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THE EXPERIENCE OF HEALTH CARE PROVIDERS WHO CARE FOR THE REFUGEE POPULATION

A Thesis Presented

by

Ashley P. MacDonald

to

The Faculty of the Graduate College

of

The University of Vermont

In Partial Fulfillment of the Requirements for the Degree of Master of Science Specializing in Nursing

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Defense Date: March 22, 2016 Thesis Examination Committee:

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Abstract

Refugees resettling in the United States face many challenges; especially within the health care setting. The purpose of this research was to add to the increasing body of knowledge about improving health care for the refugee population through investigating providers' lived experience caring for them. This study utilized qualitative research methods with a descriptive phenomenological approach. Five healthcare providers, one Nurse Practitioner, three Pediatricians and one Family Medicine Attending, were interviewed face to face through semi-structured interviews, utilizing twelve questions about their lived experience caring for the refugee population. The data from the five participants interviewed revealed three themes that described their experience: Facing Challenges; Experiencing Satisfaction; and Reframing the System. Although each provider found satisfaction within his or her current positions, there is a critical need for improved allocation of resources for housing, social support, and increased funding to help support refugee families that arrive in the United States.

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Chapter 1

Introduction

There are 263,662 refugees residing in the United States as of July 2014 (United Nations High Commissioner for Refugees [UNHCR], 2015). Many refugees arrive in the U.S. with unique health care needs including: chronic health care problems and/or neglected injuries, mental health problems including post-traumatic stress disorder (PTSD), and difficulties with language or finances. Identification of specific barriers and challenges refugees face has been found in previous research, however, there is limited research about the experience that providers have in caring for the refugee population.

Understanding the experience of delivering care to refugees from the perspective of providers is an important topic to explore due to the increasing number of refugees resettled in a state among a predominantly white population increasing in diversity. The number of refugees resettled in this state in fiscal year 2014 was 317; the majority of refugees were from Bhutan, Iraq, Burma and Somalia (Office of Refugee Resettlement, 2015). The demographics in this northeastern state continue to be predominantly white; however, with a majority of refugees and immigrants being resettled in the largest city in the state they, along with African Americans, Native Americans and Latino populations, are contributing to cultural changes and increasing diversity. The state has a refugee resettlement program that provides support for promoting self-sufficiency and acculturation upon resettlement. It has assisted over 6,000 refugees since inception. Providers practicing in this area have an opportunity to care for the unique needs of refugee and immigrant populations that are newly resettled.

The refugee population faces various challenges upon resettlement in the U.S., including lack of trust, potentially unmet basic health needs and language barriers, causing disconnect in communication between patient and provider. The goal of this research is to gain knowledge about the experience the provider has in caring for the refugee population with the hope of improving the quality of healthcare delivered.

Purpose and Significance

The primary objective of this qualitative research study was to examine the experience of providers who care for refugee patients. The qualitative research focused on providers who work with patients in a New England state. It is anticipated that the findings of this research, through in-depth interviews, will help to improve the care of refugees and immigrants by identifying specific issues contributing to health care quality and access. Previous qualitative research has examined perceived barriers refugees and immigrants encounter in health care, however, few studies have examined the experience of providers caring for this population. This research will add to the growing body of information related to caring for the refugee population and to identify factors related to refugee health from the provider perspective in order to ultimately improve the care provided. The qualitative research question for this research is: What is the provider experience delivering health care to the refugee population?

Obtaining a focused understanding of the health care provider experiences may help improve the care for the refugee population and facilitate future consideration to eliminate possible barriers and find solutions to challenges faced.

Implications for Advanced Practice Nursing

The National Organization of Nurse Practitioner Faculties (NONPF) outlines core competencies that must be met upon completion of a nurse practitioner degree, regardless of population focus (Thomas, et al., 2012). This research addressed the nurse practitioner competency of utilizing scientific foundation through critical analysis and translation of research with a goal of improving advanced nursing practice and patient care. This research required a thorough literature review and critical appraisal of current research about challenges healthcare providers face when caring for the refugee population. It also involved analyzing data collected through interviews of providers that care for the refugee population.

This research also addressed the leadership competency by requiring collaboration with healthcare providers through coordination, scheduling, and completion of interviews. Findings of this research will hopefully lead to insight and information that can be utilized to advocate for improvement of access, quality, and cost effective health care for the refugee population (Thomas et al., 2012). This research fulfilled the practice inquiry competency because it focused on provider experience caring for the refugee population with the goal of improving healthcare for refugees. It required the dissemination of evidence and investigation into how to improve health outcomes (Thomas et al., 2012). One aspect of this research focused on provider's perspective

regarding healthcare policy and the effect it has on providing care to the refugee population. Therefore, this research addressed the policy competency because it advocates for a change in policies that promotes ethical access, equity, quality and cost among patients especially the refugee population (Thomas et al., 2012).

Summary

In this chapter, the purpose and significance of this research were summarized. It was important to conduct this research from the providers' perspective because it has not been fully explored. Identifying the challenges providers face when caring for the refugee population may influence policy change and improve the quality of their healthcare. The implications for advanced practice nursing were discussed and the competencies that were addressed included: scientific foundation; leadership; practice inquiry; and policy. In the following chapter, a review of the literature that supports the importance of the study will be discussed.

Chapter 2

Literature Review

A comprehensive literature review was conducted with a focus on the challenges refugees face within the health care setting and the perceived challenges providers face when caring for the refugee population. The search terms utilized began with the inclusion criteria of refuge health care and exclusion criteria of immigrant and foreignborn without restriction of year published or country. The search terms progressed to include the terms barriers, provider, and experience. Search engines utilized were PubMed/MEDLINE, Cumulative Index for Nursing and Allied Health Literature (CINAHL), PsychInfo, Cochrane Library and National Guideline Clearinghouse. PubMed medical subject headings (MESH) added to the search builder included "refugee" and "delivery of health care."

Key topics that emerged from the literature review included the challenges faced after refugee resettlement, perceived barriers the refugee population faced from the providers' perspective, barriers refugees faced in health care, health status of immigrants and improvements that can be made when caring for the refugee population. Information regarding culturally competent care was included in the search due to the importance of this topic in caring for refugee populations. It is also important to note connotative differences in definitions of terminology among refugee, asylum seeker, and immigrant because there can be distinctive challenges faced by each group.

Definitions: Refugee, Asylum Seeker, and Immigrant

The words refugee, asylum seeker and immigrant have clear definitions under international law and are not interchangeable. The United Nations High Commission for Refugees (UNHCR) is a branch of the United Nations that is responsible for international protection of refugees and was established in 1951. The Refugee Convention provides the following definition of refugee:

Owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his nationality, and is unable to, or owing to such fear, is unwilling to avail himself of the protection of that country as amended by the 1967 protocol that withdrew time and geographic location limitations (UNHCR, 2015).

The distinction between refugees and asylum seekers is that refugees have been granted protection from persecution in their host country whereas asylum seekers are requesting protection outside of their home country and are awaiting the decision that they are determined to be a refugee. An asylum seeker is defined as an individual outside his or her country of origin seeking refugee status based on a well-founded fear of persecution on account of race, religion, nationality, social group or political opinion, but whose claim has not been legally substantiated (UNHCR, 2015).

The word immigrant is defined in the Merriam-Webster Dictionary as a person who comes to a country to take up permanent residence (immigrant, 2015). Refugees and asylum seekers are fleeing their country out of fear of violent conflict. All refugees and asylum seekers may be considered immigrants but not all immigrants may be considered refugees or asylum seekers. Providers who become aware of their own cultural bias while seeking and establishing cultural awareness and understanding are more likely to develop the ability to provide the best care possible for these vulnerable populations.

Cultural Competence

Cultural competence is an important aspect in helping refugees feel safe and secure within the health care environment. Cultural competence is defined as "a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals and enable that system, agency or those professionals to work effectively in cross-cultural situations" (Cross et al., 1989). Establishing a culturally competent system has the ability to acknowledge and incorporate the importance of culture, assess cross-cultural interactions and adapt to meet culturally unique needs.

A Cochrane review on cultural competence education for health professionals sought to evaluate the effects that educational interventions had on patient-related outcomes, health professional outcomes and healthcare organization outcomes (Horvat, Horey, Romios, & Kis-Rigo, 2014). All of the studies reviewed, based on inclusion and exclusion criteria, were observational and therefore had a low grade for evidence. Nonetheless, providing education in cultural competence in healthcare organizations is intended to provide valuable experience when caring for the refugee population. Researchers determined there is a need for standardized education practices surrounding the subject of cultural competence (Horvat et al., 2014).

Striving to provide culturally competent care toward refugee cultures, religion and family values can improve the provider-patient relationship (Perreira & Ornelas, 2011).

Health care providers and clinical staff may lack knowledge and sensitivity to the needs of the refugee population specifically, such as symptoms of torture and mental health issues (Asgary & Segar, 2011). One study investigated outcomes for the refugee population when a dedicated refugee clinic was established within the community. Researchers applied a survey study designed to assess the impact of timely, culturally appropriate care for refugees. There was a 30% decrease in wait times to see a provider and an 18% increase in refugees finding a permanent family physician within the community a year after arrival in the United States (McMurray, Breward, Breward, Alder, & Arya, 2014). Providers that are culturally sensitive with access to translation services are more likely to treat refugee patients on a primary care level, which will ultimately improve access to care (McMurray et al., 2014).

Utilizing a clinical guideline from the National Guideline Clearinghouse can help facilitate improvement with providing culturally competent care to refugees and their families. Pumariega et al. (2013) created a guideline that focuses on clinical application of cultural competence by mental health clinicians to improve the care of children, adolescents and their families from diverse backgrounds. This particular guideline may be helpful for providers caring for the refugee population by providing an overview of important interventions that can be applied during health care visits.

Challenges of Resettlement

According to Eckstein (2011), the most common health problems refugees present to their primary care provider include musculoskeletal pain, often located in the neck and back; infectious diseases such as tuberculosis and parasitic infections; and chronic disease that may have been neglected including hypertension, hyperlipidemia and diabetes mellitus. The refugee population also has increased rates of depression, anxiety, and post-traumatic stress disorder (PTSD) compared to the general population due to previous experiences of trauma, torture, fleeing their home country, and living in refugee camps.

Health care providers have the opportunity to educate newly settled refugees about our health care system and how it can be utilized during resettlement. There is also an opportunity to start a trusting patient-provider relationship. Addressing mental health needs of refugees upon resettlement is critically important to their overall care.

Establishing mental health services can be challenging related to refugee patients shame or feeling stigmatized for having a mental illness or may not recognize mental illness as such (Nazzal, Forghany, Geevarughese, Mahmoodi, & Wong, 2014). A majority of the refugees arriving in the United States have little more than the clothes on their backs. Their socioeconomic status may prohibit their ability to seek preventive care and specialty health care services (Nazzal et al., 2014). Health care literacy is another obstacle faced by refugee patients, as they may not be familiar with the importance of refilling medications or taking them appropriately. They may also have problems with keeping appointments due to lack of transportation and not understanding the process of applying for health insurance (Nazzal et al., 2014).

Researchers located in Minnesota conducted a community-based action study with an ecological framework that examined factors influencing Somali women's health experiences. According to Pavlish, Noor and Brandt (2010), interactions between Somali women and the United States' healthcare system were frequently unsatisfying and unproductive. The study found that illness is viewed by Western medicine as biomedically-driven, which was in contrast with the beliefs of the Somali culture. The participants described their health as influenced by their holistic environment including relation to self, others, and Allah [God] with symptoms that may be more attributed to spiritual or social disconnect and sadness (Pavlish, Noor, & Brandt, 2010). This type of healthcare discordance can significantly impact the quality of care refugees receive because of frequent misunderstandings. Asylum seekers in another study also felt a sense of mistrust toward medical care with one participant stating, "I really don't trust Westernized medicine" (Asgary & Segar, 2011).

Barriers to Health Care

Providers caring for immigrant and refugee population may have decreased satisfaction when caring for these populations. One study explored whether physician satisfaction during clinical encounters differed when caring for ethnic immigrant patients compared to their white counterparts. Following the analysis of questionnaire responses, researchers determined that physicians were considerably less satisfied after encounters with ethnic patients. Their main frustrations were the patient's failure to comply with advice provided regarding treatments and prevention of illness, as well as the patient's lack of understanding in regards to the management of chronic disorders (Kamath et al., 2003). There is an expectation, among Somali patients specifically, that the provider they are seeing will know exactly what is wrong with them and that they will receive a treatment to cure their ailments immediately. The concepts of screening, prevention, and management of chronic illness does not resonate with many refugee populations. Pavlish and colleagues reported that in Somali culture there is no concept of prevention and screening. Symptoms represent the illness therefore they seek a cure for the symptoms rather than an explanation of a chronic illness. Oftentimes, they do not take medications, or only take medications for a certain amount of time not realizing the purpose is to prevent illness from occurring (Pavlish et al., 2010).

An exploratory pilot study conducted in Columbus, Ohio aimed to determine health care providers' perspective of management of care for pregnant Somali refugee women with a history of female genital cutting (FCG) (Lazar, Johnson-Agbakwu, Davis, & Shipp, 2013). Interestingly, researchers found that FCG was not the primary barrier when caring for Somali women in the obstetrical environment. There were different themes that emerged including communication barriers, frustrations with Somali women resisting suggested obstetrical interventions, and a perception of mistrust towards providers (Lazar et al., 2013).

Refugee Health Status

A review of existing studies by Argeseanu, Cunningham, Ruben and Narayan (2008) compared health outcomes for foreign-born individuals from different ethnic backgrounds that migrate to the U.S. to that of native –born Americans. Foreign-born individuals had lower mortality rates, decreased likelihood of suffering from heart disease, obesity, mental disorders, cancer and were less likely to have low birth weight babies. The researchers focused on the health status that was determined upon arrival in the U.S., as the longer foreign-born immigrants lived in the U.S., the more likely they

were to adopt a similar health status to the U.S.-born population (Argeseanu

Cunningham, Ruben, & Narayan, 2008). The results of the study suggested that the body mass index (BMI) of refugees changed the longer they live in the U.S. Studies suggest that the adaptation of the American diet and lifestyle may cause the similarities in health 10 years post-resettlement (Argeseanu Cunningham et al., 2008). This subject requires further study, particularly surrounding the suggestion that those migrating are healthier in general. There is also an implication for this research related to overall health status which may be determined by the ability to overcome health care barriers.

Barriers to receiving care included three categories: individual factors, institutional factors and system-level factors. Researchers identified the most common barriers to receiving care include the burden and complexity of their illness, experience of trauma, language barriers and cultural understanding of disease (McMurray et al., 2014). Refugee families may lack knowledge of available health care services. Therefore, it is imperative to refer refugees to local agencies upon post-migration or resettlement to address social, financial, and transportation needs and issues (Eckstein, 2011).

Improving Health Care for Refugees

The goal of improving the quality of health care for refugees is multifaceted and researchers have conducted several studies to determine how it can be improved. One study discussed that the large influx of refugee and immigrant populations increased the need for establishing organizations focused on addressing barriers to accessing health and social services (Edward & Hines-Martin, 2014). Researchers reviewed literature focusing on the physical and psychological well-being of immigrant children and

discussed the difficulties immigrant parents face regarding financial and language barriers that can limit their capacity to enroll in both private and public health insurance programs (Perriera & Ornelas, 2011). According to Fennelly (2006), recommendations by providers for improving the care of refugee and immigrant populations include implementing policy changes to increase eligibility for health insurance, providing education to refugees and immigrants about the health care system upon resettlement, and formalizing education for providers about the special health care needs of this population. Providers also encouraged better outreach programs and education including clarification between the health and immigration systems (Asgary & Segar, 2011).

This literature review has provided a background understanding of health care challenges refugees face from the individual perspectives of refugees and a few studies discussed the perspectives of providers who care for them. Differentiating the terms refugee, asylum seeker and immigrant is important because there are different policy implications as the result of their status upon arrival to the U.S. Challenges of resettlement and improving health care of refugees are discussed within the context of the purpose of this research.

Summary

In this chapter, relevant literature was reviewed related to the experiences refugee and immigrant populations and providers that care for them have within the healthcare setting. A discussion of previous studies that looked at challenges of refugee resettlement, barriers to healthcare and the health care status of refugees was presented. The following chapter will present the study design, sample, data analysis, criteria of rigor, and study limitations.

Chapter 3

Methods

Design

Descriptive phenomenology was the research method chosen to guide this qualitative research. There are complex philosophical foundations within phenomenology, which leads to varied interpretations that evolve. According to Streubert and Carpenter (2011), "the goal of phenomenological research is to describe the lived experience" (p. 74). This research focuses on the experience providers have in caring for a specific population; therefore, descriptive phenomenology is an appropriate design for this study. Spiegelberg (1975) defined phenomenology as:

the name for a philosophical movement whose primary objective is the direct investigation and description of phenomena as consciously experienced, without theories about their causal explanation and as free as possible from unexamined preconceptions and presuppositions (p. 3).

Procedural interpretations of phenomenological research are available as a guideline for this research approach. Colaizzi provides procedural steps to methodological interpretations that include a nine-step process (Edward & Welch, 2011; Streubert & Carpenter, 2011).

Bracketing is a strategy used during qualitative research to suspend judgments a researcher has during data collection and analysis. It is performed before the beginning

of the study and is repeated throughout data collection and analysis. Bracketing was utilized throughout the process of this study by suspending judgment throughout the interviews and keeping an open mind to responses. Bracketing is defined as:

a methodological device of phenomenological inquiry that requires deliberate identification and suspension of all judgments or ideas about the phenomenon under investigation or what one already knows about the subject prior to and throughout the phenomenological investigation (Streubert & Carpenter, 2011; p. 78).

Sample

The goal of qualitative research data collection is to reach saturation described as repetition and confirmation of previously collected data (Streubert & Carpenter, 2011). The sample size in qualitative research is typically small and is considered adequate when participants are not adding new information and the issue is thoroughly covered. The goal for this study was to identify and interview between four and six providers.

Between the months of November 2015 and January 2016, purposive sampling was used to recruit health care providers who care for refugee patients. Clinics that care for refugee patients, located within this northeast state, were identified and specific providers were approached based on their practice of caring for refugee and immigrant populations. Participants were recruited via e-mail, which described the purpose of the study.

Participants included pediatricians, family medicine physicians, and nurse practitioners who had interactions with refugee patients on a frequent basis, defined as seeing at least four refugee patients in their practice setting per week. All five participants currently work in clinics where they care for immigrant and refugee populations on a regular basis. There were three female and two male participants in the study.

Protection of Human Subjects

Before the initiation of this research, this study was granted approval by the International Review Board of the University of Vermont (Appendix A). Each participant was provided a written consent form that was reviewed and signed before the start of the interview (Appendix B). Participants were assured that information from this study would only be presented in aggregate form and individuals would not be identified. It was communicated that participation was voluntary and that they could withdraw from the study at any time.

Data Collection

Data were collected using semi-structured, open-ended interviews conducted face to face, which are considered the "gold standard" for qualitative research (Kumar, 2012; Streubert & Carpenter, 2011). Interviews with the five participants lasted approximately 35 to 45 minutes. Interview locations were predetermined between the researcher and interviewee; each of the interviews was conducted at their place of work except for one which was conducted in a private setting. The interviews were semi-structured utilizing twelve open-ended questions that focused on investigating the provider's experience caring for the immigrant and refugee population (Appendix C). Clarifying statements were utilized to gain a deeper understanding of a subject. The interviews were voice recorded and transcribed verbatim by the researcher. Voice recordings were stored digitally and password encrypted. Numbers were used to identify participants.

Data Analysis

Colaizzi provides procedural steps to methodological interpretations that include a nine-step process which were utilized for data analysis (Edward & Welch, 2011; Streubert & Carpenter, 2011). The procedural steps include:

- 1. Describe the phenomenon of interest.
- 2. Collect participants' description of the phenomenon.
- 3. Read all participants' descriptions of the phenomenon.
- 4. Return the original transcripts and extract significant statements.
- 5. Try to spell out the meaning of each significant statement.
- 6. Organize the aggregate formalized meanings into clusters of themes.
- 7. Write an exhaustive description.
- 8. Return to the participants for validation of the description.
- 9. If new data are revealed during the validation, incorporate them into an exhaustive description.

In this study, data was collected through semi-structured interviews with healthcare providers and recordings were transcribed verbatim. Each interview transcript was thoroughly reviewed with significant statements extracted. The significant statements were reevaluated to determine their meaning. Once the reevaluation was complete and the meaning of these statements was formulated, groups of similar themes were organized together. Synthesis of themes developed into findings for this qualitative study. The goal of the data analysis was to described the lived experience of healthcare providers caring for the refugee and immigrant population

Criteria of rigor. According to Streubert and Carpenter (2011), "the goal of rigor in qualitative research is to accurately represent study participants' experiences" (p. 48). Establishing rigor in this research is important for determining credibility of research findings. Guba and Lincoln (1994) provide four criteria of rigor for consideration in qualitative research: credibility, dependability, confirmability, and transferability.

Credibility. Credibility was established through "prolonged engagement" with observation of participants via the interview process and consultation with a qualitative researcher who assisted the researcher with interpreting data (Struebert & Carpenter, 2011, p. 48).

Dependability. Dependability is reliant on the credibility of research findings and is achieved when similar conclusions can be drawn through the use of raw data and analyzing documents (Streubert & Carpenter, 2011).

Confirmability. Confirmability requires evidence of thought processes and documentation that helped lead to research conclusions (Streubert & Carpenter, 2011). Notes and documentation utilized throughout this research, including identification of significant statements, documentation of themes, key words, key phrases and direct quotes, were kept in an organized file to constantly reference throughout the data analysis.

Transferability. Transferability occurs when study findings have meaning in similar situations and requires thorough descriptions and verbatim quotations from participants

(Streubert & Carpenter, 2011). Although the researcher is not able to generalize results of the study, the results allow those interested in the experience of caring for the refugee population to reach a conclusion about whether or not transfer to other settings is possible.

Limitations

Findings in this study are based on a small sample of providers who were located in one geographic region and findings are therefore, not generalizable. The research offers foundational knowledge from the provider perspective regarding their experience caring for refugee patients in one North East city however; it would be beneficial to conduct research from the perspective of the refugee and immigrants in the same community to analyze priorities of both groups. It would be beneficial to compare the current issues providers face and the current issues refugees face. Although, previous studies discuss challenges and barriers refugees experience, research could benefit the community on a larger scale by influencing policy reform and better allocation of resources.

Summary

In this chapter, research methods were described that were utilized for this qualitative study. This research utilized a phenomenological approach, purposive sampling, and semi-structured open-ended interview questions to collect data about the experiences health care providers have when caring for the refugee population. The criteria of rigor provided credibility for themes and findings that emerged and limitations

were discussed. In the next chapter, findings from this qualitative research will be discussed.

Chapter 4

Findings

There were five providers interviewed for this qualitative research study. Current experience in their roles ranged from 5 months to 41 years. Their titles were pediatric nurse practitioner, pediatric physician, and family medicine attending. Each provider worked within the same city of a northeast state therefore a number of the cultures cared for overlapped including, Bhutanese, Somali, Somali/Bhantu, Iraqi, Congolese, Burundi, Nepali, Burmese, Sudanese and Vietnamese. The challenges that providers encounter when caring for the refugee and immigrant population are numerous, however, through the face-to-face interviews providers indicated a strong desire to work with refugee patients and families throughout their careers. They also discussed how their interest in caring for this population led to their current positions. Three themes emerged from the analysis of the qualitative data: Facing Challenges, Experiencing Satisfaction, and Reframing the System.

Facing Challenges

The refugee and immigrant population presents various challenges to the providers who care for them. The providers interviewed discussed the challenges they encountered in caring for this population related to differing cultural role expectations, utilization of interpreter services, mental health care needs, and socioeconomic factors impacting health.

Differing cultural expectations. Deference to authority that can lead to paternalistic interactions during visits with providers was discussed in the interviews.

The Western medical culture emphasizes a collaborative approach during medical or nurse practitioner school training that is focused on an individual level. This can lead to disconnect with different cultures that expect paternalistic interactions. One provider stated:

There is a paternalistic "just tell me what to do" which is hard because how we have been trained now revolves around joint decision making and they [the patient] need to be the one making the decisions and people sometimes don't like

that. Therefore, you have to learn how to give people options while guiding them. The refugees may also believe that community involvement should be considered when making decisions regarding an individual's health. There was also an emphasis placed on respecting their community and viewing the community as "valid". One provider explains:

Often a lot of the culture of how we practice medicine doesn't match the culture of other people because the U.S. is very much about the individual including individual rights, individual decisions, individual treatment plans and that is often not effective without looking at the community. I think it forces you to practice medicine much more on a community level to be effective; [therefore] there are more public health approaches but there is also creating a relationship with the community as opposed to creating a relationship with just the patient. To be effective you really have to have a relationship on many levels, most physicians in western styles just have a relationship with their actual patient and that is not effective; you really need a relationship with patient, family and community. Refugees and new immigrants with no exposure or education about Western healthcare system practices are at risk for miscommunicated information and misunderstandings. Misunderstandings surrounding logistical practices may lead to missed appointments, lack of follow up and difficulty reaching families via telephone. The concept of making appointments to see providers may not be comprehended, which delves deeper into the struggle of the ability to receive health care as discussed by a provider who stated, "showing up late or no shows [for appointments], just the whole concept of scheduled visits, as opposed to just walking in when you need something can be challenging."

Interpreter services. Language and communication barriers were uniformly the most significant challenge for providers working with this population. One provider expresses this sentiment by stating, "The communication part is the biggest challenge; it's hard figuring out if it is just a language barrier or a cultural barrier or just an individual barrier; it's really hard to tease all of those things out." Utilizing interpretation services was a challenge each participant discussed. The in-person interpreters are able to follow the conversation more thoroughly while able to infer nonverbal cues such as body language thereby reducing misunderstandings. Many liked having in-person interpreters for clinic visits because of the ability to interpret body language and get the full message across. One provider stated:

The in-person interpretation is outstanding, there are favorites and we find some interpreters are excellent at interpreting what we want said and not more than that or no less than that. Also, they interpret quickly with the right type of body

language and also don't try to over step their bounds as the potential health care provider.

Another benefit of having in-person interpreters is to review forms and make sure paper work is completed adequately before seeing the provider. One provider stated:

There is a lot of stuff that we do such as using screening tools...it would take 15 minutes of going through questions...we are able to enlist our interpreters to be able to sit down and then we can review the results with them, it allows us to do more.

Another provider discussed a similar sentiment by stating:

We have paperwork that in-person interpreters can help with such as with questionnaires and development screenings, whereas that does not happen with phone interpreters. We would need extra time during the visit to run through those questions and one of the ways we short cut time, rightly or wrongly, is to have the in-person interpreter go over the forms so we are not repeating everything, we are revisiting it but not in such a detailed fashion that it is less time consuming.

Each clinic always had a phone interpreter option available during visits, however, there were challenges discussed including difficulty conveying a message when an exam room was noisy with multiple people present. Each provider discussed the increased time it takes to complete visits when interpreters are necessary. There was a need for increased time allotted for these appointments due to the extra step required to communicate adequately. A provider stated, "the logistics of it are challenging just using the interpreters takes twice as long as for someone that doesn't need an interpreter. You have to have a lot of patience but that is always challenging. The days can sometimes run long".

Various types of interpreting are utilized within health care offices including inperson interpreters that are physically present during encounters and telephone interpreters that are called through national services. According to the providers interviewed, there are advantages and disadvantages to both services. One provider describes what a positive in-person interpreting experience is by stating, "they interpret quickly with the right type of body language and also don't try to over step their bounds as the potential health care provider and also don't have a personal relationship with the family".

The disadvantages of in-person interpreting include a wide range of training, issues with confidentiality and difficulty with coordinating appointments around interpreter availability. Oftentimes, the in-person interpreters live in the same communities as the patients they interpret for, which may lead to confidentiality issues or patients not feeling comfortable discussing certain aspects of their health. Some of the providers interviewed discussed other challenges including interpreters refusing to work with families or on the contrary, families refusing certain interpreters. Both situations pose challenges for the providers and could be an overlooked aspect when caring for patients who do not speak English. One provider stated:

Occasionally a family will let me know if they are not comfortable with an interpreter. Every new interpreter gets a talk about patient confidentiality and

then any time it is a sensitive subject I remind the interpreter that they are held to the confidentiality agreement.

Interpreters are also utilized through national telephone interpretive services. Advantages of this service include providing anonymity and confidentiality, there is a larger group of interpreters from which to choose and there is usually an interpreter available for a wide range of languages. The telephone interpreters can present disadvantages including the inability to visualize nonverbal clues during conversations and difficulty communicating during visits especially when there is more than one person present in the room. Each provider had their own opinions on telephone interpreter experiences. One provider stated, "For the most part, [the phone interpreter services] work fast, they're reliable and you're not waiting for in person interpreters to show up for the appointments." In contrast, another provider stated, "I find the phone [interpretation] is almost useless; it is only good when getting through a sick visit; it is never helpful obtaining finer details."

Mental health needs. Providers discussed the mental health needs of the refugee population and expressed the high prevalence of continual stress from trauma that the refugees experienced before fleeing to the U.S. The needs are numerous and there are not enough resources allocated which makes it even more challenging to address and treat the mental health issues. Many of the providers would like more "levels" of support including more access to social workers and psychologists. One provider summarized the experience of caring for mental health needs by stating, "It is so deep and so

challenging; mental health extends from everything from dealing with trauma to dealing with food insecurity here to dealing with parenting issues..."

There are stigmas attached to mental health issues that add another challenge for providers. Refugee patients have to be willing to accept that there is a problem and then be willing to undergo treatment such as therapy or medication. One provider states,

There is a high rate of PTSD, high rate of domestic violence, corporal punishment and some of this is cultural; some of this is the "norms" of the culture from which people came; although they are prevalent in the U.S. too even though we don't talk about them.

Refugees may also experience trauma surrounding racism and xenophobia, one provider stated the "current political climate" might contribute to these feelings. Mental health needs may be the most difficult to meet because of the challenges discussed and the lack of resources available to meet these needs, which would be beneficial to both patients and providers.

Socioeconomic challenges. Refugee and immigrant patients often struggle socioeconomically specifically because they do not know the English language. Providers discussed the socioeconomic factors that impact the refugee population's health including financial hardship, substandard housing and the stress that results from basic health needs that are not met. Although physical access to health care may be improving, the ability to meet basic needs is challenging due to scarce resources and social work systems that are already overburdened. Social determinants of health were discussed in each interview including providers' thoughts on the responsibility related to attempting to rectify these issues.

Financial hardship is common among refugees and their families and it can ultimately affect their health. If a refugee has difficulty with the English language there is a high likelihood they will have a low paying job if they can find work. If they have a low paying job and have difficulty affording housing they may live in substandard living conditions or have food insecurity which will likely increase their stress levels causing adverse effects on their health. Their financial hardships begin with arrival in the U.S. and resettlement within this northeast state as one provider describes, "We've added to the fact that we've moved people into poverty, these people are not only in poverty but they're moved into poverty without a lot of supports that people who have been established may have." Many of the providers discussed financial and housing stability as being more important than having access to health care because the "access" part has improved but many of the support systems and resources are not present. A quote by one provider sums up this sentiment well by stating:

I think just in general in medicine with the understanding more of the social determinants of health, until you help someone with their housing situation, they could care less about their medical situation. It's just not their priority. Until we are addressing people's priorities and where they are at, I think the interplay of their health, with their environment; with the bigger picture we have a lot of problems. [Therefore] The amount of social work support, the amount of coordinated support that we get is insufficient for the need.

Experiencing Satisfaction

Discussing the experience providers have caring for refugee patients would not be complete without asking about the satisfying aspects of their current positions and the motivation behind continuing to work with these families. Each provider found his or her work rewarding. Throughout the interviews, positive aspects of their work were illustrated. One provider discussed their motivation for caring for refugees by stating:

It allowed me to practice global health locally. There was a lot of infectious disease and a lot of new medical things that I got to practice. But then it had this overlay of really interesting cultural pieces such as geography, history and culture and it was really a very organically and holistic approach to health care. That is how I like to practice and it works really well.

Another provider enjoys becoming an advocate while having the ability to witness social and academic lives flourish and stated, "I think when you have a kiddo that has been resettled here and they are thriving in their schools. That is when I feel we have really done well."

All participants expressed that the learning experiences that come from caring for refugees were a satisfying aspect of their work. They discussed being interested in learning about different cultures particularly within their practice of medicine. Building relationships by establishing trust led to appreciation for their service because many refugees have not had access to health care before. Providers sought out their current positions because of the desire to work with these families and each provider described their experiences as being rewarding overall. One provider summarized the experience by stating:

It is fun to build relationships and talk to people. Specific to not just immigrants but the refugees in particular because the process to come here and the things that people have been through, it's pretty awe-inspiring to be a part of and become a trusted resource for them and to be able to provide support and help along the way, it is really nice. It is very rewarding.

Reframing the System

Refugee access to health care is difficult because of communication, transportation and financial barriers. Interestingly, from provider perspectives, physical health care access in this particular county is adequate however, the conversations on this topic focused less on managing actual diagnoses and more on managing social aspects that affect overall health. Every provider involved with this study wanted improvements to social aspects of care including better allocation of resources, increased resource funding, and more support from social workers or liaisons. They felt grateful for the current support however, current social work staff are overburdened and overworked. One provider stated:

I think just in general in medicine with the understanding more of the social determinants of health, until you help someone with their housing situation, they could care less about their medical situation. It's just not their priority. Until we are addressing people's priorities and where they are at, I think the interplay of their health, with their environment; with the bigger picture we have a lot of

problems. [Therefore] The amount of social work support, the amount of coordinated support that we get is insufficient for the need.

Providers discussed the need for better global awareness of the difficulties refugees face. When asked about their thoughts on improvements for health care delivery, there was a range of suggestions. System level change called for single payer health care making it easier for refugees and underserved populations to access care while placing a priority on incentivizing the best quality of care not just revenue. One provider stated, "The incentive is never about the best quality of care; the system is always about finances and where money is going to end up in whose pocket".

Support on the community level requires resettlement programs that include education about our health care system while immersed in it and for the community to become more tolerant of not only refugees but also different perspectives of each individual. Providers discussed continuing to advocate for patients needs and reevaluating current practices to better accommodate refugee challenges. A provider stated:

I feel a better global awareness of how hard it is to be a new American and what their challenges are even understanding just the communication piece. I can't imagine how difficult it can be for people that have to go to the pharmacy to pick up medicines and try to understand how to take them so, the more these things are integrated into society the better overall care will be.

Although each provider found satisfaction within their current positions, there is a critical need for improved allocation of resources for housing, social support and increased funding to help support refugee families that arrive in the United States.

Summary

In this chapter, findings of the study were presented. Direct quotations from the providers interviewed were analyzed and synthesized into three themes: facing challenges, experiencing satisfaction, and reframing the system. The theme facing challenges produced a sub-set of four themes including differing cultural expectations, interpretation services, mental health needs and socioeconomic challenges. The theme experiencing satisfaction illustrated how providers feel about caring for this population and the satisfaction they find within their work despite ongoing challenges. Reframing the system looked at the need for improved social services and the change in healthcare policy that is needed to better support not only care for refugees but for underserved populations as well. In the next chapter, a discussion about the study findings is presented with comparison and contrast to similar previous research.

Chapter 5

Discussion

The purpose of this qualitative research study was to add to the growing body of knowledge about refugee care from the provider perspective, which is important to improve care and identify specific issues contributing to health care quality. The research was conducted through face-to-face, semi-structured interviews with five providers who care for the refugee and immigrant population and investigated the experience they have caring for this population.

Each provider discussed challenges experienced when caring for the refugee population. Three main themes emerged after analysis including: Facing Challenges, Experiencing Satisfaction and Reframing the System. There were also subthemes under one main theme, Facing Challenges, that emerged including differing cultural expectations, interpreter services and socioeconomic challenges. Interpreter service issues and communication were the most significant challenges providers experienced. Issues refugees experience, including financial insecurity, substandard housing and meeting basic needs were discussed in the interviews with providers suggesting policy change to help improve access to meet these needs. Providers also identified numerous mental health challenges and needs for improved allocation of resources for social workers. They identified that mental health needs were difficult to meet due to stigma surrounding mental health in communities. There was discussion regarding changes to the current healthcare system into a single payer system. Further change to the system included a suggestion to incentivize providing high quality care over revenue, which is the basis for the current system.

Each provider found his or her work satisfying and rewarding. They identified learning experiences about different cultural practices and appreciation for their work as drivers for continuing in their current position working with the refugee population. Previous research studies have been conducted regarding caring for the refugee population from the provider's perspective and it is important to discuss them in comparison to this research study.

A similar qualitative, ethnographic study was conducted in a southern metropolitan city. The study involved understanding provider perspective regarding social services provided for refugees and immigrants (Edward & Hines-Martin, 2014). The study was small, only ten participants were interviewed, but researchers also incorporated surveys, observations and document reviews. Providers identified challenges within the social needs of refugees including marginalization within communities geographically that lead to a decrease in accessibility to social services (Edward & Hines-Martin, 2014). Immigration status inhibited their ability to access affordable health care because of existing laws and policies; their findings indicated the need for policy reform to improve access to social services, which will improve social disparities and health outcomes (Edward & Hines-Martin, 2014).

In comparison to this research study, providers had similar opinions regarding the need for improved social service access including changes on a policy level. The

overburdened current system leads to an imbalance of service and consequently social disparities. Although providers' were grateful for the current social support, they discussed a desire for improved allocation of resources through policy change in order to fulfill current needs.

Another qualitative, ethnographic study was conducted which focused on health care access for refugees with disabilities. The researchers interviewed 18 participants who were key to identifying health care barriers affecting disabled refugees. The researchers identified three broad themes including inadequate health insurance, language and communication barriers and a complex maze of service systems (Mirza et al, 2013). There were barriers that occurred on the system level, provider level, and individual level. The findings indicated that the U.S. healthcare system is "ill equipped" to accommodate the needs of disabled refugees because of the lack of resources, limited knowledge of interpretation standards and difficulty with finding trained interpreters (Mirza et al, 2013). Their recommendations included policy changes to improve interpreter and health insurance access, increased collaboration between refugee agencies and disability service networks, and empowering refugees by educating them about the healthcare system by informing them about services that are available (Mirza et al, 2013).

Although the study focused on disabled refugees, there were similarities to this research regarding providers wanting an improvement of access to resources whether it is through specific policy change or overall healthcare reform. There needs be a better distribution of resources within the community, state and nation.

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The exploratory study by Fennelly, in which 62 health care and social service providers were interviewed about their perceptions regarding the needs of immigrant and refugee patients, discovered similar themes to this research. These included difficulty finding affordable housing, inadequate mental health resources and barriers to healthcare that include lack of health insurance (Fennelly, 2006). According to Fennelly, the recommendations to improve refugee and immigrant health care include policy changes to increase eligibility and access, assistance with negotiating the healthcare system and providing education for refugee and immigrant populations. Providers interviewed in this research also discussed the need for improved resources through either policy change or reform of the current healthcare system.

This research study was limited and specific to providing information about provider experience caring for the refugee population within the healthcare setting. The providers identified a need for increased resources surrounding social services, such as the ability to hire more social workers and expand current programs to assist refugee and new immigrant families financially and to improve substandard housing. The findings suggest that a priority should be placed on policies that improve access to resources at the community, state and nationwide levels. The current fractured and cumbersome healthcare system is difficult to navigate and there needs to be a more streamlined process for those who are not proficient in English. The implications for policy and healthcare change not only affect refugees but also other underserved populations. Refugees and immigrants are at a far greater disadvantage in terms of health care

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disparities. However, general awareness of their struggles and the barriers they face may open up opportunities to improve healthcare through policy change.

Summary

This study provided a qualitative, phenomenological view of the experience of caring for the refugee population from the provider perspective. In this chapter, findings from previous studies were compared to this study with recommendations to improve refugee care. Information gained from this study can help influence future research about refugee healthcare and may help influence changes to healthcare policy by prioritizing both the health needs of refugees and the needed support for the providers who care for them.

Appendix A



Committees on Human Subjects Serving the University of Vermont and the UVM Medical Center

RESEARCH PROTECTIONS OFFICE 213 Waterman Building 85 South Prospect Street Burlington, Vermont 05405 (802)656-5040 ph www.uvm.edu/irb/

CHRBSS: 16-125

Protection of Human Subjects Assurance

Title: The Experience of Health Care Providers who Care for the Refugee Population Principal Investigator: Ashley MacDonald, Institution: University of Vermont and State Agricultural College, Burlington, VT 05405

This institution has an approved assurance of compliance on file with the Department of Health and Human Services which covers this activity.

University of Vermont and State Agricultural College: FWA 00000723 Expiration Date: Nov 12, 2018 The UVM Medical Center: FWA 00000727 Expiration Date: November 12, 2019 IRB number 00000486

Certification of IRB Review

This activity has been reviewed and approved by an IRB in accordance with the requirements of 45 CFR 46, including its This activity has been reviewed and approved by an intermeters of 21 CFR 50 and 21 CFR 56. relevant Subparts; and, when applicable, with the requirements of 21 CFR 50 and 21 CFR 56. NOV 04 2016

Date of approval

Date of expiration

IRB Review Type: Expedited review

Institutional Signature/Date:

11/5/15 RA

NOV 0 5 2015

Name and Title of Official: Sara Barry, MPH, Associate Chair,

Committee on Human Research in the Behavioral and Social Sciences

Informed Consent

Title of Research Project:

The Experience of Health Care Providers Who Care for the Refugee Population

Principal Investigator: Ashley MacDonald

Faculty Sponsor: Jeanine Carr - University of Vermont Department of Nursing

Sponsor: Department of Nursing at University of Vermont

You are being invited to take part in this research study because you have been identified as a health care provider (Physician, Nurse Practitioner or Physician Assistant) that cares for patients within the refugee and immigrant population. A student in the Department of Nursing is conducting this study.

This form is designed to give you information about this study. We encourage you to ask questions and take the opportunity to discuss the study with anybody you think can help you make this decision.

Why is This Research Study Being Conducted?

The goal of this research is to add to the body of knowledge about health care for the refugee population by interviewing providers about their experiences caring for this population. A description of providers' experience will be the outcome of the study and will enhance understanding of caring for the refugee population with a goal of improving quality of care. This research will add to the growing body of knowledge related to caring for the refugee population and to identify factors related to refugee health from the provider perspective in order to ultimately improve the care provided.

How Many People Will Take Part In The Study?

Ideally, approximately 4-6 providers will be participating in this study.

What Is Involved In The Study?

You are being asked to take part in an open-ended interview, conducted face to face, will be used for data collection. The interviews will be tape-recorded and transcribed verbatim. The interview will be unstructured however; clarifying questions may be used to gain a deeper understanding of a statement. Following data collection, the researcher will provide participants the opportunity to read the interview transcripts and provide further input or clarification if necessary. Handwritten notes will also be taken while the interview is being conducted. The interviews will last approximately 45 minutes to 2 hours.

You will be asked questions such as the following:

- How much experience do you have in your field? In working with the refugee and immigrant population?
- How did you become interested in working with the refugee population?
- What do you find most satisfying and challenging about working with this population?
- Tell me about your experiences related to communicating with patients for whom English is not their native language?
- · Are you able to remain flexible in your practice through accommodating refugee patients with

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certain health status challenges?

What types of resources do you think would improve health care utilization for this population?

What Are The Risks and Discomforts Of The Study?

Your participation in this study does not involve any physical or emotional risk to you beyond that of everyday life.

What Are The Benefits of Participating In The Study?

There may be a possible indirect benefit to participation in this study such as talking about or reflecting on an experience may lead to a better understanding of oneself. You may also not benefit directly from participating in this study. The goal of this research is to gain knowledge about the experience the provider has in caring for the refugee population with the hope of improving the quality of health care delivered

What Other Options Are There?

You may choose whether or not to participate in an interview.

Are There Any Costs?

There are not financial costs involved in this study.

What Is the Compensation?

You will not be paid to participate in this study.

Can You Withdraw?

You may discontinue your participation in this study at any time.

What About Confidentiality?

A research record will be kept in a confidential form at the UVM College of Nursing. The security of your record will be maintained by keeping all files confidential and participants will only be identified as a number. The results of this study may eventually be published and information may be exchanged between investigators, but your confidentiality will be maintained. The sponsor Jeanine Carr or their appointed designees as well as the Institutional Review Board and regulatory authorities will be granted direct access to your original research records for verification of research procedures and/or data.

Contact Information

You may contact the Principal Investigator Ashley MacDonald eat 978-973-0113 or Dr. Jeanine Carr, the faculty sponsor in charge of this study, at 802-656-2253 for more information about this study. If you have any questions about your rights as a participant in a research project or for more information on how to proceed should you believe that you have been injured as a result of your participation in this study you should contact the Director of the Research Protections Office at the University of Vermont at 802-656-5040.

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Statement of Consent

You have been given and have read or have had read to you a summary of this research study. Should you have any further questions about the research, you may contact the person conducting the study at the address and telephone number given below. Your participation is voluntary and you may refuse to participate or withdraw at any time without penalty or prejudice.

You agree to participate in this study and you understand that you will receive a signed copy of this form.

Signature of Subject

Date

This form is valid only if the Committees on Human Research's current stamp of approval is shown below.

Name of Subject Printed

Signature of Principal Investigator or Designee

Date

Name of Principal Investigator or Designee Printed

Name of Principal Investigator: Ashley MacDonald Telephone Number: 978-973-0113

Name of Faculty Sponsor: Jeanine Carr Address: Rowell 228 – University of Vermont Telephone Number: 656-2253

> Committee on Human Research Date Approved <u>11-05-2015</u> CHRBSS# <u>10-125</u>

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Appendix C

Interview Questions

1	What is your title in current position and length of time spent in current position?
2	What is your motivation for working with the refugee population?
3	Tell me about how you became interested in working with the refugee population.
4	What is satisfying about working with the refugee population?
5	What are your general feelings about working with this group?
6	What is your experience meeting their health needs?
7	What is your experience with interpretation services?
8	What is your perspective on meeting their health needs?
9	What are your thoughts on policy issues in the current healthcare systems that affect the refugee populations?
10	What are your thoughts on the types of resources needed to improve care?
11	How do you feel about the support and training you have received in caring for this population?
12	What is your experience with support surrounding mental health issues within this population?

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