third-world women focused lens in order to essentialize the experience of women by centering their perspectives and narratives of prenatal care. A constructivist grounded theory approach is specifically appropriate for this lens because the methodology acknowledges the complexities of social structures and allows critical inquiry to form as an open-ended discovery of data (Charmaz, 2017).

Research Design

Grounded theory is an inductive, emergent method which allows researchers to not only conceptualize the data but also to construct theoretical interpretations unique to the data (Charmaz & Belgrave, 2019). This approach to qualitative methodology is especially important when we do not have much information about the area of study. In this instance, maternal health information about refugee women is sparse, and research on maternal health is generally limited.

In addition, refugee women's health histories are unique due to their multiple displacement and varying maternal health experiences that vary by maternal country of birth, access to health resources in the country of displacement, and health practices post resettlement. However, current literature does not adequately assess these multidimensional health impacts of refugee women and instead, are categorized as 'hard to reach' (Abrams, 2010) populations. Therefore, approaching this area of study through an emergent method allowed construction of data findings unique to the population and their consequent health outcomes.

A constructivist grounded theory in particular, allows ways of conducting critical inquiry by asking questions about the data as well as the researcher's positionality in research (Charmaz, 2017). This aspect of critical inquiry in constructivist grounded theory is a transformative paradigm that embraces a social justice approach to doing effective research (Charmaz, 2017). As such, constructivist grounded theorists view data as co-constructed between researchers and research participants which is a crucial consideration to this study's decolonial approach. The co-construction assures trustworthiness of the data interpretations and engages participants throughout the research process.

A constructivist grounded theory also allows researchers to locate data within the social, historical, and structural context, thereby, developing an in-depth understanding of the data (Charmaz & Belgrave, 2019). However, Charmaz also stresses on the importance of not reducing social and political issues to individual behavior. This is especially true for refugee communities since their psychosocial positioning is a result of the social and structural factors throughout their displacement and resettlement. Therefore, it is important to understand refugee health status and outcomes within the context of their socio-political environments. A grounded theory approach as such, not only helped us to understand women's experiences, but it also allowed us to study

how care is both provided and received. Through this, we were able to develop a process model that provided a comprehensive cycle of patient-provider interaction throughout the care process.

In terms of methodological strategy, the study's analysis remained consistent with other qualitative data analysis strategies such as memoing and coding (both open and core coding). A qualitative analysis software Qurikos was used to develop and organize the memos and analyze them within and across-data coding. Constant comparative analysis through memoing and open coding were central to the analysis in order to allow true interpretations of data findings.

Researcher Positionality

As a bicultural researcher, it was important that I considered my positionality in this study. Reflexivity as a part of my prior ethnographic research was crucial to understanding the research process while in the field to be able to appropriately interpret the data. This is because all aspects of my interaction with the population had a contextual impact that were culturally influenced, and my interpretations of the data had to be devised using a cultural lens. Furthermore, I share the commonality of language and gender with these women, and as such, while in the 'field', the women's perception of my relationship with them is approached through multiple dynamics as a fellow member of the 'community', a cultural 'daughter', and as a potential resource to their community due to my affiliation with the university and the greater community of Greensboro. An in-depth reflection of this work can be found in my recent publication (Denzongpa et al., 2020). Thus, in addition to my insider/outsider role, I also had to consciously reflect on my interactions with the women with respect to these cultural roles throughout the analysis process. Based on these experiences, the consideration for reflexivity became more crucial for the constructive grounded theory analysis (Mills, Bonner, & Francis, 2006) to be able to accurately construct culturally relevant interpretations of the data.

Research Setting

As of 2007, the US accepted the largest Bhutanese refugee population of 84,819 refugees. North Carolina is one of the top 10 states that resettled Bhutanese refugees in 2011. As of 2011, the Triad area of NC had resettled over 1600 Bhutanese refugees (cdc, 2011). Guilford County has a considerable population of Bhutanese refugees concentrated in Greensboro and High Point. Initially, this study was focused to take place within Guilford County in North Carolina mainly around High Point and Greensboro. However, due to data recruitment difficulties, the scope of recruitment was expanded to Forsyth County and Virginia. Study utilized previously collected CBPR approached ethnographic data as well as primary data collection.

Secondary data

A community based participatory research (CBPR) focused ethnographic approach was utilized to understand ethnic Nepali-speaking Bhutanese women's. Participant observation data and semi-structured interviews were collected between Fall 2017-Fall 2018. Data consists of a total of 58 participant observation documents collected between Fall 2017-Fall 2018. Additionally, there are 12 semi-structured interviews inquiring about Bhutanese refugee women's maternal care experience collected between Summer 2017-Fall 2018. The interviews inquired about women's maternity experiences in the displacement camps in Nepal and in the US post resettlement. Data also consists of information on the social environment in the camps, and the camp's healthcare structure, women's access to the healthcare resources, and the quality of healthcare women received in the camp as well as US clinics.

An apartment complex that predominantly houses refugee populations served as the 'field' for the ethnographic process. The study was pursued in collaboration with the community's 'women's group'. The women's group consisted of 4-5 Bhutanese refugee women

who initially joined the citizenship tutoring sessions led by Andrew Young, a research fellow at the Center for New North Carolinians (CNNC). The women shared a common interest in improving the community's health which inspired them to officially form a non-profit group under the guidance of Andrew Young. All community events led by the women are operated through the GH community center. The community center at GH is operated by CNNC and organizes several after school programs and activities for both adults and kids residing at the apartment complex. Thus, all community events have to be approved by the CNNC.

I was introduced to the women and the GH apartment complex in Summer of 2017 by Andrew who discussed the women's interests in understanding their community health issues and potential ways in which their community capacity could be extended. In Fall of 2017, the team pursued a CBPR project focusing on ethnic Nepali-speaking Bhutanese refugee women's maternal health in partnership with the women's group, the Bhutanese American Association of the Triad, and UNCG. During the ethnographic phase, I met with the women every Friday during the women's group meetings and spent about 1-2 hours in the community interacting with the women (mostly) and their family members. Thus, participant observation notes were collected during women's group meetings, interactions with the community, driving the women to and from their clinic appointments, and during community events. The documents also include informal conversations with the women about their maternal experiences. Interview guide of the study can be found under Appendix A

Primary data

New data was collected through semi-structured interviews among Bhutanese women and healthcare providers who have ever served refugee women. All these women resided in in the High Point area. I worked with Dev Bhandari who is the community liaison for Bhutanese

refugees in the High Point area and collaborates with university researchers to pursue various health research among the population. Thus, all recruitment related work with Bhutanese women were conducted in consultation with Dev.

These interviews focused on Bhutanese women's navigation in the US healthcare systems, their interactions with the healthcare providers, their understanding, attitudes, and practices of maternal care. All interviews with the women were conducted virtually via phone call. No interpreters were needed for the interviews since I spoke the community's native language, Nepali.

The inclusion of healthcare professionals in the data sample provided a broader perspective on the healthcare interaction between providers and refugee women. It allowed the study to gain insight on the structure of the US healthcare system and the ways in which care is provided to refugee women who may have varying needs compared to native born women. The healthcare professionals were able to provide a different perspective on the challenges and needs associated with providing adequate care to refugee women. Since provider care does not focus on one specific population, their perspectives and experiences were shared across various refugee groups.

Sample/Participants

Throughout the course of the study, interviews took place with the Bhutanese refugee women, and healthcare professionals such as OB/GYNs and midwives who have ever provided prenatal care to refugee women. All Bhutanese refugee women who had recently given birth or were pregnant at the time of data collection were considered for participation. Similarly, all healthcare professionals who have ever provided care to refugee women or women of refugee origin were considered. There was no matching of women with providers in order to expand the

pool of participants. Inclusion criteria for women included refugee women of ethnic Nepali origin who entered the US as a Bhutanese refugee and are at least 18 years of age. Therefore, ethnic-Nepali speaking Bhutanese women of refugee origin were included in the study (some of whom may have already become naturalized as US citizens). The study utilized a combination of convenience sample and snowball sampling to recruit both women and healthcare professionals. Inclusion criteria for healthcare professionals included those who have ever provided care or were providing care at the time of data collection to women of refugee origin. Providers were recruited through voluntary sampling using their work email and snowball sampling. An overview of the study was described in the email and voluntary participation was requested. This excerpt can be found in Appendix B.

Due to the nature of the grounded theory approach, data analysis co-occurred with data collection, and as such, there was a need to adjust the sampling frame based on the preliminary findings. These included medical interpreters and resettlement officials who significantly contributed towards the care giving process.

Data Collection & Instrumentation

Data consisted of secondary ethnographic data and key-informant semi-structured interviews from women in addition to new data collected among women and health care professionals.

Interview data collection procedures with Bhutanese refugee women

Primary interview data was collected among Bhutanese refugee women through semi-structured interviews in Spring of 2021. All interviews with women were conducted in their native language Nepali and no interpreter was used. Phone interviews took between 45 minutes to an hour. All interviews were recorded using an audio tape specifically assigned for interview

audio recording. All interview recordings were taped in a single audio recorder. Verbal consents were taken from all participants. Interviews were transcribed verbatim and translated into English for analysis. At the end of the interview, participants were asked if they can be contacted for follow-up interviews if needed. However, all the women were non-responsive after the first interview. All women participants were compensated with a gift card worth \$25 for completing the interview. I applied and got approved for the Thesis/Dissertation fund at the UNCG graduate school association at the beginning of Spring semester 2021. Upon consent, participants were asked about their experience with the US healthcare system during their prenatal care process. The interview guide (in Appendix C) consisted of grand tour questions that asked the women to talk through their experience during a prenatal visit with potential probes. Specific questions around their interactions with the provider, the way they navigate the clinic and clinic officials, and their childbirth experiences were also asked. Based on their responses, participants were probed with follow-up questions as appropriate. Probes included further elaboration of their response, clarification of certain responses, and asking for more details with their responses.

Interview data collection procedures with healthcare professionals

Semi-structured interviews were conducted among n=11 providers who have ever provided service to refugee women. Verbal informed consent was obtained from all the providers at the beginning of the interview. All interviews were audio-recorded upon consent and each interview lasted between 45minutes to an hour. All interviews with healthcare practitioners were conducted via Zoom, and the interviews with interpreters and resettlement official were conducted via phone call. Providers were not compensated for their time and had the option to stop the interview at any point in time. The interview questions (Appendix D) inquired about their experience when providing care to refugee women, their interactions with the women, and

their understanding and perceptions of the women, and the women's healthcare practices. Questions were probed as appropriate.

Data management

All electronic data were password protected. All participants were given pseudonyms upon enrollment in the study to ensure privacy. All audio recordings were uploaded to a password protected computer and deleted from the recorder immediately after transfer to the computer. Deidentified translated interviews will be uploaded to the qualitative software Qurikos for analysis.

Data Analysis

An inductive constant comparative analysis is critical to grounded theory (Mills, Bonner, & Francis, 2006). The initial process of this data comparison occurred within the data and across the data. I utilized memoing as a strategy for this data to data comparison. Memoing is central to the process of investigating a phenomenon in qualitative research because they provide a mechanism for articulating assumptions and providing perspectives in a subjective form (Birks et al., 2008) while staying true to the data. As such, memos extract meanings from the data because it enables the researcher to understand what is really happening in the data. Vertical and horizontal memos were developed for all interviews. A vertical memo is developed using a single interview while a horizontal memo is developed by comparing a set of vertical memos that discuss common topics and occurrences in the data (Maxwell, 2009). This process was similar for the observation notes. I then followed an open coding process using the memos and translated them into codes and categories. The open coding was done sequentially; two to three memos at a time (vertical first, and then horizontal). I then compared the codes as I worked through each set of 2-3 memo documents. Diagramming was an essential component of structuring and

visualizing codes that allows us meaningful interpretation of the data. After several rounds of open coding, I then created a core category (Mills et al., 2006) of emerging themes that helped me create constructs to develop the care interaction process model.

Another essential component of grounded theory analysis was the verification of data which alludes to co-construction of the analysis. As such, all preliminary data interpretations were verified with my dissertation chair and a methodological expert on qualitative analysis.

Secondary data

Participant observation notes (n=58) and interviews (n=12) were analyzed simultaneously with the primary data collection. Out of the 58 observation notes, 28 notes were selected as appropriate to the grounded theory study and used for further analysis. The rest were removed from the data pool. Preliminary analysis from this data allowed us to refine our interview questions. All interviews from the secondary data were manually transcribed and translated which were then uploaded to Qurikos for analysis. An open coding process was conducted as an earlier step since transcription is not needed for these data.

Primary data

Data transcription and translation began right after the first data was collected. Since all interviews with healthcare practitioners were conducted virtually in English, a transcription software OtterTi was used for the interview recording. The automated transcriptions were then manually verified for accuracy and consistency. With each completed translation, the documents were uploaded to Qurikos and memos were generated in congruence with continuing data collection. Emergent themes via memos and codes were developed as a part of this process.

Trustworthiness and Value

The concept of validity and reliability is assessed differently in qualitative research (Shenton, 2004). The epistemology of qualitative research embraces reflexivity of data that is not only grounded in theory, but also in practice (Morrow, 2005). Trustworthiness or rigor of qualitative research depends on the quality of the study with respect to data collection, interpretation, and findings (Connelly, 2016), and is often determined by the paradigmatic underpinnings of the discipline in which the study is conducted (Morrow, 2005). Concurrently, a researcher's reflexivity with data and research, and their paradigmatic approach to analyzing data is crucial in determining the 'validity' and 'reliability' of the data.

A constructivist grounded theory approach that allows co-construction of data findings contributes to the credibility in data analysis; equivalent to internal validity of a positivist paradigm. A decolonial focused lens that centralizes Bhutanese refugee women's maternal experience was useful in understanding other refugee populations with similar socio-political health histories, thereby, providing transferability which is considered as external validity in a positivist paradigm. In addition to the co-construction, a data audit trail was included where both the process and the raw data were shared my dissertation chair

My approach to qualitative research was grounded in a constructivist understanding of data, and my social positioning within the population of study and the field of research provides value to the area of study. I have spent a considerable amount of time with the community as a part of the CBPR approached ethnographic study which allowed me to gain trust and build meaningful relationships in the community. Continuation of my research praxis will further the relationship between the community and research. As such, opportunities to explore necessary

health areas in this community may be approached with adequate cultural appropriateness in the future.

Additionally, Guba and Lincoln (1994) state authenticity of data as a relevant intrinsic criterion to assess trustworthiness. Use of multiple methodologies such as CBPR, ethnography, constructivist grounded theory approach, and various data collection methods such as participant observation and key informant interviews assure authenticity of the study.

Delimitations

The study focused on Bhutanese refugee women's maternal health understandings, experiences, and practices post resettlement. The study focused on the healthcare structures in this US and how refugee women navigate and experience this healthcare system. All interactions and interviews with the women were conducted in the women's native language and the analysis considered cultural contexts and its influence in women's understandings and practices of maternal care. I had language and culture familiarity with the women which minimized misunderstandings and misinterpretations of data during transcription, translation, and interpretation.

Limitations

One of the significant limitations to this study included inability to observe the healthcare interactions of the women and the healthcare professional due to social distancing precaution in response to Covid-19. I also was not able to meet with the women in-person and build trusting relationship with them. I had to rely on the community liaison for all recruitment and as such, women were hesitant in sharing their maternal care experiences over the phone. I was also limited in my capacity to recruit healthcare practitioner. Reliance on virtual platforms of recruitment led to a lot of non-response from healthcare professionals. A common limitation with

qualitative research includes the sampling strategy that is not random. The study utilized a combination of convenience and snowball sampling. However, this sampling strategy assured trustworthiness among the participants to willingly share their perceptions and experiences around care giving and care receiving.

Timeline of the study

The study approximately took about a year to complete. It began in December 2020 and ended with a dissertation defense in December 2021

Data collection stage

The data collection stage began in Spring 2021 and took approximately six months to complete. Recruitment of participants remained a significant challenge due to restrictions in in-person interaction and reliance on virtual engagement.

Data Analysis Stage

Data analysis occurred simultaneously with data collection. All interviews were transcribed, translated, and uploaded into Quirkos software. All secondary ethnographic data were uploaded to the software.

Data Defense

Data defense to the committee occurred in August 2021 upon completion of data collection. Draft of dissertation began immediately upon end of data collection while analysis continued to occur simultaneously.

Ethical concerns

Research with refugee populations may invoke culture influenced conflicts, and procedural ethical issues (Tracy, 2010) was anticipated during certain stages of the research. Firstly, I had to acknowledge that the women would have limited exposure to research. Mikesell

and colleagues (2013) deem participants to be treated as autonomous agents who should be given sufficient information about the entire study process. Therefore, providing clarity and transparency to the women as well as the providers in terms of the data collection and dissemination process were of prime importance to the study. As a bicultural research associate with the community, I was offset some of the culturally associated ethical issues by contextualizing all interactions through a cultural lens. Relational ethics that was anticipated at the beginning of the research study was not applicable since all interactions with the women during primary data collection was virtual and restricted to interview.

Protection of human subjects

The study was submitted to UNCG's Institutional Review Board (IRB) and concerns were addressed prior to the commencement of the research study.

Potential risks

Minimal risk is associated with the study. Women sometimes sounded uncomfortable responding to certain questions so I would skip the question and move on to the next. I made sure to remind women they have the option to be selective of the questions they felt uncomfortable answering certain questions. They were reminded that the information they shared were confidential and that their identity would not be disclosed to anyone. In terms of data storage and management, all data were de-identified and stored electronically in password protected computer. I was the only one who had access to the participant pseudonym chart.

Potential benefits

There are many potential benefits of the study. As one of the first studies to examine Bhutanese refugee women's perspectives and experiences on maternal health, our study adds to the current body of literature on refugee maternal health. With the choice of methodology, the

study allowed Bhutanese refugee women to share their maternal stories and experiences of healthcare in the US. Additionally, the providers also gained opportunity to discuss their challenges and needs in serving various groups of refugee women. Findings from the study provides insights on the culturally appropriate ways to serve refugee women's health needs.

Strategies to protect participant rights

Protection of participants and their rights were of prime importance to the study. Anonymity of their identities were prioritized. All participants were provided with a unique ID and no one other than me had access to the chart that associated the participant with the ID. Verbal consent were read to the participants in detail and participants had the opportunity to ask for any clarification prior to the start of the interview.

Summary

This constructivist grounded theory study aimed to gain a deeper understanding of how refugee women navigate, understand, and experience the US healthcare services throughout maternity, childbirth, and postpartum. With additional insights from the providers' perspective, the study developed an in-depth understanding of the care interaction processes through which refugee women receive perinatal care services in the US post resettlement. Findings from the study addressed culturally responsive ways to provide adequate care to refugee women, and also highlighted the gaps associated with challenges that providers experience when providing care to the refugee women.

CHAPTER IV: EXPLORING PERINATAL CARE CONTINUITY AMONG RESETTLED

REFUGEE WOMEN IN THE US

Abstract

The purpose of this grounded theory study was to examine factors within the interactive process of care giving and care receiving experience between refugee women and providers. Study explored perinatal care interactions between resettled refugee women and providers to understand ways in which refugee women experience care and the provider's approach to care giving. Data consists of semi-structured interviews with Bhutanese refugee women (n=15) exploring their understanding and experiences of maternal care during displacement and in the US post-resettlement. Data also consists of providers (n=11) examining their perspectives and experiences providing care to refugee women. Continuity of care was recognized as an important construct within the care interaction model. Findings explore three major factors impacting perinatal care continuity. These factors discuss the importance of refugee women's care ownership within the structural models of care, influence of pre-resettlement cultural care experiences of care, and care initiation and care compliance as complex interconnections of structural and cultural challenges unique to refugee experience. Implications of study highlight the need to restructure and redirect the ways in which research and medical systems perceive patient's (in)abilities to maintain compliance.

Key words: perinatal care, care continuity, refugee practitioners, refugee women

Introduction

In recent years, the need to improve maternal care access and quality of care has been well documented in research. Care continuity particularly during pregnancy and labor has been examined as an important component towards quality of maternal care. Traditionally, care continuity referred to individual patient care and the promotion of appropriately directed care (Kerber et al., 2007). Over the years, this concept has been integrated into the perinatal care process because researchers argue that continuity of care for maternal health ensures that women receive essential services during pregnancy, delivery, and the postpartum period (Singh et al., 2016). However, there has not been much emphasis on the postpartum period. This is because care particularly during prenatal and labor is considered most crucial due to the vulnerability of infant health (Rylander et al., 2013). Continuity of perinatal care has been associated with improved outcomes for women when compared with fragmented care (Cummins et al., 2019). Specific components that assess care continuity are reported as care given in the same facility throughout pregnancy and labor (Liu et al., 2012), consistency of caregivers throughout the perinatal course (Green et al., 1999), and access to reproductive health choices and care during pregnancy and childbirth (Kerber et al., 2007). Consequently, care received in different facilities, with multiple caregivers, and limitations in access and use of reproductive health choices throughout perinatal care are recognized as fragmented care. Our study explored these components as it relates to refugee women.

Research on refugee women is sparse, and the field of maternal health research in Global North countries continues to under-represent refugee women's maternal health practices, access to care, and the quality-of-care women receive from the resettled healthcare system (Jassens et al., 2006). Majority of the refugee populations are displaced in Global South countries for a

significant amount of time until they are resettled in Global North countries (Malebranche et al., 2019). Therefore, their understanding of healthcare post-resettlement is shaped by their environments during displacement and pre-resettlement. In most Global South countries, primary health centers (PHCs) or community health centers (CHC) are the most commonly accessible medical care centers (Rao & Sheffel, 2018). These centers seldom have medical doctors and are mostly facilitated by nurses, residency students, or general physicians. As such, refugee women's experience with advanced medicalization of care like the US healthcare system is non-existent. Thus, their navigation in the resettled Global North country is further complicated by their unfamiliarity of the advanced medical systems.

Understanding the context in which refugee women navigate the US healthcare system and receive care from their providers is essential in examining factors that add to the continuity of care engagement and contribute to refugee women's maternal health experience. To do this, it is important to explore the care engagement processes that occurs pre-resettlement which in turn, influences their care experiences post-resettlement. Additionally, exploring provider perspective within the spectrum of refugee women's healthcare experience adds important insight to the health interactions between the women and providers, and well as the structural challenges and barriers to care giving. Therefore, the purpose of this study was to examine patient-provider experiences and identify care continuity across the care interaction process as a critical construct.

Methods

Study design

The study was approached using a constructivist grounded theory framework to examine the overall care interaction process between refugee women and providers. Grounded theory is an inductive, emergent method which allows researchers to not only conceptualize the data but

also to construct theoretical interpretations unique to the data (Charmaz & Belgrave, 2019). This approach to qualitative methodology is especially important when we do not have much information about the area of study. In this instance, research on care interaction between refugee women and their providers is limited. Furthermore, the concept of care continuity specific to refugee women has not yet been examined. A grounded theory approach as such, not only helped us understand refugee women's experiences, but it also allowed us to study how care was both provided and received. We were then able to develop a comprehensive understanding of care continuity from the perspectives of both the women and the providers.

Study setting and participants

Initially, study was proposed to take place within Guilford County in NC. However, a constructivist grounded theory approach allows for theoretical sampling since data collection and analysis occur simultaneously. Sampling strategies for providers were therefore, revised according to preliminary findings from the collected data. As such, the scope of study setting was expanded for provider recruitment which included Forsyth County and Virginia in addition to High Point and Greensboro. Previously collected ethnographic data of Bhutanese refugee women were collected primarily in Greensboro, NC- one of the largest refugee resettlement cities in the country. Additional semi-structured interviews with Bhutanese refugee women who resided in High Point were also collected. As such, our study includes previously collected semi-structured interviews of ethnic Nepali speaking Bhutanese refugee women prior to the COVID-19 pandemic (n=12), which were collected as a part of a larger ethnography focused Community Based Participatory Research (CBPR) study. Study also consists of semi-structured interviews with Bhutanese women pregnant during the pandemic (n=3), and various providers who ever provided care to refugee women (n=11). Providers include OB/GYNs (n=3), certified midwives

(n=2), family practitioner (n=1), medical interpreters (n=4), and a resettlement official. Our study focused on Bhutanese women's perspectives and experiences to care receiving. A brief overview on Bhutanese refugee women's health status is described below.

Bhutanese refugee women's health status in the US

There is little to no existing literature on Bhutanese refugee women's maternal health. Bhutanese refugees are ethnically Nepalese and spent a significant amount of time in the displacement camps in Nepal with restricted healthcare facilities. According to CDC (2014) health profile for Bhutanese women, most Bhutanese women had never received a mammogram or a Pap smear prior to arriving in the United States. Within the post-resettlement US environment, the most common health concerns among Bhutanese women include reproductive and gynecologic care (Maxym, 2010). As such, there is a need to explore Bhutanese refugee women's maternal care needs and maternal status post resettlement.

Data collection procedures

All interviews with the providers were conducted virtually. The study utilized a combination of convenience sample and snowball sampling to recruit both women and healthcare professionals. Practitioners were recruited from the Triad area of North Carolina as well as the University of Virginia through snowball sampling. Preliminary findings from the medical practitioners led for the need to interview interpreters and the resettlement official. Providers who ever cared for refugee women were included in the study. Since providers do not focus on only one refugee population, their responses include perspectives and experiences with various ethnic refugee groups. They shared their experiences providing care to refugee women as well as the structure of healthcare systems within which the care interaction takes place.

Inclusion criteria for women included refugee women of ethnic Nepali origin who entered the US as a Bhutanese refugee and are at least 18 years of age. Therefore, ethnic-Nepali speaking Bhutanese women of refugee origin were included in the study (some of whom may have already gained naturalized US citizenship). The first author is fluent in the population's native language and therefore, was able to directly communicate with the women without the help of an interpreter. The interviews with Bhutanese women inquired about their maternity experiences in the displacement camps in Nepal and in the US post resettlement. Data also consists of information on the social environment in the camps, and the camp's healthcare structure, women's access to the healthcare resources, and the quality of healthcare women received in the camp as well as US clinics. Complications in data collection during COVID19 resulted in recruitment challenges particularly with Bhutanese women since the population values direct engagement and are less likely to engage in a virtual platform.

Data Analysis

Interviews with women were conducted in their native language Nepali which were manually transcribed and translated by the first author. Transcription software Otter.ai was used for transcribing provider interviews which were conducted in English. These automated transcriptions were manually proof-read by the first author for accuracy. Data transcription and translation began right after the first data was collected. All transcripts were then uploaded to Quirkos for memoing and open coding in congruence with continuing data collection. Emergent themes via memos and codes were developed as a part of this process.

An inductive constant comparative analysis is critical to grounded theory (Mills, Bonner, & Francis, 2006). The initial process of this data comparison occurred within the data and across the data through the development of memos. Memoing is central to the process of investigating a

phenomenon in qualitative research because they provide a mechanism for articulating assumptions and providing perspectives in a subjective form (Birks et al., 2008) while staying true to the data. As such, memos extract meanings from the data because it enables the researcher to understand what is really happening in the data. After completion of open coding, core categories (Mills et al., 2006) of emerging themes were created as constructs of the care interaction model. Multiple iterations of this model were developed which led to the exploration of care continuity as an important construct within the care interaction model.

Findings

Thematic findings in this study were grounded in the experiences of Bhutanese refugee women and various providers. The importance of continuity in care was highlighted as pivotal to understanding the care interaction process between refugee women and their providers. Consequently, challenges that impacted the care continuity process were interpreted through three major factors that were categorized as post-resettlement structural factors, pre-resettlement cultural factors, and conflicts between structural and cultural factors. Descriptive themes within each factor were further examined and interpreted.

Post-resettlement Structural factors

Participants in our study described structural challenges within the healthcare system post-resettlement that impacted refugee women's care continuity throughout their perinatal phase. They included the model of care practice, appointment system, and extended support as necessary to healthcare navigation and continued care.

Model of care

Practitioners described an overarching model of care in relation to healthcare delivery as a common model of practice in their health institution. This model of care is termed as the laborist

model of care which was adapted from the hospitalist model to emulate obstetric care. The hospitalist model is a system of care in which all primary care providers manage their own hospitalized patients or rotate this responsibility among themselves at infrequent intervals to voluntary or mandatory systems in which patients are handed off to the care of an inpatient physician, the hospitalist (Watcher, 1999). Similarly, the laborist model assumes responsibility of care for all obstetrical care during labor with the attempt to minimize the prevalence of planned c-sections and allow for ‘natural’ birth (Srinivas et al., 2016). Structurally, the model is set up in a way that women are seen by a different practitioner each time with the intention that women have met the practitioner attending their labor care at least once during their prenatal appointments. For refugee women, this structural model of care may have varying impacts. This is because most refugee women are dependent on government insured pregnancy Medicaid which provides them with limited options available for prenatal care. In our study, all Bhutanese women who gave birth in the US relied on government insured pregnancy Medicaid to access perinatal care. All the women reported to have been referred to the county’s public health department for all their prenatal appointments but were instructed to deliver at a hospital setting. Interpreters in our study shared the same situation for other refugee groups. Consequently, the obstetrical and labor care functioned as two different care units.

From the practitioner’s perspective, our study explored three different practitioner care approaches to refugee women’s perinatal care within the laborist model. They are: 1) an externally funded program for ethnically responsive residency centered low-risk care 2) holistic certified midwifery low-risk care, and 3) US standard OB care.

Specific county hospitals in NC have implemented programs that identify ethnically diverse physician practitioners who are able to care for refugee and immigrant patients they share ethnic

and lingual similarities with. These providers are mostly resident family practitioners who function as the main healthcare provider for refugee women. Although they provide culturally responsive care, refugee women lose care support from their providers once they ‘risk out of care’. Quote below is from an Arabic speaking family practitioner who shared her challenges in providing continued care to Arabic speaking refugee women.

‘If they (refugee women) needed referrals, (I try) to make sure they understand and some it is very difficult to really understand, because they (are) like, ‘okay well I'm going to lose you speaking Arabic’, but they're high risk that they need to be with the high risk so there's some challenge like, losing that ability to just speak with someone who can explain to them in their own language and their own culture’ .

NC practitioners also include certified midwives who are advanced practice providers trained to serve low risk underserved populations through a holistic approach. However, region-specific practice restrictions impacted their ability to provide continued care. Quote below describes this restriction.

‘North Carolina is really restrictive for midwifery care. In the state of North Carolina, midwives are considered advanced practice providers, and we have a supervisory relationship with a physician. In other states, including Utah, or just in Virginia, that is not true. You can be an independent provider, and if you did need an OB service, they've risked out of your care, or labor is not going well and you need physician intervention, then you have to refer them’ .

Finally, we have obstetricians and gynecologists who provide US standard prenatal and labor care at all risk levels. While they are clinically equipped to care for high-risk patients, the laborist model of care requires them to ‘relearn patient health history’ each time they see a new

patient which further contributed to disrupted perinatal care. For Bhutanese women, receiving care from different practitioners during each of their prenatal visits highlighted the risk of inadequate care assessment. Quote below is from a Bhutanese woman (pregnant at the time of interview) who shared her incident with the system of care visit that put her at risk for wrong care recommendations due to inaccurate measurement.

‘What I found out was... every appointment they give you a different doctor. So you don’t know which doctor is going to be there on your delivery date. If it was up to me, I would’ve liked the same doctor throughout the process. Because... see what happened is... last time I went to the doctor at 21 weeks... 21 weeks 4 days exactly... but when the doctor measured it, he only measured 21 weeks exactly. But that was not correct. And then I went at 26 weeks. I had another appointment. It was a different doctor again. That doctor measured me as 29 weeks out. When in fact I was 26 weeks. See... if I had the same doctor I could’ve asked, “why was it 21 weeks last time and now suddenly you’re saying 29 weeks” but I couldn’t...’

Appointment system

Refugee women’s experience with appointment system pre-resettlement was a major infrastructural challenge post-resettlement. Even after initiating prenatal care, continuing care throughout their pregnancy remained a challenge due to differences in pre- and post-resettlement healthcare infrastructure. The US healthcare system of appointment (re)scheduling and cancellations are unfamiliar systems for refugee populations. Interpreters in our study identified appointments as one of the biggest challenges to certain refugee women’s perinatal care continuity as described in the quote below.

‘After the visit to the doctor they give them the doctor summary, and in this document, they put the date of the next appointment. Because they don't know how to read, maybe the appointment was at 10am they come at 12, then they need to reschedule it again. Most of the language they don't read when they come for the next appointment. Sometimes they bring the appointment letter back and they give it back it to the doctor, I say no, this is just for you not to give to the doctor. They don't understand it is for them to keep’

However, Bhutanese women in our study shared this appointment system as a positive care experience compared to Nepal's refugee camp clinics where they waited in line all day to see a provider as described in the quote below.

‘Everything happens through scheduled appointments. Even when they keep us for a long time, they are still nice about it. Over there (Nepal camp) we wait all day. Sometimes the doctors aren't even there. Sometimes they never come’

The differences in how different refugee groups experience healthcare systems in the US varies. For Bhutanese women, they had a comparative care experience pre- and post-resettlement that made them appreciate a newer care system that was relatively ‘better’ than the previous one. However, Congolese women's lack of exposure to a medical visit system created challenges for continuity of care. As such, refugee women's healthcare experience post-resettlement is unique to their pre-resettlement experiences that should not be generalized across all refugee groups.

Extended support

In addition to healthcare practitioners, medical interpreters and resettlement agency's contribution within this structural practitioner dynamic is pivotal. Both impact the transition of care but experience structural limitations to care continuity. Interpreters are health communication bridges between healthcare practitioners and refugee women since most refugee

women do not speak English. However, practitioners shared challenges in accessing interpreters for certain languages, and the quality of interpreters that are accessible on video vs. in-person. Therefore, interpreter access and quality of interpretation impacted women's care continuity specific to care communication. Resettlement agencies on the other hand, set the foundation for refugee care initiation. They are the first points of contact for incoming refugee populations and responsible for helping them navigate the US healthcare system. However, care support from resettlement agencies is guaranteed only for a short period of time due to limitations in funding. As such, 'refugees lose continuity in care beyond the window of support'.

Pre-resettlement Cultural factors

Study findings show that refugee women's cultural understandings and experiences of healthcare pre-resettlement influenced their perceptions and approach to medical care post-resettlement. Specific experiences included spousal engagement and cultural influences to experiences with healthcare pre-resettlement.

Spousal Support

The importance of spousal engagement as a form of positive care experience was highlighted as an important cultural influence on women's care continuity. The forms of spousal engagement, however, may be unique to each ethnic group. Quote below describes a cultural nuance that indicated support but may be perceived as intrusive to western perception.

'A lot of American doctors (think), 'why is the spouse doing all the talking?', and then feel like are they trying to be overbearing on the wives? but that's not true. I know they're doing it, even though the woman understands English and she's nodding her head, she's not really understanding everything so he's explaining. And so that's the difference between me being from another country and understand why is doing all the talk.

Because a lot of times I've heard from other colleagues saying he's doing all the talking so that is a problem'.

A Bhutanese woman shared how spousal presence during labor and delivery in the US strengthened spousal support postpartum.

'Back in Nepal, they don't allow men to be there with their wives when they are giving birth. They remain outside (the birthing room). So they don't get to see what women go through during childbirth. Here, the husband has to accompany you throughout the process... So he got to see the extent of pain I had to endure to give birth... He saw it all you know... so seeing all of it... he says, 'I salute all women... All mothers'

Quote below was shared by a Congolese interpreter who suggested spousal engagement to help women navigate the healthcare system and ensure uninterrupted care.

'May be to the appointment I think that it will be good for both parents to go inside. I think that because one person can forget but if there are two, one can remember you know the one that the doctor said, they can complete each other'

Culturally influenced pre-resettlement healthcare perception

Refugee women's pregnancy experience post-resettlement was heavily dependent on the socio-cultural environment they were displaced from. Quote below was shared by the resettlement official who describes certain refugee women's pregnancy experience post-resettlement influenced by their unaddressed postpartum issues pre-resettlement.

'I see a lot with moms from the Middle East who may have come from Syria, or had come from a very conservative country like Pakistan or Afghanistan, and cultural beliefs they have about birth and babies, and trauma, specifically, because they have experienced trauma, in terms of war, terrorism... Those things are typically not discussed or talked

about, but then they come to the US, they go through this dramatic process, and the (trauma) all kind of comes out’

An interpreter provided a more specific incident that impacted her perception on post-resettlement care recommendation that was based on her pre-resettlement care experience.

‘(There was) one situation where she was very scared. She worried because in her home country, apparently the doctors had neglected her, and she said that she was in the same room with another woman giving birth. Only one decided to do an epidural. She was the one who had asked for it but they (doctors) gave it to the other, they neglected who they gave the epidural’.

Additionally, practitioners also recognized the unfamiliarity of refugee women in navigating the US healthcare system as reported by an Arabic speaking family practitioner by sharing that, ‘They definitely do not know how our system is so, I think it takes time for them to understand the system.’ Certified midwives acknowledged this challenge to healthcare navigation and proposed midwifery care as a culturally responsive care approach better equipped to care for refugee women described in the quote below.

‘There's just more of a holistic approach to midwifery care. I think some midwives may sort of self-select just knowing this is somebody that just really needs more holistic care. And, sometimes I think for all the different reasons it may be such that our midwives may see more refugee women, and speaking anecdotally, but it tends to be a very good fit because there's a little more of an inclination to kind of stop and explore and take one more time with the teaching and exploring, just kind of, social situation and things like that’

Conflicts between structural and cultural factors

Our study identified the need to understand cultural and pre-resettlement experiences of specific refugee groups because of the ways in which their conflict with structural systems of health differed significantly. The US healthcare system of prenatal care initiation and patient care compliance conflicted with the women's pre-resettlement cultural perceptions and practices.

Care initiation

Initiation of prenatal care is an important aspect of care continuity. Providers report pregnancy Medicaid, one of the most utilized prenatal care insurance programs among refugee women as an essential determinant of when women receive their first visit. Structurally, refugee women experience barriers to care initiation because of insurance dependent care. Quote below is from a practitioner who described this challenge.

'I will say, getting access to even pregnancy Medicaid can be really challenging. Often there can still be a language or literacy barrier for those women to apply for pregnancy Medicaid because the Medicaid process, incredibly confusing even from a health care like for health care providers because it changes so frequently'

Culturally, Bhutanese women tend to initiate care much earlier than other refugee groups as reported by a practitioner, 'Most of those (Bhutanese) women had planned pregnancies and present to care fairly early in their pregnancy' This may be because Bhutanese women are well connected to the US medical system and therefore, have a better structural support as shared by one of the women in the quote below.

'I had family plan Medicaid... I had made the appointment through my family plan Medicaid... but the doctor there told me he'll help me apply for pregnancy Medicaid...

‘Bring your pay stubs’, he said. So I took all my paystubs, and they helped me apply. It got approved’.

However, other refugee groups may not have established this structural support. The resettlement agency official shared that exposure to medical care pre resettlement varies across ethnic groups.

‘A lot of our central African clients really don't give birth in a hospital. They don't have access to the hospital. So they really did a lot of it on their own, with like a local community member, (or) doula. Some of our middle eastern women had the opportunity to give birth in a hospital, but they may not have been given all of the services that they needed in order to take care of themselves’

Interpreters in the study specifically shared cultural influences in care initiation. A Spanish speaking medical interpreter shared the quote below specific to a Spanish migrant who simply was not familiar with prenatal care due to their non-exposure to medical maternity care prior to arriving to the US.

‘(Pregnancy) maybe like five-six months, and the provider asks, ‘why did you wait so long?’ ‘I didn't really think I needed to come. I knew I was pregnant, but I don't see a problem with it’. And then sometimes they do wonder like, ‘do I still need follow up every week?’ They just didn't think it was necessary they just thought, if I wasn't feeling badly, then I don't need to go to the doctor’

Patient care ‘Compliance’

Processes of compliance or adherence to medical care recommendations are more complex for refugee women considering their cultural beliefs and pre-resettlement experiences

around medical health. Quote below was shared by one of the certified midwives who described her experience of patient care compliance across ethnic groups over time.

‘I've been learning ethnicity wise it seems there's such a difference in how refugee women are perceived as compliant versus non-compliant. Some populations are known to be extremely compliant because of how compromised their care was before coming to the US and so when they come here, they're like oh, everything is wonderful, so they're like, I'll do everything, but then some of them, their cultural beliefs are so strong that it sort of wins over some of the medical perceptions’

Other providers described compliance specific to whether certain recommendations were followed. An interesting example of non-verbal non-compliance is described below.

‘The refugees that I've worked with, they'll smile nod, and they'll say okay. We send the prescription to the pharmacy; they never get picked up or they never get started’

Specific to care continuity, compliance was considered in the extent to which refugee women attended their appointments as shared in the quote below.

‘They (refugee women) are typically pretty compliant about making their next appointment. The challenge comes into if they have to reschedule it and calling in on an English-speaking line and leaving a message if they can't get through to somebody, they have to leave a message that is not always clear to them. So that's where I think we get some no shows’

Practitioners who had a longer experience caring for refugee women recognized the structural barriers that disrupted women’s appointment visits which otherwise could be perceived as non-compliance. Although providers acknowledged the cultural influences and legitimate

barriers to women's 'non-compliance', they were limited by structural processes of healthcare documentation as shared by a practitioner in the quote below.

'I think being a provider and documentation is so important to prevent liability, and sadly, that's really what drives documentation. And when you'll see your medical records, the word non-compliant (shows up), and that can have a real negative connotation to it'

Discussion

The study aimed to examine factors that influence perinatal care interaction among refugee women within the US healthcare system. Findings suggest that women's care continuity is pivotal to adequate care interaction and is impacted by factors that are structural, cultural, and those embedded within the structural and cultural factors. While structural barriers in provider care giving impacted patient care ownership, refugee women's pre-resettlement cultural beliefs on healthcare practices contributed towards their care experience post-resettlement.

Who has ownership of refugee women's care?

The structural factors explored in this study hint to the issue of patient care ownership because women are seen by different practitioners throughout their prenatal visit, an important component of care continuity as reported in Kerber and colleagues' study (2007). This majorly impacted women's ability to receive continued care support from a specific provider.

Additionally, our study aligned with Liu and colleagues' (2012) assessment of care given in the same facility as an important aspect of care continuity. Bhutanese women and interpreters in our study reported separation of obstetric and labor care. As such, this required women to transfer their care between pregnancy to labor which was identified a major contributor towards fragmented care within the healthcare system. Professional OB/GYN practitioners who are equipped with the professional training to care for all risk groups, acknowledged and identified

the barriers to refugee care continuity but were limited in their resources. The process of re-learning women's health status and establishing relationships with them became complicated for practitioners when care was fragmented. Therefore, the adverse impacts of care disruption were experienced by both the women as well as their practitioners.

While certain programs helped connect refugees with ethnically familiar practitioners, they experienced challenges in maintaining care continuity once the women risked out of the practitioner's care. Structurally, the US medical system is limited in its access to culturally diverse maternal care practitioners (Rabo, 2011). As such, the programs that center ethnically responsive practitioner care also remains limited. In our study, the Arabic speaking practitioner was able to advocate for her patients but only until they had ownership of care for women who were low risk. Midwifery care perhaps, may be able to mitigate the lack of ethnic diversity through their holistic and bi-directional approach to care. Women's preferences for midwifery care is well documented in research (Perimann et al., 2018; Dove & Muir-Cochrane, 2014; Cummins et al., 2015). Certified midwives are formally trained in providing care to underserved populations and therefore, have a sense of cultural understanding when working with refugee women. Structural restrictions such as state laws pertaining to midwifery care capacities, however, limit their ability to providing continued care once women risk out of their care as well.

Specific to our study, extended support in the form of interpreter access, quality of interpretation, and access to resettlement resources also contribute to care continuity. Losing resource support from resettlement organizations and lack of good quality interpreters impact patient-provider communication which limits their ability to distinctly understand their choices in care recommendations.

Consensual informed decision making

Women's healthcare autonomy has been studied as one of the prime maternal health indicators (Vedam et al., 2019). This concept of autonomy, however, is a bit more complex among refugee women. The study findings explore the concept of collective consensual autonomy as it fit to refugee women's complex cultural and familial dynamic. For Bhutanese women, active involvement of their spouses throughout their care denoted women's ability to make informed consensual decision. For Congolese women, their familial involvement in care was perceived as a positive contributor towards their healthcare decisions. Similarly, for Arabic women, receiving care from a culturally familiar practitioner allowed them to be more accepting of medical procedures. As such, it is important that practitioners understand the cultural nuances of women's perception of healthcare autonomy. If autonomy is only perceived through a western lens of women making their decisions alone, practitioners may adversely impact refugee women's ability to make informed consensual decisions. We saw this in the example shared by a practitioner whose western colleague perceived an Indian immigrant woman's spousal engagement as intrusive and disruptive. Thus, cultural, and relational positionality in refugee women's care process collectively determine how they approach, and experience continued care post-resettlement.

How do we assess refugee patient 'compliance?'

Research heavily documents the importance of patient compliance or adherence and its impact on health outcomes and economic outcomes (Martin et al., 2005). Majority studies assess aspects of patient health behavior to measure compliance, and as such, medical systems are limited in their abilities to identify patient 'non-compliance' through those standard measures (Elkins et al., 2005). Refugee care is, however, complex, and multifaceted. Their access to care

and their understanding of US healthcare goes beyond individual health behavior and health literacy (Farley et al., 2012). Navigating the advanced culture of health systems in the US through their cultural lens in addition to their comparative poor care experience pre-resettlement and distrust with the providers majorly impact the extent to which refugee women follow ‘compliance’ (Hugo, 2002).

Our study findings explored this complex interconnection of culture and health continuum. Physical barriers of transportation and rigid work schedules, structural barriers of women’s inability to interpret appointment documents, cultural barriers of women’s unfamiliarity with the US medical system, and poor pre-resettlement healthcare structure impacted refugee women’s care continuity which are misinterpreted as non-compliance. Current literature documents refugee women identifying appointment system as positive care experience (Novick, 2009). However, findings in our study suggest that the experience of this system varies across ethnic groups and suggests its importance in care continuity. While Bhutanese refugee women benefited from appointment system due to their poor pre-resettlement clinic experience, refugee women from African countries experienced disrupted care because of their unfamiliarity with the medical system. CDC health profile reports 59% of Congolese refugees have no oral English skills, and more than 65% cannot read or write in English (CDC, 2021). As such, understanding and interpreting the appointment document remains a structural challenge for pre-literate Congolese refugee women. This further confirms the need to avoid aggregating refugee groups and assuming one group’s experience to be generalizable across all refugee groups.

Even when the practitioners acknowledged these structural and cultural barriers, they were bound by the structural system to document these instances as ‘non-compliance’. In the example of the Hispanic woman’s hesitance with using epidural, her ‘resistance’ stemmed from

her poor pre-resettlement experience that adversely impacted her relationship and trust with the medical practitioners. On the other hand, the practitioner's perspective on Bhutanese refugees being mostly compliant stems from this concept of 'passive obedient compliant' refugees (Muekne, 1983). This concept implies that refugees from South Asia generally view healthcare practitioners as authority figures who cannot be directly questioned or opposed. As such, they may be perceived either as very compliant or non-verbally non-compliant. Health care as a cultural context, therefore, is pivotal in approaching ethnically and culturally diverse patients.

Implications to research and practice

In this study, care initiation time and reasons of early vs. late care initiation depended on the structural challenges of receiving timely pregnancy Medicaid as well as women's cultural understanding of medical care that impacts their use of US healthcare system. As such, initiation of healthcare information and navigation pre-conception through community assistance doula programs and group reproductive care simulations in the community may help them receive timely pregnancy Medicaid and may also encourage women to initiate early prenatal care. Another significant restriction to refugee care continuity involved the financial limitations of refugee resettlement programs, and access to interpreters and quality of interpretation. Extending these support systems improve continuity of support in terms of communication and health resources.

Lastly, research and medical practice may also need to reconsider and deconstruct what we really mean by compliance especially as it applies to refugee patients, and possibly other ethnically minoritized populations. If the healthcare system is moving towards equitable healthcare access (Oliver & Mossialos, 2004), perhaps removing the individual burden from patients, and instead restructuring the social determinants of health may result in better

healthcare use and care experience. Redirecting non-compliance as patient's challenges to care continuity allows the healthcare system to identify and target those challenges to help alleviate care continuity. It also positions care givers to remove the burden from individual health behavior, and rather address the structural and cultural challenges to patient care continuity.

The study warrants some limitations. One of the major limitations of the study include recruitment challenges due to COVID restrictions. Study only includes Bhutanese women's perceptions and experiences of care engagement in the US. Providers shared their experiences with various refugee groups which helped us contextualize other refugee women's experience within the care engagement process. Additionally, relying on third party recruitment for Bhutanese women and inability to connect with the community discouraged active participation. However, interviews conducted with Bhutanese women pre-covid provided adequate information on their healthcare experience. Providers in the study identified two major care clinics where majority of refugee women receive their prenatal appointments, but providers from these clinics were unresponsive to email requests for participation. Therefore, this study was not able to examine provider perspectives and experiences from the two sites. However, study included providers from Virginia who provided care to a diverse group of refugee women including Bhutanese refugees and shared their experience accordingly. Despite the limitations, study contributes towards one of the first to examine US provider care perspectives and experiences in the care interaction process. We provide insights on the importance of care continuity specific to refugee women's perinatal care experience.

CHAPTER V: HEALTH HISTORY TAKING: BARRIERS TO REFUGEE MATERNAL CARE HEALTHCARE DOCUMENTATION

Abstract

Patient health history is a vital healthcare documentation that assesses important risk factors during the care process. Maternal health history taking specifically requires extensive personal and family health history inquiry to ensure positive birth outcomes for both the mother and the child. Refugee women's health history taking may be more complex due to their pre-settlement health experiences which are poor and limited in documentation. Our study examines the important factors contributing towards refugee women's maternal health history taking. Study is a part of a larger grounded theory framework and utilizes ethnographic participation observations (n=28) of ethnic Nepali speaking Bhutanese refugee women and providers (n= 11) who care for refugee women in the US. Study findings highlight the need for cultural interpretation as a crucial need to understand refugee health history. Study also discusses a more nuanced understanding of refugee health literacy specific to refugee women's pre-settlement backgrounds and exposure to healthcare.

Key words: refugee health history, health literacy, refugee maternal care

Introduction

Refugee maternal health is an understudied global public health issue. Refugee women's disposition in the global world and their restricted access to healthcare in addition to their displaced cultural understandings and practices of health post-resettlement is complex (Mehta et al., 2018). Overall healthcare documentation on refugee health is sparse with little to no existing record of refugee women's displacement and pre-resettlement maternal health status. The complexity in health systems around the world compounded by inaccuracy in vital records because of inadequate health information systems (Firoz et al., 2013) adds to the complexity in refugee healthcare assessment.

Patient health history, a vital healthcare documentation, is an important risk factor (Yoon et al., 2004) that allows practitioners to provide early detection of morbidities, timely care intervention, and appropriate healthcare recommendations (William et al., 2005). Maternal health history specifically, requires extensive healthcare documentation that inquire about prior pregnancy experiences and any pre-existing conditions or family history of chronic health diseases, and maternal behaviors such as smoking, alcohol consumption, and dietary needs/restrictions. All the information that healthcare professionals obtain from the women are entirely self-reported and care measures are adapted according to the patient report. For refugee women, this health history taking becomes complicated. Barriers of language, lack of education and healthy literacy, and culturally unfamiliar health practices further complicates women's ability to share their health history. Without adequate understanding of patient health history, practitioners may be limited in their abilities to detect morbidities on time which could lead to adverse maternal health outcomes.

Adequate assessment of health history is crucial in ensuring women experience positive birth outcomes (Zolotor & Carlough, 2014). Factors such as maternal origin has been recognized as an important contributor to pregnancy outcomes (Gibson-Helm et al., 2014). Studies show that refugee women have varied risk factors that may be inherent or acquired and differ by maternal country of origin (Cripe et al., 2010) and acculturation (Fuentes-Afflick et al., 2014). Identification of maternal country of origin during health history taking therefore, may be important to contextualize patient health profile.

Pregnancy and pregnancy related events are intricately tied to the ways different societies define and practice culture (Sideris, 2003). Healthcare providers, therefore, may be unaware about certain cultural understanding, attitudes, and practices of refugee women that may significantly differ from the US healthcare. They may also be unaware about the women's complicated health accounts prior to resettlement which may be crucial to provide appropriate care respective to their health status needs. Thus, their approach to health history documentation may impact the ways in which they are able to care for refugee women during pregnancy and labor. As such, it is vital for research to explore the components of health history taking for refugee women that impact their care experience and care outcomes. Cultural differences pertaining to expectations of adequate prenatal care and hospital delivery may limit the ways in which refugee women engage with the US healthcare system (Small et al., 2014). Establishing effective communication during care initiation, therefore, becomes crucial in ensuring women are familiar with the care system. Current research has examined refugee dissatisfaction with healthcare to be based around issues of impaired communication, poor understanding of system logistics in receiving countries, and issues of care that are not culturally appropriate (Johnson et

al., 2005). Our study will explore these factors in relation to health history taking which is one of the major care processes during refugee women's care initiation visit.

Methods

Study design and data collection

This study is part of a larger grounded theory framework developed to examine refugee women's care continuum during the perinatal phase. This study focused on one of the major themes of the overall grounded theory model. Data for this study utilized ethnographic participation observation notes (n=28) of ethnic Nepali speaking Bhutanese refugee women as our sample population. Participant observation data was collected as a part of a larger community based participatory research (CBPR) during fall 2017-Spring 2018. Data consists of information on the social environment in the camps, their cultural understandings of health and maternity, and women's access to the healthcare resources during displacement.

We also utilized semi structured interviews with providers from the grounded theory study. Provider data included healthcare practitioners (n=6), medical interpreters (n=4), and a resettlement official (n=1). Provider interviews were collected in Spring 2021. Specific practitioners include gynecologists, a family care practitioner, and certified midwives. Preliminary findings from the medical practitioners led for the need to interview interpreters and the resettlement official. Providers shared their experiences providing care to refugee women as well as the structure of healthcare systems within which the care interaction takes place. Providers who have ever provided care to refugee women or women of refugee origin were considered for the study. The study utilized a combination of convenience sample and snowball sampling to recruit providers.

Analysis

Data were uploaded to the qualitative analysis software Quirkos for analysis. Data transcription began right after the first data was collected. All interviews were conducted virtually. Transcription software Otter.ai was used for transcribing provider interviews which were conducted in English. The first author manually proof-read the transcriptions for accuracy. All proof-read transcripts were then uploaded to Quirkos for memoing and open coding in congruence with continuing data collection. Data analyzed as a part of the larger grounded theory model utilized open coding and memoing. First step involved development of emergent themes as a part of this process. Next, a deeper analysis of each thematic finding in the grounded theory model led us to examining each of those themes as its own stand-alone topic for further analysis. Memos were then drafted specific to each topic to allow for a robust analysis. Memos as such, were central to the study analysis.

Ethical approval for the study was received from the authors' university. Verbal consents that were recorded prior to the interviews were received. Ethical recommendations were followed ensuring that participation is voluntary, all the information remains confidential, and participant identity is not disclosed.

Findings

Our study examined health history taking as an important factor towards refugee women's prenatal care giving and care receiving experience. Five major thematic areas identified around health history taking were pre-resettlement health documentation, cultural understanding in storytelling, cultural understanding in communication, visit time, and refugee identity documentation.

Pre-resettlement health documentation

Our study findings showed that most refugee women do not possess any documentation of their pre-resettlement health experiences. A practitioner confirmed this by sharing that ‘a refugee patient is not going to have access to any formal records anywhere. And then we're just going off of them giving you their verbal history. Somebody may say they don't have significant history (but) that doesn't mean it's not there. That might mean they just don't know what to report to you’.

This lack of health history prior to resettling in the US is recognized due to the poor healthcare systems available to refugee women during displacement. In instances where refugees do have some documentation, they are usually ‘limited to immunizations and vague information’. Quote below was shared by a practitioner who described their experience reviewing a refugee woman's pre-resettlement health history.

‘I don't think whoever is doing the physical (exam) outside the country is really digging deep to ask about family history or personal history. So, I gather a lot of information myself when I do history taking’.

As such, practitioners are required to take extensive health history information to adequately assess their health status. Quote below is from a practitioner who described how missing crucial health information almost led to a refugee woman's death postpartum.

‘This woman that I took care of had severe valve disease and almost died a few days postpartum. I had not cared for her during her prenatal visits, and she had gone to a private practice that I don't think it's on their radar as much the kind of infectious diseases women from some countries might have been exposed to and then, some refugee women are from countries where they might have just a very minimal healthcare’.

Since there are no adequate health information of refugee women prior to their resettlement, practitioners shared that they must accept and interpret refugee women's verbal recollection of their health as the truth. A practitioner expressed this by saying that 'you have to really believe what they say even though the evidence from history taking exam is not showing any risk'. However, refugee woman may not always be able to recollect their health accounts which becomes a challenge in proper healthcare documentation. The resettlement official shared in the quote below how they navigated health information during such instance.

'It is really hard for us to assess (health status) because they themselves don't always know when or remember when some of their health issues started. So sometimes we like, make an assumption based on the little information they provide but very well may have been based on their pregnancy'

A possible practice of navigating individual specific non-existent health information as shared by a practitioner in our study was to examine refugee women's pre-resettlement status: 'To provide proper care, you really have to know where they were born, where they lived, and where their camp was'. This is because although refugee women may have severe health issues that are not reported in their health history, some of their health risks may be unique to their country of displacement. As such, reviewing the overall health status in the women's country of origin and displacement 'through CDC and UNHCR websites' may provide providers with foundational information on the population which could allow practitioners to ask appropriate questions.

Furthermore, a certified midwife suggested contextualizing women's verbal recollections to properly diagnose their health issue in the absence of health records. For example, she shared,

‘You know she might not tell me she has asthma, but she might tell me she often gets short of breath and coughs a lot. I might find something more in the review of systems than in the actual health history. I try to be more focused on physical exam.’

Cultural understanding in Storytelling

Since refugee women lack documentation of their pre-resettlement health histories and providers mostly rely on their verbal recollection, our study explored women’s storytelling as an important practice of how they explained their healthcare pre-resettlement. Interpreters of refugee women shared how women were unable to provide a ‘direct’ response to the doctor’s questions but would try to explain why they may be experiencing a certain health issue. Quote below provides an example of this instance.

‘When the doctor asks if they have pain because they stand a lot or? But the woman will try to start with, ‘at the camp, we sleep on the floor, we do this...’ we must say to them that the doctor wants to know about your health. Sometimes I try to bring it back to health, but it is not easy’.

Even a question as simple as whether it’s the woman’s first pregnancy was explained through the context of their life in the camps as, ‘okay when I was in the refugee camp, maybe I had a pain in my leg... that started when I was in refugee camp’.

Women’s cultural beliefs and practices during displacement played an essential role in the ways refugee women understood, practiced, and prioritized healthcare. Specific to storytelling as mentioned above, women also incorporated their pre-resettlement experiences and cultural practices into their storytelling. For example, Bhutanese women referred to the placenta as the ‘baby’s friend’ and their birthing experience was explained through their cultural practices of farming. As such, when asked about their birthing experience in the camp, Bhutanese women

would begin their storytelling by explaining their role in the farm field, how they worked in the field until the day of labor, how they birthed their baby by themselves in the middle of the field and would cut off the ‘friend’ with their field knife, and how they wrapped their newborn with the shawl used for covering their head from the sun during farming. Without a cultural understanding of women’s experiences, practitioners in the US may not be able to understand women’s use of cultural terms to explain their maternity experience.

Additionally, refugee women’s prioritization of certain health issues was based on their pre-resettlement health environment. A midwife shared her experience when she attended a Congolese refugee women’s group healthcare simulation. She found that in terms of prioritizing health issues, they perceived diarrhea to be more severe than a foot infection. The cultural understanding being that diarrhea has adverse health outcomes which can lead to death due to lack of access to clean drinking water and high rates of malaria in the woman’s home country. A foot infection, however, is something that heals overtime despite infections that could lead to foot amputation at the most but would not lead to death. The midwife discovered this cultural prioritization of health issues among Congolese women by attending a community workshop that was beyond the scope of her ‘medical duty’.

Cultural Understanding in communication

One of the most common challenges to communication for adequate history taking were barriers of language. Verbal communication is an essential component of patient-provider communication. Differences in language nativity between the women and their providers challenged the providers in effectively understanding women’s health experience. Interpreters, therefore, become key to bridging communication between the women and providers. One of the practitioner states, ‘Language is a barrier that masks emotional connection’. Communication via

interpreters restricts practitioners from connecting directly with the women, and as such, they find it difficult to understand how women may be processing the information. Practitioners also shared their preference for in-person interpreters over video interpreters because they allow for a smoother information transfer, but practitioners identified limitations in access to in-person interpreters for a lot of ethnicities they serve. However, the role of interpretation was recognized to go beyond language translation. The need for cultural understanding was identified as crucial to appropriate communication. Quote below is from an interpreter who shared the importance of cultural understanding even when there is commonality in language.

‘It is nice for us interpreters to be able to understand the culture of the patient. There are differences in languages, words... When I started the profession, I’ve read on my own about different cultures and their beliefs, and their ways of thinking’

In fact, an interpreter shared a story where a doctor was disturbed by a refugee patient’s lack of eye contact. After observing both their body languages, the interpreter had to interject beyond verbal interpretation, and confront the doctor that the woman was displaying an act of respect by lowering her eye contact. She shared that, ‘the doctor appreciated that and understood the explanation, so the situation became better’. Practitioners have also recognized this complexity of culture within interpretation. A midwife describes that ‘there's a surprising amount that you can do ~~that you can do~~ without the language’. Cultural barriers, however, are more complex and require a more nuanced understanding of the woman’s pre-resettlement and cultural background. This is because there may be cultural conflicts among ethnic groups even when they share the same language. A practitioner reported such instance in the quote below.

‘I’ve learnt there are very significantly different dialects of Arabic... When the interpreter is from a different cultural group or sometimes one where there is conflict, we

realized that there was some, we never knew exactly what was going on, but we realized that this patient was just really clammed up with this particular interpreter, and we realized that her kind of ethnic subgroup group was in great conflict with the interpreter's'

Within the cultural lens of communication, practitioners were often faced with the challenge of effectively communicating with the women about why a certain procedure in the US is important. They themselves were often torn between how the US healthcare system functions versus their understanding of refugee women's cultural perception of maternal care. Quote below was shared by a midwife who struggled communicating to a refugee woman the potential scenarios of birthing.

'The culture here in the US is to induce, induce, induce... so I'm trying to explain to these women who have arrived to the hospital to not have their first baby (vaginally) and try to explain how different it is'

Cultural challenges to communication were experienced by practitioners as described in the quote below.

'We can have these really complicated conversations where they are explaining a health problem via interpreter through their lens of their culture, through the lens of somebody having low literacy, and here you are trying to piece together what it is that she's talking about, and you piece it together, and finally... oh, she was not filled with the spirit, she had a seizure'.

An Arabic speaking practitioner who provided care to Arabic speaking refugees, however, shared a different view on communicating with the women. She said, 'You (doctors) are not always the teacher. The patient is a teacher too. They can be your teachers in a situation

so just be open to it, and just listen, ask the question politely and listen'. The practitioner asserted the importance of listening to their patients rather than making assumptions about the patients which may have adverse impacts to their care process.

Visit time

Providers identified limited visit time as a major structural challenge to refugee women's health history taking. Limited visit time contributed towards rushed interactions and inadequate documentation of health information. According to the providers, 'a total of 20 minutes time is allotted for history taking'. While this may be barely sufficient for English speaking patients, providers argue that visit time should be extended for refugee care. This is because providers not only have to rely on third-party interpreters for communicating with the women, but interpreters also have an added responsibility of providing context and examples of medical terms to walk through the health questionnaire. This entire process takes twice as much time. There are instances where interpreters in our study felt doctors did not give them enough time to interpret, but the doctors themselves have a restricted time for the overall visit.

Refugee identity documentation

The need to document refugee origin identity were perceived differently by practitioners in our study. Some practitioner institutions had documented usefulness of documenting refugee origin identification by sharing that, 'We knew all of our refugees because we had a documentation system. It was actually for research to improve the quality of care'. Others, however, grappled with the ethical stance around 'stigmatizing' refugee identity because most attain residency or citizenship after resettlement, and as such, documenting their refugee identification meant creating a 'flag' on their health charts. Although stronger arguments for the usefulness of documenting refugee identification included, 'I do think there are benefits from

having a flag to give us a cue that this person may need some additional support, and there can be some exposure risks, different things related to parasites... going through the lens of this person as a refugee that they've had a different origin than what maybe we're natively used to or accustomed to is helpful'.

Discussion

The study aimed to examine refugee women's health history taking during their pregnancy and labor care as an important contributor towards refugee care giving and care receiving experience. Both the women and their providers were impacted by the extent to which refugee women's extensive health histories were (un)documented. Study findings explain the complexity in refugee health history taking due to their multiple displacement with little to no healthcare documentation of pre-resettlement care experiences, and culturally challenged health communication barriers in addition to restricted refugee care focused health systems.

Study findings show that refugee women rely on storytelling to explain their health history. Providers, therefore, have an added responsibility of contextualizing refugee women's healthcare experiences through women's storytelling instead of expecting direct responses to health questions. Rushing through women's stories may leave out important health information which was reflected in the example of a woman who suffered severe heart failure due to lack of adequate health history documentation. This aspect, however, seems to be structurally challenging since providers have limited interaction times. Limited time adversely impacts the entire care process where communication is restricted and rushed. Extending visit time as such, becomes crucial to providing adequate care to refugee women.

Refugee women's pre-resettlement health experience also seem to vary across ethnic groups dependent on their country of displacement. In our study, the arguments around

documentation of refugee origin identification during history taking highlight the sensitivity associated with refugee pre-resettlement exposure. For certain refugee groups, their identification is associated with allocation of relief aids pre-resettlement (Feldman, 2007). Post-resettlement, refugee populations' level of acculturation determines their perception around identification of their refugee origin (Vigod et al., 2017). As such, future research should examine this aspect of refugee origin identification and its impact on refugee health experience.

The thematic findings around cultural understanding and communication points to the lack of US health literacy among refugee women. Health literacy, generally, is a major issue across the US even within the native population (Mancuso, 2011). Low health literacy is expected for refugee populations (Riggs et al., 2016). In addition to language and socioeconomic barriers, they are also grappling between two different cultures of health pre- and post-resettlement. Prior studies report refugee women expressing their inability to carry out their own cultural practices around the time of childbirth, as negative aspects of their interaction with Western medical practice (Kentoffio et al., 2016). The concept of health literacy, therefore, could be understood as a bidirectional competency. Since refugee women's communication with the healthcare practitioners is mostly dependent on interpreters, the interpreters are required to display competence in cultural nuances within their language translations. This is because interpreters are chosen by languages spoken which does not always translate to their compatibility with the women's ethnicity specific culture. Providers on the other hand, must have the ability to identify, acknowledge and incorporate refugee women's cultural health perceptions and experiences during their history taking.

We suggest a concept of care co-partnership as a critical bridge between provider-patient interaction that can ensure efficient health communication for adequate health history taking. Co-

partnership of care goes beyond the more recognized ‘teach-back’ method of health communication. This method intends to ensure patients’ understanding of provider recommendation by asking them to repeat everything the doctor suggested (Tamura-Lis, 2013). There is an implication of knowledge hierarchy which may be certainly true for majority populations but may be a bit complex with refugee populations. Our study findings reveal that practitioners who care for refugee populations experience new knowledge discovery unique to each refugee group throughout the care process as shared in the example of the midwife attending a Congolese women’s group session beyond the scope of her work schedule. Specific to history taking, providers in fact, are consistently learning about refugee backgrounds. A co-partnership care approach utilizes practitioners’ competency of patient’s overall cultural backgrounds as the foundation of knowledge building but requires them to customize care recommendation to be patient specific. Refugee women, therefore, are more likely to understand, interpret, and accept US healthcare practices.

Concurrent to this concept, the need for cultural interpretation was recognized as an important aspect of effective health communication during history taking. Throughout this process of history taking, interpreters become the focal point of communication for both the women and the providers. Structurally, there appears to be a disparity in interpreter access and use. In-person interpreters although preferred to be efficient are limited in access across ethnic populations. Cultural interpretation can mitigate this issue of access when providers are able to understand nuances of health, wellness, and severity through the women’s cultural backgrounds. A foundation of education on refugee health backgrounds is necessary for providers to make sense of refugee women’s specific cultural practices during the care giving process. As mentioned by a practitioner, language then becomes secondary.

Limitations in our study should be acknowledged. Firstly, study was unable to include two main refugee serving clinic and health departments in North Carolina due to non-response. Findings in this study as such, could be missing important insights from the two centers. However, study includes perspectives from refugee serving clinic in Virginia and offered strong insights on refugee specific care. Only one refugee group was used for representing women's perspective. However, the women's perspectives offered a robust understanding of their pre-resettlement healthcare experiences that allowed us to identify and examine the importance of women's storytelling and their connections to healthcare navigation post-resettlement. These experiences were comparable to the interpreter and resettlement officials' description of other refugee groups.

Despite the limitations, our study contributes to the sparse literature on examining provider care giving experience to refugee women. We included a diverse group of providers such as interpreters, midwives, and resettlement official instead of simply assessing doctor (OB/GYN) perspectives. Therefore, our study provides important insights on refugee women's care receiving experience at different points of contact with each provider. Furthermore, broadening the description of providers (to be any service providers that contributed towards refugee women's care experience) allowed a robust analysis within the care continuum.

CHAPTER VI: EPILOGUE

Summary of Study Goals and Findings

The goal of this dissertation was to explore the care continuum of refugee women's maternal healthcare in the US post resettlement. This continuum of care was examined through the process of interaction between refugee women and their providers during women's perinatal care process i.e. pregnancy, childbirth, and postpartum. Examining the care interaction process allowed us to identify crucial factors that impacted women's experience of care receiving and provider's capacities of care giving throughout the perinatal phase. The care process was examined using a constructivist grounded theory model (Charmaz, 2017) through an inductive constant comparative analysis using semi-structured interviews with Bhutanese refugee women (n=15), field observation notes from a larger CBPR study (n=28), and semi-structured interviews with providers (n=11) such as healthcare practitioners (n=6), medical interpreters (n=4), and resettlement official (n=1). Grounded theory approach's theoretical sampling allowed us to broaden our understanding of providers that weren't limited to healthcare practitioners and provided us with robust perspectives on care interactions of women at different points of contact with each provider.

Research has well documented the poor maternal health outcomes of women in the US. Research has also reported poorer health outcomes for refugee women across the globe. However, there is not enough information on refugee women's maternal care status in the US post resettlement. Much of refugee women's post resettlement health experience and outcomes have been assessed in countries of Europe and Australia. Our study, therefore, contributes towards the sparse literature on US resettled refugee women's maternal care experience. We examine two major thematic findings in the grounded theory model that impacted refugee

women's care interaction process: care continuity and health history. These findings were grounded in the experiences of Bhutanese refugee women and various providers who shared their experiences giving care to refugee women of various ethnic and regional origin.

Factors contributing towards women's care continuity or the lack of determined the type of experience women received and the challenges providers experienced to care giving. They were divided into three categories: 1) post-resettlement structural factors that impacted both the women and their provider's ability to experience uninterrupted care in terms of the consistency in practitioner visit, appointment systems to be able to attend all care visits, extended support in the form of resettlement agency resources and interpreter access and quality. 2) pre-resettlement cultural factors included women's cultural beliefs and spousal support that influenced their attitudes and practices of healthcare post-resettlement. Finally, 3) conflicts between cultural and structural factors that were explained through the concepts of care initiation and patient care compliance.

The second thematic factor on health history taking discussed pre-resettlement health documentation, cultural understanding in storytelling, cultural understanding in communication, visit time, and refugee identity documentation. All these factors explain the journey of healthcare experience and documentation (or the lack of) that is crucial for adequate care assessment and recommendation. Refugee women often do not possess any health records prior to resettlement and experience cultural conflicts of explaining their health history. As such, providers are often challenged to explore culturally responsive strategies to care giving which is specific to each ethnic/regional affiliation of refugee women.

Between the two major thematic findings, below are the conclusions made from the study:

1. Patient-care ownership is a crucial aspect of care continuity that impacts women's healthcare experience
 - a. These include transfer of care from prenatal to labor phase, low risk to high-risk care
2. Cultural understanding and contextualization of refugee women's pre-resettlement cultural beliefs and healthcare experience is vital to post-resettlement care assessment and appropriate recommendation
 - a. Exploration of a co-partnership approach where health communication is bi-directional may help practitioners in better understanding refugee women's care needs
3. Deconstructing the assessment of patient compliance is key to a culturally responsive tool to approaching refugee women's care receiving and care giving experience
4. Addressing structural challenges to refugee women's care initiation

Implications for the Field and Future Direction

Findings from the study has implications for research as well as practice. From a practice perspective, healthcare practitioners can adapt co-partnership approaches to care giving with refugee women. Learning from refugee women's pre-resettlement healthcare experience will provide them with the adequate information to appropriate care for refugee women. Additionally, re-assessing health care system's understanding of the term patient compliance will be pivotal to addressing refugee women's care continuity challenges. Examining women's challenges to adequately following provider care recommendations and practitioners will contextualize the reasons for their perceived 'non-compliance'. A public health approach to examining healthcare

barriers specific to care compliance includes examining the social, environmental, and structural barriers to care continuity instead of documenting these challenges as non-compliance.

From a research perspective, care continuum as a framework for adequate maternal care to refugee women can be explored across various ethnic/regional groups where studies are grounded in their experiences. Study findings discuss the adverse impacts of aggregating refugee experiences. As such, future research needs to explore various refugee sub-groups' perinatal care experience in the US. Expanding the pool of providers to examine the care giving process will offer meaningful insight to the care interaction process. In fact, my research plan over the next 3 to 5 years will be to expand my understanding of the care interaction process within the framework of care continuum across different sub-groups of refugee women, include various types of providers with a higher level of engagement and participation of the healthcare system. My long term research goal includes program implementation and evaluation of reproductive and prenatal care education simulation in refugee communities, and measure the impact of education programs on women's abilities to early care initiation and healthcare navigation.

Personal Reflection

My journey in the doctoral program and throughout dissertation has been a process of personal growth and reflection of my place in the world. I was fortunate to have been guided by strong mentors like Dr. Nichols and Dr. Morrison who trusted me to lead my very own community based participatory research project at the beginning of my doctoral program. Being exposed to the study field early on in my doctoral studies was truly instrumental to my growth as an academic researcher. Through research, I was able to connect to the larger refugee community in Greensboro and for the first time in 6 years since I had moved to the United States, I was able to speak a language that connected me closer to home. The connections I built with the

Bhutanese community in Greensboro and High Point not only furthered my research agenda, but they also helped me feel closer to home. Ever since I graduated from college, I struggled with my evolving identity that was steadily assimilating to the US social structures. When the Bhutanese women would invite me to their homes and feed me foods that made me reminisce my memories of home, it motivated me to continue my journey in this program because I was able to empathize with the women's journeys of displacement and resettlement in a foreign country. As an immigrant, I voluntarily chose to move to this country, but as refugees, these women were forced to leave their country. If they were able to hold onto their cultural practices despite all the challenges that they experienced as displaced people, I felt that I should be able to do the same. For the first time in my life, I experienced a sense of privilege when interacting with the women. For immigrants and refugees, our idea of a home is extremely complex yet simple. As much as I missed home and my family back home, I was reminded that the choice and the feasibility for me to go back home will always be open. However, these women can only reminisce their memories of home, but will never be able to go back. This place of privilege although somewhat comforting for my own selfish reasons was also a reminder of how I can utilize it to bring forth my support for these communities. Refugees are one of the most vulnerable groups of people for whom their sense of home is only fragments of their memories from the past.

These experiences with the Bhutanese women sparked my interest in refugee research. Their disposition in the global world restricts them from experiencing an autonomous life. In this context, I perceive autonomy in terms of their access to healthcare, social and environmental surroundings, education, and a lifestyle that is unfamiliar and difficult to navigate. As a refugee focused researcher, I want to better understand how their communities experience health in their resettled countries. I plan to utilize the professional training, support, and guidance I have

received from my doctoral program to approach this research with consistent reflexivity of myself as well as the methodologies I utilize towards each project.

My entire journey in the doctorate program as a researcher as well as teacher has been challenging but worthwhile. While Dr. Nichols' critical thinking in research and writing expertise helped me become a better scholar, Dr. Morrison's mentorship towards my teaching motivated me to approach my teaching with passion and willingness to fail, face criticism, but not give up. I feel fortunate to have had them as my mentors, and I am truly thankful to them for believing in me and allowing me to grow into a young professional. These past five years in the program have been truly instrumental and I look forward to the future opportunities that will allow me to grow as a scholar and a teacher. I thank my entire dissertation committee for being so supportive, flexible, and transparent throughout this process. Dr. Echeverria and Dr. Ross are such dynamic scholars of color who have enriched the quality of my scholarship through their expert feedback and immense support. To the department of public health, I am grateful for all the professional experience in and outside of the classroom.

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APPENDIX A: ETHNOGRAPHIC INTERVIEW GUIDE OF SECONDARY DATA

Note: The questions below are general questions but won't be conducted in any specific order to accommodate a natural flow of conversation around pregnancy and care. The questions are subject to change/alteration depending on the interviewee responses but will remain within the context of the research. The interviews may also be conducted at different timepoints to prevent interviewee fatigue and to accommodate those with limited time to spare. This will ensure I receive ample information from the participants.

- Camp specific health questions
 - How was your daily life like in the camps? Or Tell me about your time in the camps?
 - Were there any health conditions that you encountered during your years in the camp?
 - If yes, tell me about the experience. What health condition did you suffer and what kind of care did you receive? Who provided the care?
 - What about medical professionals in the camps? How was that like?
 - What about women during pregnancy?
 - Do you have any experience witnessing pregnant mothers in the camp? How was it?
 - Do you recall if there were any professionals who helped these pregnant women? Tell me more about that
 - Do you have any experience with these professionals? Tell me *about the experience*

I am interested in knowing more about your health and the health of your family

b. Culture and family related health questions to all women

- Prior to coming to the United States, had you ever received any form of care from a gynaecologist (maternal/child health professional) or a midwife?
 - If yes, how often did you visit this professional?
 - If not, what were the reasons for not visiting a health professional?
- Have you sought any healthcare here in the United States? Any related to pregnancy care? Family planning?
- How would you describe the differences in health care here in the United States and back home (the camp or the other country you lived in)? Or When you think about health care in the camp or in Nepal, how is that different from the healthcare system here in the United States?

Now let's talk about your health and your family

- Could you describe who is responsible for looking after every family member's health in your household?
- What about your husband?
- (What role does your husband play in terms of your reproductive or pregnancy health?)
- What kind of support do you think he provides?
- Does he encourage you to visit a health professional such as a gynecologist or midwife or traditional birth attendant?

- What is an acceptable way to treat a wife?
- What happens if there's a disagreement about health decisions between you and your husband? You and your in laws?
- What is the proper way to treat a pregnant woman?
- What about your mother? How does she support you in your health? Who else has a role in your health? Father? Sister? Grandma?
 - Does your mother-in-law make any health decisions for you? In terms of carrying a child, or using contraceptives, or seeking/getting medical care?
 - Whose role is most important in your health? Why?
 - Is there something that you do that your family members would be afraid of your unborn child's
 - health?
 - Are there specific things that suggest you do to have a healthy child?
 - What does your husband do or say to protect your unborn child?
 - What does your mother-in law do or say to protect your unborn child?
 - What about your mother? Sister?
 - Who took care of your older child when you were pregnant with your younger one?
 - Now let's talk about family support:

- Who did the shopping and household chores when you were pregnant and initial months after giving birth?
- Who helps you if you are afraid of your health during pregnancy?
- Who helps with the finances, paying bills?
- How does your mother-in law feel about your health during pregnancy?
- Does your mother in law care about your emotions during pregnancy?
- What about your husband?
- How do you personally feel about seeking health care? And reproductive health care to be specific?

Now let's talk about your diet

- What was your diet like during pregnancy?
 - Who was in charge of your dietary decisions when you were pregnant?
 - How were those decisions made?

Now, let's talk about your child:

- Once your baby was born, did the support from your family members change?
 - In terms of providing care?
 - Did it shift from you to the child?
 - Or was equal care given to the both of you?
- How often did you visit the gynecologist during pregnancy? And who influenced this decision to go?

- c. How important is breastfeeding to you?
- d. Why do you think so?
- e. What are the certain things you do after your child is born?
- f. When you think of Nepal or Bhutan, how do mothers with young children take care of the child?
- g. Now, when you think about mothers in America, what is different?
- h. What is the same?
- i. What are certain things you've changed about child rearing after coming to the US?

Now in the U.S., when you came here or just even now,

- Do you get annual check ups from the gynecologist here in the united states?
- Have you ever received a mammogram or pap smear? If yes, how often? If no, what are the reasons for not getting one?
- Tell me about women's healthcare in your culture....
 - Can you tell me about some cultural beliefs for pregnant women in your culture?
 - Did anything change when your mother had you?
 - Can you recollect if your mother shared her experience of pregnancy with you? What was it like?
 - What are the things you did different from what your mother did?
 - What did they do different from what you're doing now?

- What are the things that are different here than how it was in the camps?
- Did you receive any external assistance (outside your home) for health care here in the United States?
 - If yes, how? From who?
- How important is a woman's health especially during pregnancy?
 - How important is this to you?
 - Tell me about your own experience with health as a pregnant woman?
- You stated earlier that you did not make your own health decisions. If possible, would you like to make your own health decisions?
 - If yes, how would you go about it?
 - If no, what do you feel are the benefits of having other people make health decisions for you?
- Overall, what would you recommend to other women from your community in terms of care and decision making in terms of pregnancy health?

Specific narrative version of the questionnaire:

Intro: We are interested in learning more about the support women receive for their health/pregnancy before coming to the US and in the US. We are interested in support from professionals and from family. I'd like to start with the support you received before you came to the US

Q1: Can you tell me a little bit about your health experiences in the camps/before coming to the US?

Transition: I'd like to ask you a few questions about your health experiences since you've come to this country.

Q2: Can you tell me about your experiences with health professionals here?

Transition: We've been talking a lot about health professionals but I am also interested in learning more about the support you've received from your family. I am particularly interested in your family's support during and after your pregnancy.

Q3: Can you tell me how your family supported/supports you during your pregnancy?

What support did you receive from your mother? your husband?

Who else in your family can you/could you go to for support?

What type of help do they give?

Transition/Q4: This is giving me a better understanding of family support during pregnancy, can you tell me about the ways your family supported you after you had the baby?

APPENDIX B. EXCERPT OF PROVIDER RECRUITMENT

My name is Kunga Denzongpa, a PhD candidate from the department of Public health at UNC Greensboro. I am reaching out to you with regards to my dissertation project examining pregnancy related maternity care processes of Bhutanese refugee women in Guilford county, NC. I am interested in learning about the process through which Bhutanese refugee women receive pregnancy and postpartum care in the US post resettlement. I would like to gain the perspectives of health professionals such as yourself who provide care to this population. My goal is to be able to develop a model that represents the care interaction process between the women and the providers. I will follow up with a phone call if you have ever provided care to Bhutanese refugee women or Bhutanese women of refugee origin and are interested in interviewing.

I am happy to discuss the details of my study with you via phone or zoom.

Thank you so much for your time.

Your participation in this will be instrumental towards my dissertation study.

I look forward to hearing from you.

Thank you.

Sincerely,

Kunga

APPENDIX C: BHUTANESE REFUGEE WOMEN PARTICIPANT INTERVIEW GUIDE

Purpose: The reason I would like to talk with you today is to understand your experiences

and interactions with healthcare professionals during your prenatal visits here in the US.

As a Bhutanese refugee who has experience navigating the healthcare system during a pregnancy, your insight is valuable to this project.

Confidentiality: There are no right or wrong answers. I just want to know what you've experienced. I will be tape-recording this discussion with your permission and I will be the only one who will have access to this recording. You will not be identified by name. Please answer questions as honestly as you can. You can choose not to answer any question and you may leave the study at any time. Thanks again for agreeing to participate in this discussion today. Do you have any questions before we begin?

Interview questions:

- Please walk me through how you secured your first prenatal visit?
 - How did you get the referral with this provider?
 - What was it like making the appointment? (depending on who made the appointment- themselves or someone else)
 - When and how did you first realize of your pregnancy?
 - When did you get your first prenatal care appointment?
 - How do/did you get to your appointments?
 - Who goes with you to your appointments?
 - What is it like when you first enter the clinic?
 - Can you walk me through your first clinic appointment?"

- Can you tell me how about your interactions with the clinic staff?
Receptionist/nurse?
- Tell me about the person who provided your care for your first visit.
 - How comfortable did you feel with this person?
 - How easy was it to talk to or communicate with this person?
 - How easy was it to understand the information being provided to you?
- What kind of relationship do you have with your provider?
 - How comfortable are you asking questions to the staff? To your doctor?
 - Do you ever use an interpreter? If so, when have you used one? Tell me about the process. What is it like communicating with your provider through an interpreter?
 - How easy is it for you to communicate with the doctor through an interpreter?
- How have the rest of your visits compared to that first one? What, if anything, has changed?
 - What are some of the challenges you experienced during your visit?
- What are some of the advantages of receiving care here in the US OR What aspects of the US care do you like?
- Can you tell me about any pre-resettlement care experience that may be similar or different than the care you received in the US?
- Can you share with me any concerns about receiving care or birthing in the hospital because of COVID?
 - How do you feel COVID precautions are being handled in the clinic?
- (For those who have given birth): Please walk me through the day you gave birth
 - How did your labor start?
 - What did you do once you realized you were in labor?

- When did you call your provider?
- When did you go to the hospital? What happened once you got to the hospital?
- How did the nurses care for you while you were in labor? What did they tell you?
- What about your midwife/doctor? How long were you in labor? What happened next?
- I want to know about what happens after childbirth. Could you please tell me how long you stayed in the hospital for?
 - Who provided you care?
 - What were you told about the recovery process?.
- For general: How does the care in US differ from Nepal? (maybe be probed at any point in the interview depending on the women's response)
 - What are some of the significant differences?

Overall maternity care questions:

- What do you prioritize in terms of maternity care?
 - What does a good quality of maternal care look like for you?
- What are the advantages of getting maternal care in the US?
- What are the disadvantages of getting maternal care in the US?
- What do you wish that US clinics had in terms of care?
 - What are some recommendations you would like to make?
 - Can you tell me anything about receiving care in the US that you would like me to know?

After the interview: "I'd like to thank you for your help today. Would it be ok if I contact you again in case I have additional questions and to make sure that I have understood everything you said today?"

APPENDIX D: HEALTHCARE PROFESSIONAL INTERVIEW GUIDE

Purpose: The reason I would like to talk with you today is to understand the healthcare interactions between Bhutanese refugee women and their healthcare providers. As a healthcare professional providing care service to Bhutanese refugee women, your contribution is valuable to this study.

Confidentiality: There are no right or wrong answers. I just want to know what you've experienced. I will be tape-recording this discussion with your permission and I am the only one who will have access to the recording. You will not be identified by name. Please answer questions as honestly as you can. You can choose not to answer any question and you may leave the study at any time. Thanks again for agreeing to participate in this discussion today. Do you have any questions before we begin?

I'd like to start with asking you a few questions general questions about your professional profile

- How long have you been in this career for?
- What made you want to be in this profession?
- If you were giving a quick overview of what it means to be a [their profession] to someone who knew nothing about it, what would you say?
 - How has Covid affected this?

Study specific questions

- How many women do you typically see in a day?
 - Can you tell me how the referral process works?
 - When was the first time you provided care to a Bhutanese refugee woman?
- Can you tell me about your experience providing care to Bhutanese refugee women?

- Can you elaborate on your communication experience with the women?
- How often are interpreters used during your interactions with Bhutanese women?
 - What are some of your observations when communicating with the women- with AND without an interpreter?
- Can you tell about the type of information provided to the women during their visit?
 - How well do you think they understand the information provided to them?
 - How often do they ask you questions related to their health?
 - Are there any common questions that Bhutanese women ask during their visit?
 - What are some of the common concerns among the women?
- What are some of the prevalent health issues you've observed with this population, if any?
- What are some major differences you have observed regarding your experience with providing care to refugee women vs. non-refugee women?
 - How, if at all, are your interactions with Bhutanese patients different?
 - What are some of the challenges associated with providing care to refugee women?
- Are there any experiences you have had with a Bhutanese refugee patient that sticks out in your mind?
 - Can you describe what it was like and why you remember it?
- What were some of the intriguing things you learned about the women during the visit?
- What are some potential areas for improving interactions between the women and providers?

- Any recommendations you may have in terms of care quality?

After the interview: “I’d like to thank you for your help today. Would it be ok if I contact you again in case I have additional questions and to make sure that I have understood everything you said today?”