



2019

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### Recommended Citation

Mutitu, Anne; Zabler, Bev; and Holt, Jeana M. (2019) "Refugees' perceptions of primary care: What makes a good doctor's visit?" *Patient Experience Journal*: Vol. 6 : Iss. 3 , Article 5.

DOI: 10.35680/2372-0247.1382

Available at: <https://pxjournal.org/journal/vol6/iss3/5>

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### Cover Page Footnote

Funding Acknowledgement This project was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) Nurse Education, Practice, Quality and Retention (NEPQR) Interprofessional Collaborative Practice (IPCP) and Interprofessional Education (IPE) Cooperative Agreement under grant number, UD7HP28542, for \$1,337,115. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government. This article is associated with the Patient, Family & Community Engagement lens of The Beryl Institute Experience Framework. (<http://bit.ly/ExperienceFramework>). You can access other resources related to this lens including additional PXJ articles here: [http://bit.ly/PX\\_PtFamComm](http://bit.ly/PX_PtFamComm)

## Refugees' perceptions of primary care: What makes a good doctor's visit?

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### Abstract

Redesigning primary care is a national priority, as the United States (US) struggles with issues of poor access, high cost, and suboptimal quality. Refugees are among the populations who suffer from America's disjointed health care system, resulting in disproportionate health disparities. Although there are many studies on refugee health, few share refugees' perceptions of primary care. We asked local refugees who were seen for primary care services at a midwestern academic nurse-led clinic, what makes a good doctor's visit? The clinic served as the hub of a federally funded refugee Community Centered Health Home (CCHH) pilot project. This qualitative study adds to the growing body of literature that captures the voices of resettled refugees as they reflect on their health care experiences in their new home. The purpose of this study was to elicit the criteria refugees used to evaluate the quality of their care. Individual interviews were conducted with seven refugees as part of the larger CCHH pilot project. Through qualitative thematic analysis, four themes were identified that participants considered aspects of a "good visit": 1. The ability to communicate without language barriers; 2. Open reciprocal dialogue with providers; 3. Provider professionalism; and 4. Accurate diagnosis and treatment. We offer recommendations to improve patient experience in the refugee population which may lead to better health outcomes. Future study is proposed to gain knowledge of how refugee perceptions of quality of care may change over time as they become more familiar with US health care system.

### Keywords

Refugees, primary care, patient-centered care; patient satisfaction; patient experience; quality of care; nurse-led care; qualitative method

### Introduction

Redesigning primary care is a national priority, as the United States (US) struggles to solve issues of poor access, high cost, and suboptimal quality. Refugees are among the populations who disproportionately suffer from health disparities.<sup>1,2</sup> Since 1975, more than three million refugees from 125 different countries have fled to the US in search of a better life. According to the United States Committee for Refugees and Immigrants, 263,662 refugees were residing in the US in 2014.<sup>3</sup> Refugees often flee from violence and human rights violations in unstable countries to places of exile, where nearly two thirds will spend at least five years awaiting a permanent home.<sup>4</sup> Additionally, while living in uncertainty without economic or social stability, refugees are especially vulnerable to poor health outcomes.

Once in the US, refugee populations continue to face barriers to receiving optimal care. Barriers include language differences, a lack of knowledge about how to navigate the complex US health care system, and misalignments of their cultural preferences and traditions with Western medicine.<sup>5-12</sup> The incongruence in the known health care system of the refugee's homeland and

the US system may contribute to a significantly lower health care utilization than that of the national population.<sup>13</sup> Lower use persists despite all refugees receiving federally funded Refugee Medical Assistance (RMA) for eight months from their date of arrival in the US.<sup>14</sup>

Navigating the US health care system is a major challenge for refugees, and significantly adds to their stress and hardship during resettlement.<sup>10, 15-19</sup> This includes their utilization of primary care services. In the US, nurse-led clinics have emerged over the past 40 years as an effective primary care delivery system, most often staffed primarily by Advanced Practice Registered Nurses (APRNs).<sup>20,21</sup> Nurse-led clinics were formally recognized as a primary care delivery model in the Affordable Care Act.<sup>22</sup> The primary care services in nurse-led clinics have become more critical in the US health care system, in part, because of their philosophy of comprehensive and coordinated care and the willingness of APRNs to provide care to vulnerable populations including refugees.<sup>23</sup>

Primary care services are the cornerstone of a strong health care system that ensures positive health outcomes and health equity.<sup>24</sup> Evidence shows the quality of health

care services at nurse-led clinics, delivered by APRNs have met and exceeded national benchmark standards of care.<sup>20-21</sup> These studies validate the increasingly important role that nurse-led clinics play in the health care safety net, provide evidence of quality care, and confirm the cost-effectiveness of APRNs' care for vulnerable populations.<sup>22-23</sup> While there are wide variations in public, academic and private nurse-led care practices, they share the common goal of creating health care that is highly reliable, value-focused, patient-centered, high in quality, and safely delivered.<sup>24-27</sup>

All these characteristics of nurse-led primary care relate to an improved patient experience, which is a current metric in primary care. The overall goal of the "Triple Aim" of the Institute for Healthcare Improvement (IHI) is to optimize the performance of health systems.<sup>28</sup> The Triple Aim has three linked dimensions: 1) improving the individual experience of care, 2) improving the health of populations, and 3) reducing the per capita costs of care for populations. This study addressed the first dimension, the individual experience of care, through exploring refugees' perception of primary care quality, or in their words, 'a good doctor visit.'

This study was part of a larger federally funded project, *Teaching Today's Students for Tomorrow's America* (TTSTA), serving refugees in Milwaukee from 2015-2018. One outcome of the project included the creation of a refugee community-centered health home (CCHH).<sup>29</sup> An interprofessional collaborative practice (IPCP) was implemented through an across-system CCHH partnership, including an academic community-based nurse-led clinic, a health care system (HCS) refugee health screening site, and a community-based organization (CBO) focusing on refugee resettlement.<sup>30</sup> The CBO resettled primarily African refugees in the neighborhood near the nurse-led clinic. In the CCHH partnership, the interprofessional collaborative practice project team offered resettled refugees primary care services at the nurse-led clinic and education on the US health care system during their CBO resettlement visits and HCS health screenings. The project goals were to improve access to and quality of primary care for refugees while educating current and future health care providers to better serve this population.

This qualitative study adds to the growing body of literature that captures the voices of newly resettled refugees as they reflect on their overall primary health care experiences in their new home.<sup>10,15,16,18-19</sup> There are many studies on refugees' health, including the challenges refugees experience gaining access to health care and few that examine the quality of their visits.<sup>1,5,6,15,31-35</sup> No studies were found that focused on refugees themselves defining quality health care. The purpose of this project was to elicit the criteria that refugee patients at a Midwestern

urban academic nurse-led clinic used to evaluate the quality of their primary care.

## Methodology

Semi-structured audio recorded interviews were conducted as part of a study on patient-perceived quality of primary care at a Midwestern, urban, academic nurse-led clinic. As a critical sub-population, refugee patients who received primary care at the nurse-led clinic were contacted to be interviewed for their perceptions of a "good doctor's visit." The first author conducted all the interviews to facilitate the consistent gathering of qualitative data.

The term "doctor" was used in this study since the TTSTA project team noted that the refugee patients used that term to designate anyone providing health diagnoses and treatments. Refugees referred to the advanced practice nurses as "doctors" regardless of academic achievement. Also, the term "doctor visit" is a generic term used by the refugee patients to refer to any health care encounter. Therefore, to capture data on the refugee patients at this nurse-led clinic, the term "doctor's visit" was used in the interview questions. Before conducting the study, approval was granted by the administration of the nurse-led clinic and by the University Institutional Review Board.

## Participants

The first author recruited and interviewed a convenience sample of seven refugee patients, 18 years of age and older, who received primary care at the nurse-led clinic between January 1, 2016, and January 15, 2017. The inclusion criteria for this study was intentionally broad to allow for diverse experiences of adult refugee patients who migrated to the U.S from any African country. The sample criteria excluded individuals who were less than 18 years, had a diagnosis of mental illness or cognitive delay, and refugee patients for whom a linguistically appropriate translator could not be found.

A list of ten patients, who met the inclusion criteria, was obtained through the nurse-led clinic's electronic health record (EHR). Seven of the refugee patients responded to an initial call from the first author through an interpreter and agreed to be interviewed. One patient was contacted and declined to be interviewed. The remaining two had relocated to different states and we were unable reach them with their contact information on record. Seven refugees completed face-to-face interviews.

Table 1 displays the demographics of the participants' sample. Dates, location, and time for the interview were chosen based on the patient's preference.

The individual interviews of all seven refugee participants were conducted face-to-face by the first author. After

**Table 1. Demographics of Refugees Participants (Patients) (N=7)**

Characteristics	Number of Patients	Percent
Gender		
Male	6	86
Female	1	14
Age (years)		
Range	26 - 62	--
Mean (SD)	38.57 (11.802)	--
Length of time in the US		
0-3 months	0	0
4-12 months	3	43
1-5 years	4	57
Over 5 years	0	0
Country of Birth		
Ethiopia	2	28
Eritrea	5	72

completing a patient-perceived quality survey, one open-ended question, *what makes a good visit with your doctor*, was asked followed by clarification questions specific to each participant's response. Examples of these questions include 1. *Were you satisfied with the doctor appointment?* 2. *How would you improve your doctor's visit?* 3. *What is it that your doctor needs to know to care for you well?* 4. *What would make a difference for a better visit to your doctor?*

Professional translators interpreted for six of the interviewees whose preferred language was Tigrinya. The preferred methodology was to have a face-to-face professional translator available. A limited number of professional Tigrinya interpreters were available locally. Five interviews were conducted face-to-face and one interview was conducted using a professional telephonic translation service. The final interviewee did not require a translator as he was proficient in speaking English and declined translation services. All the interviews were audio recorded, professionally transcribed and de-identified before returning to the authors. The interviewer also recorded field notes as part of the interview process.

### Data Analysis

A qualitative thematic analysis was conducted across the de-identified interview data.<sup>36</sup> Content of the transcribed interviews were coded through multiple iterations by the authors. Themes were initially derived by the authors independently to identify and describe patterns in the data by question. First, the authors derived themes from the question on the participant's perception of a good doctor visit. Then, the authors reviewed the responses to the question regarding the participants' perceptions of their experiences of what makes a good doctors' visit and quality of care. The authors used the same iterative process

to identify and describe patterns of data by questions as a group until they reached consensus on the themes.<sup>36</sup>

### Results

All seven interviewees replied to one open-ended question: What makes a good doctor visit? Four themes emerged from their responses (1) *The ability to communicate without language barriers*. This theme was discussed by all the seven interviewees (100%) as a major indicator to quality of care. (2) *Open, reciprocal dialogue with providers*. This second theme was mentioned among four (57%) of the interviewees as a consideration to quality of care. (3) *Provider professionalism*. This theme was a concern to six (86%) of the interviewees. and (4) *Accurate diagnosis and treatment*. This theme also ranked high by all interviewees (100%) as a characteristic of quality of health care just as ability to communicate without language barriers. These themes will be explained in the following sections with qualitative exemplars supporting the themes.

#### *The ability to communicate without language barriers*

The ability to communicate despite language barriers emerged as an integral marker for the quality of care. One participant shared, "There was an interpreter there, so the visit went okay." Most interviewees preferred that the provider would speak their language. Some refugee respondents indicated that a language barrier was the main obstacle to accessing the care that they need. "My problem is the language barrier.... Yeah, because I can't do it on my own." Many who had difficulty communicating with health care providers in the past felt reluctant to seek additional medical services. As one refugee patient stated, "I have to find somebody or an interpreter to help me interpret." Another refugee mentioned the challenges of speaking English as a second language and the difficulties

of having to communicate through an interpreter. Some refugees reported not having interpretation readily available during health care visits. The ability to adequately communicate with their health provider was perceived as a barrier to quality care.

#### ***Open, reciprocal dialogue with providers***

The theme of open, reciprocal dialogue with providers emerged as an essential aspect of the participants' perceptions of primary care quality. As one refugee specified, the doctor "should have an open discussion with you regarding your health." All the interviewees expressed their desire for "a chance to explain" their health concerns and ask questions. One participant explicitly stated, "When I visit a doctor, I go to let them know what I'm feeling and for them to let me know what's going on and give me answers, which I need to get." Another explained, "I just want to tell (the doctor) what my problems are."

#### ***Provider professionalism***

The theme of provider professionalism was threaded throughout the interviews of the refugees. Some interviewees mentioned that they expected their doctor to be professional when providing care. One aspect of professionalism mentioned by an interviewee was punctuality. "The doctor is supposed to be there on time." Another expressed that professionalism included care coordination, where the doctor "helps me follow up" with health services. A sense of caring was also considered part of professionalism by one interviewee. "When the patient comes, they are supposed to get encouragement." One interviewee included outreach as an aspect of professionalism. They wanted "a doctor who can care about me and will contact me." Finally, empathy was voiced by one refugee interviewee as an important indicator of professionalism in a health care provider, saying, "treat me as a sick person or as a patient, that's my expectation."

#### ***Accurate diagnosis and treatment***

A final quality marker the refugee participants identified was the ability to receive accurate diagnosis and treatment. As one participant specified, "find out the disease or sickness" or as another succinctly expressed, "solve the problem," which was echoed by most of the interviewees. Another interviewee clearly stated, "I expect him to find out what my disease is (during the visit)." Refugee patients may be disappointed if their provider refrains from making a definitive diagnosis and refers the patient to a specialist for further testing. Refugee patients believe that seeing one health care provider is a 'one-shop-stop' doctor visit and they expect to have all their health care needs to be resolved in that one visit.

## **Discussion**

For a refugee, expectations for health care practices in their resettled home are shaped by their varied experiences. Refugees may have health care experiences in their country of origin, during their migration to their new home, and dwelling in refugee camps.<sup>9,24,31</sup> The fragmented nature of the US health care delivery system may be frustrating to newly arrived refugees. Often before entering the US, a sole provider met all their health care needs, in one location. Primary care practices in the US need to develop models of care that holistically address the complex needs of refugees and provide education on navigating the health care system to serve this vulnerable population better.<sup>42</sup> The next sections of the discussion will address each of the four themes relating to refugees' perception of primary care quality and their criteria of what makes "good doctor visit" more in-depth. This will be followed by a summary of recommendations based on the findings and finally, discussion of the study limitations.

#### ***Theme 1: The ability to communicate without language barriers***

One of the challenges to achieving quality primary care for refugees is the language barrier. It is difficult for patients who are early English language learners to engage with their health providers fully and advocate for their health care needs. A language barrier may prevent refugee patients from disclosing personal health information and understanding test results and treatment plans.<sup>9,31,37</sup> Results from numerous studies demonstrate that delaying medical care leads to adverse health outcomes.<sup>15,38-41</sup> The participants in this study reported interpreter services assisted in communicating with their provider. They preferred a provider who spoke their language as this was their experience in their countries of origin. Hence providing care coordination with translation services could encourage refugees to seek medical care, ensure the quality of care, and improve their perceptions of health care delivery.<sup>16,34,38,41,42</sup> Affordable Care Act rules, enacted in 2016, significantly affect the law of language access, mandating all health care services to offer "qualified interpreters" to immigrants including refugees and limited English proficient patients either in person or remotely via telephone or remote video devices.<sup>40</sup>

#### ***Theme 2: Open reciprocal dialogue with providers***

Ensuring that the voices of patients are known in healthcare including their experiences and expectations, opens an avenue where they may become more involved in their care. Their role in defining and judging the quality of care and contributing to client assessment of care may become motivators to healthcare services' efforts in client-centered care provision.

Ellis et al. found that a lack of cultural awareness forms a barrier in providers' relationships with patients from other countries.<sup>43</sup> Spirituality and religion are dimensions of culture and play a significant role in the refugee population's motivation to access or avoid health care services.<sup>10,43-45</sup> Some of the refugee patients in studies by both Cavers and West et al reported forgoing some health care services in favor of prayer and spiritual healing by community religious leaders.<sup>44,45</sup> An open dialogue with patients could help uncover the spiritual and traditional beliefs that influence their patients' overall approach to health. These insights could help a provider offer supportive care and improve health outcomes.

### **Theme 3: Provider professionalism**

Some of the refugee participants in this study identified professionalism in their providers as another marker of health care quality. Provider professionalism in primary care was not found in the literature as an aspect of quality until recently.<sup>44-48</sup> A study by Kennedy et al identified quality of care in primary care.<sup>47</sup> The same professional attributes such as listening, explaining, and thoroughness were affirmed by this study's refugee participants.

The predominant markers of health care quality in the current primary care literature include a person-centered approach to care, appropriate diagnosis, and treatment of common conditions, and coordination and integration of specialty care.<sup>34</sup> Aspects of person-centered care and care coordination align with the expectations voiced by the refugees in this study for provider professionalism.<sup>15,34,49-52</sup>

Several articles discussed the notion of professionalism related to the quality of care specific to the health care professions of medicine and nursing.<sup>39,44,45,47,48</sup> Cavers emphasized that doctors were to uphold the virtues of professionalism and by holding one another accountable.<sup>44</sup> This would enhance their professional satisfaction and the patient experience and provide the highest standard of health care. Providers maintaining professionalism through cultivating their interpersonal and communication skills can support while improving their patients' deal with their barriers and generate the best possible patient experience.<sup>47</sup>

An evidence-based practice project by West and colleagues showed the standardization of nurse uniforms in health care systems had a positive impact on patient experience.<sup>45</sup> They found by decreasing the variation in nurse appearance, the patient increased their focus on the quality of care. Surprisingly, a consistent professional image of the nurse yielded better perceived patient experiences. Attending to the elements of professionalism is necessary for all providers as patients are becoming more involved with their health care, and their expectations of quality care are changing. Ensuring health care is convenient, and

available, with good and attentive services allow the patient's expectations to be met.<sup>39-42, 44-50</sup>

### **Theme 4: Accurate diagnosis and treatment**

Refugees expected a diagnosis, treatment, and resolution of health conditions during their doctor visit. This expectation may have been the norm in their countries of origin. The reality of the US primary care system, with its 10 to 15-minute appointment times, is that most often patients need to schedule follow-up appointments, obtain health care specialist referrals, and reconcile health insurance coverage limitations. Multiple researchers found that refugees often struggle with the navigational challenges of the US health care system, which are different than their experience in their country of origin.<sup>10,15,19</sup>

The theme of *Accurate Diagnosis and Treatment* in this study supported the findings by Worabo et al. and Ospina et al., whose results indicated that the National Center for Quality Assurance Primary Care Medical Home (PCMH) model can be especially beneficial for refugees because it allows patients to make their initial and follow-up appointments with the same provider at the same location.<sup>49-51</sup> Continuity of care with refugee patients enhances trust, which, in turn, will aid in refugees' acceptance of concepts that may be new to them, such as preventative care, health screenings, infectious disease management and chronic illness management.<sup>31,32,51-53</sup> Therefore, the US health care system needs to continue to evolve new models of primary care delivery, listening to the voices of all patients, and include their experiences and expectations to improve the quality of care.

### **Implications for Practice**

The themes emerging from this study on refugees' perceptions of quality primary care can inform strategies for assisting newly arrived refugees to navigate the US health care system. A patient-centered care approach is needed to direct the clinical encounter to specific aspects that matter to each patient. Providers must adhere to the federal policy by providing language services in health care practices by having readily available qualified translation services and translated health materials.<sup>22</sup>

Also, health care providers must not assume that refugee patients are facing the same barriers to quality health care that other marginalized populations experience. Providers need to look beyond commonly known barriers to recognize the unique barriers associated with the refugee experience of resettlement and acculturation.<sup>15</sup> When serving refugee patients, health care providers need to keenly listen to each patient and address health care needs related to his or her resettlement journey, such as exposure to communicable diseases, malnourishment, post-

traumatic stress, and unmanaged care of chronic diseases.<sup>51-52</sup>

The Center for Immigration Studies reported that the US population is continually changing and diversifying due to immigration.<sup>53</sup> For providers to have a mutual exchange with the refugee patients they serve, they need to bridge standards of care with cross-cultural care practices that are meaningful to their patients. Although most health care providers are aware of the importance of culturally competent care, it is one thing to know it and another to do it.

Leininger's Cultural Care Theory emphasizes that cultural awareness is the beginning of cultural competency.<sup>54</sup> Therefore, increasing cultural awareness and education among health care providers is vital to the efforts to provide quality care to culturally diverse populations. This theory further highlights the importance of cultural competency in a cross-culture care environment. Similarly, Worabo et al discuss the relevancy of health care providers to maintain the concept of culture preservation refer to actions that allow individuals from any culture to retain and preserve relevant values. Hence, the refugee patients can feel accepted and supported.<sup>51</sup>

Although this study focused on refugee patients' perceptions of quality primary care, the findings could be useful in other health care settings. This study highlighted refugee patients' perceptions of quality of primary care. The study findings may be used to implement changes in practice to better serve and care for refugee patients as their voices are heard. And, hopefully, these findings may also inform care for other vulnerable populations.

As more refugee patients are being served in the US health care system, there is an urgency among interprofessional stakeholders to consider patient perceptions of quality in future policy decisions. Fennelly urged health care providers to advocate for better care for refugee populations, including increasing eligibility for health insurance, providing education about navigating the US health care system, and formalizing training for providers about the unique health care needs of this population.<sup>55</sup>

A recent concept analysis of patient experience in primary care, Holt explained that when patients feel listened to and partnered with in the deliverance of health care, they report positive health care exchanges, improving the patient experience.<sup>56</sup> Interviewing refugee patients in this study allowed them to be more engaged in their care. Primary care providers need to regularly ask their refugee patients about the quality of their care. By sharing their experience and expectations of health care, refugees can influence quality of care and health care delivery practices, which in turn may ultimately improve refugee patients' perception of care. Continual appraisal of refugees' experience of care is needed as their expectations of "a

good doctor visit" may evolve. A future study is recommended to gain knowledge of how refugee perceptions of quality of care may change over time as they become more familiar with the US health care system.

### Limitations

The results of this study may not be generalizable to the broader refugee population in the US as the participants represented a specific clinic sample. Most of the participants were from only two African countries (Table 1) due to the CBO resettling primarily African refugees. Refugees from other continents may differ in how they perceive quality primary care. Further, only one participant was female, limiting voices across genders. Finally, the small sample of refugee patients in this study may not reflect the same themes of satisfaction and perception of quality that a larger sample might identify.

### Conclusion

Patient's perception of the delivery of high quality of health care is a precursor to positive health care experiences. As part of its "Triple Aim," the IHI describes the "patient experience of care as including both care quality and patient satisfaction, suggesting that these features are interrelated".<sup>57,58</sup> A strategic focus on gathering and evaluating patient feedback along the care continuum is essential to improve the health of populations continually. Significant findings for quality improvement from these interviews of refugee primary care patients in a nurse-led clinic included issues such as cross-cultural care, language barriers, communication, and professionalism. The results of this study provide support for other health care settings which render services to refugee patients in their efforts to improve the patient experience within their facilities.

It is a fundamental principle in quality improvement that patients have a voice in evaluating the care they receive. This study allowed refugee patients to share their health care experiences and expectations. It was evident from their responses that these refugee patients wanted communication without language barriers; valued understandable, open dialogue with providers; and desired provider professionalism and accurate diagnoses and treatments, facilitated by continuity of care with the same providers. Further exploration of the refugee's perceptions of quality health care would add to the small, but growing body of literature relevant to refugee patient experiences and expectations. Consideration of patient experiences and expectations has the potential to increase satisfaction, improve methods of delivering care, and support the redesign of care practices to promote wellness, safety, and quality of care in all health care settings while decreasing or containing costs.



## Funding Acknowledgement

This project was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) Nurse Education, Practice, Quality and Retention (NEPQR) Interprofessional Collaborative Practice (IPCP) and Interprofessional Education (IPE) Cooperative Agreement under grant number, UD7HP28542, for \$1,337,115. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government

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