Experiences of Healthcare Among Sudanese Refugees and Their Healthcare Providers

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Abstract

Refugees experience significantly more traumatic events than the general population (Ehntholt & Yule, 2006), which has been correlated with high rates of physical and mental health concerns (Bentley, Thoburn, Stewart, & Boynton, 2012). Several unique barriers have been noted that may prevent refugees from seeking healthcare (Eckstein, 2011). The present study employed a qualitative design to explore refugees' experiences when seeking healthcare and the perspectives of healthcare service providers who work with them. Refugee participants tended to express positive views of the United States (US) healthcare system, providers, and quality of care. Their primary concerns were scheduling medical appointments in advance and receiving last minute reminder phone calls about the appointments, struggling to communicate with providers due to limited English fluency, and a lack of knowledge about their health insurance coverage and mental healthcare options. Providers expressed concerns related to time constraints, language barriers, and lack of formal training in refugee healthcare.

Keywords: Refugee health, Sudanese, healthcare utilization, mental health

Experiences of Healthcare Among Sudanese Refugees and Their Healthcare Providers

According to the most recent figures, there are approximately 10.5 million refugees worldwide (United Nations High Commissioner for Refugees [UNHRC], 2011). In 2011 alone, 800,000 individuals were displaced as refugees across international borders, the highest number in more than a decade. As of January 2014, the UNHCR estimated that 649,331 refugees, world-wide, originated from Sudan. Sudanese refugees have been displaced from their homes due to two decades (1983-2005) of continuous civil war in their homeland. The war stemmed from ethno-religious conflict between Muslims and non-Muslims. In addition, in 1983 oil was discovered around the border of the southern territory of Sudan which escalated the conflict such that citizens of the southern territory were killed in an attempt to pump southern oil into northern Sudan (Beswick, 2001). Citizens fled the country due to mass killings, sexual slavery, and gang rapes perpetuated by government and rebel forces alike (British Broadcasting Corporation, 2014).

The gendered components of war have been documented by several sources (Beswick, 2001; Mosher & Clark, 2001; Turshen, 2001). Militarism uniquely affects women in that it intensifies women's subordination and escalates the violent acts performed against women. When women flee conflict zones it is often assumed that they are provided security in "safe havens." Unfortunately it is at these times that insecurity and violence often intensify for women since they may have left their male family members in their homeland. Refugee camps are a specific example of a place where legal and societal rules and laws that dominated in their home countries break down (Turshen, 2001). Therefore, women's voices are especially important to represent because their perspectives are often muted and left unheard (Beswick, 2001).

The traumatic nature of the aforementioned events can often result in refugees experiencing severe emotional states during and after their migration. Helplessness, grief, anxiety, depression, somatization, shame, anger, survivors' guilt, sensitivity to injustice, and shattered assumptions are all examples that have been documented in previous literature (Victorian Foundation for Survivors of Torture [VFST], 1998). In addition, such pre-and post-migration trauma may also affect physical and mental health once resettled (Tempany, 2009; Tipping, Bretherton, & Kaplan, 2007; Schweitzer, Melville, Steel, & Lacherez, 2006).

A number of studies have focused on the specific pre-and post-migration trauma experiences of Sudanese refugees. For instance, pre-migration traumas (i.e., separation from family, experiencing violence, witnessing murder of family or friends, deprivation of basic needs, rape) among Sudanese refugees were significant predictors of post-migration mental well-being, as it was directly related to posttraumatic stress disorder (PTSD) symptoms and somatization (Tempany, 2009; Tipping et al., 2007; Schweitzer et al., 2006). Post-migration difficulties (i.e., family not living in the host country, unemployment, adjusting to the cultural life) also predicted psychological well-being. Specifically, more difficulties in post-migration resulted in increased depression, anxiety, and somatization (Schweitzer et al., 2006). Further, female refugees appear to experience more mental health problems than male refugees (Tipping et al., 2007). Overall, the existing literature supports a strong connection between pre-migration trauma and increased rates of mental health problems among refugees.

The literature on trauma and physical health reveals that trauma survivors disproportionately utilize the healthcare system by presenting to medical facilities with both physical and emotional symptoms (Rosenberg et al., 2000; Solomon & Davidson, 1997). Individuals with PTSD average at least 30% more health care visits with physicians than individuals with partial PTSD or no PTSD (Deykin et al., 2001) and are more likely to seek treatment from medical providers than they are from mental health providers (Calhoun, Bosworth, Grambow, Dudley, & Beckham, 2002). Specific considerations must be given to trauma survivors who are also refugees because of unique documented social and cultural differences (Goodman, 2004; Kirmayer, 2001; Kirmayer, 2006; Schoevers, van den Muijsenbergh, & Largo-Janssen, 2009).

Refugees often present to their primary care physician with the following physical health concerns: musculoskeletal and pain issues, infectious disease, and longstanding undiagnosed chronic health conditions (Eckstein, 2011). Studies addressing the specific physical health complaints amongst Sudanese refugees were unable to be located. Refugees also tend to present to their primary care physician with mental health concerns that manifest in the form of physical complaints for which there are no known organic pathologies (i.e., pain, fatigue, and gastrointestinal issues; Kirmayer et al., 2004). However, unlike individuals from the majority culture, refugees' complaints can often go unrecognized as mental health concerns because patients from minority cultures tend to rely on culture-specific bodily idioms ("in my blood I can feel hunger because my brother is suffering. In my stomach I am okay, but in my blood I am suffering," [Goodman, 2004, p. 1184]) to express their level of distress (Kirmayer, 2001). Further, previous literature has found that refugees may be hesitant to report mental health symptoms to physicians because they are afraid that their concerns will not be understood or will be deemed inappropriate for a medical setting (Schoevers et al., 2009; Whitley, Kirmayer, & Groleau, 2006). Although, the literature has documented the presenting health problems of several refugee groups, few have been specific to the Sudanese.

In recent years exploring the barriers to healthcare utilization in refugee populations is an area that has received a significant amount of research attention. Specifically, studies have demonstrated that the following barriers are prevalent in many refugee groups: language difficulties, lack of information about the health care system in the host country (i.e., insurance systems, types of physicians, etc.), and social status and integration (Eckstein, 2011; Kirmayer et al., 2011; Norredam, Mygind, & Krasnik, 2005). Some suggestions for addressing barriers include: specifically asking about refugees' perceptions of barriers (i.e., factors that they believe prevent them from using the health care system), using trained interpreters, meeting with families, and consulting with community organizations (Kirmayer et al., 2011). Although there are specific suggestions for addressing barriers, studies addressing the implementation and effectiveness of the proposed strategies have not garnered the same attention. The main purpose of the current study was to understand the experiences of Sudanese refugees seeking healthcare in the US as well as potential barriers and facilitators of care.

Finally, the previously stated findings also suggest the need to assess physicians' understanding and experiences working with refugee patients. Although this issue has yet to be well documented, some important contributions have been made to detail the struggles practitioners face in addressing refugee health needs. For instance, practitioners often struggle to obtain medical records of refugee patients which can decrease continuity of care (Jones & Gill, 1998). Further, language barriers, time pressure, and cultural differences are hurdles for providers who work in refugee healthcare (Burnett & Peel, 2001; Jones & Gill, 1998; Ramsey & Turner, 1993). In addition to these studies, papers have been written advising practitioners on how to best work with refugee patients (Adams, Gardinier, & Assefi 2004). Specifically, Adams and colleagues (2004) advocate for providers to understand refugees' quality of life in refugee camps, use of herbal or traditional medicines, reproductive history and ritual female genital surgery, trauma history and somatization. The current study investigated health providers' experiences working with refugee patients.

In sum, the current qualitative study aimed to understand and describe refugees' experiences when seeking healthcare in the US and the perspectives of healthcare service providers who work with them. A key focus of the current study was to understand the refugees' and healthcare providers' perceptions of barriers and facilitating factors when accessing healthcare services.

Method

Participants

Participants included five Sudanese women with US refugee status and five medical professionals who work with refugees in the US healthcare system. The Sudanese women ranged in age from 23 to 39 years and all were married with children. One participant reported a college education, one reported an "elementary" education, one reported completing the equivalent of sixth grade, one explained that she had no formal education but studied the Koran, and one reported having received no education. They were all unemployed at the time of the interview and four of the five participants stated that they were actively searching for employment. All of the women self-identified as practicing Muslims. At the time of the interview, the participants reported that the length of time since their resettlement in the US ranged from 8 months to 5 years. Each participant had medical insurance coverage at the time of the interview.

The medical professional sample was comprised of two registered nurses and three physicians. Four of the participants identified as female and the other as male. They ranged in age from 34 to 60 years and their time in their respective professions ranged from 17 to 38 years for nurses and 7 to 8 years for physicians. Participants reported that the total number of refugees seen throughout their careers ranged from 100 to 120. Participants' answers varied when responding about the specific number of Sudanese refugees they have treated over their career such that two participants did not provide an answer, one could not estimate the number, and the other two reported working with between 16 and 50 Sudanese refugees. In regards to race and ethnicity, two participants identified as Caucasian, one as African-American, one as Japanese, and one as half Chinese and half Caucasian.

There were seven researchers involved in the data collection, between interviewing and data analysis. Six of the researchers were doctoral candidates in clinical psychology and the other was a doctoral level psychologist. Five of the researchers performed coding during data analysis and two participated in administering the interviews to participants. Two of the researchers identified as male while the rest identified as female. The researcher who completed the refugee interviews identified as a Caucasian female and the researcher who completed the healthcare provider interviews identified as a Caucasian male. No researchers endorsed refugee status. Two of the coding researchers identified as Caucasian, one identified as South Asian, and two others identified as Asian-American.

Procedure

According to Patton (2003), purposive sampling is a conscious selection of a few data sources that meet particular criteria. In this case, the criteria were as follows for refugee participants: Sudanese individuals over the age of 18 years who were displaced to the US from Sudan with no evidence of active psychosis or neurocognitive disorders as reported by the referring case workers. Criteria for medical professional participants included individuals who have current or past experience working with refugee populations on, at least, a weekly basis.

Refugee participants were recruited through the assistance of a public non-profit refugee resettlement organization located in a large urban area in the Northeastern section of the US.

They were invited to take part in the current study through a written description detailing the aims of the study, time frame of interview, compensation for participation, and provision of interpretation during interview. The description was translated into Arabic by the translation service at the non-profit organization and then dispersed by an agency case worker. Five women were provided with the invitation to participate and all five agreed to participate and were purposely selected for the study. The five medical professional participants were also purposefully recruited with the assistance of the healthcare coordinator of the non-profit agency mentioned above. The coordinator put the primary investigator into contact with a nurse at a local primary care clinic for the initial medical professional interview. Further participants were recruited via word of mouth through established participants as well as through personal contacts of one of the authors. Approximately eleven medical professional participants were contacted personally to participate in the study (45% response rate). A memo detailing the study was also posted in one of the refugee health clinics but this did not yield any inquiries about participation.

All participants were provided with a consent form detailing the purpose of the research, expectations of participation, risks and benefits of participating in the study, limits of confidentiality and data protection, and compensation for participation ($20 gift card to large chain discount store for refugees, $10 gift card to coffee shop chain for medical providers). In the consent form provided to refugees there was also a section noting that they would be provided with interpretation services in the interview at no cost to them. Further, it was made clear to all participants that they could choose to stop the interview at any time without being penalized and still receive compensation.

Qualitative data was collected from the refugee participants through individual interviews with the author of the study and from the medical professionals through individual interviews with a trained research assistant. Both interviewers were clinical psychology doctoral students. The refugee participant interviews took place in a private room at the non-profit agency noted above and lasted approximately 70 minutes. The interviews for the medical professionals were held either in a private room at their place of employment (health clinics) or via telephone and lasted approximately 30 minutes. All interviews were audio-recorded. Interviews with the refugee participants were conducted with the assistance of a phone interpretation service. The service provided interpretation between English and Arabic, or Sudanese Arabic.

An interview guide with relevant open-ended questions guided the face-to-face interviews. The interview guide for the refugee participants included questions that requested the participants to describe (a) their general well-being (i.e., mental and physical) after arriving in the US, (b) their general well-being before their flight from Sudan, (c) their utilization of medical and mental health resources both pre- and post-resettlement, and (d) general challenges in obtaining health care after resettling in a new country. Sample prompts include: “How have you been feeling since arriving in the US?,” “How were you feeling before you relocated to the US?,” “What surprised you about your first doctor’s visit in the US?,” “What type of doctors have you seen in the US?,” “What prevents you from attending doctor appointments?,” “What helps you to attend doctor appointments?,” and “Tell me about your healthcare experiences before relocating to the US.”

The interview guide for medical professionals was comprised of questions addressing (a) medical professionals’ general experiences providing healthcare to refugee patients, (b) unique factors associated with refugee health appointments, and (c) training opportunities in the area of refugee health. Sample prompts included: “Walk me through an appointment with a refugee,” “What is your experience when working with Sudanese refugees?,” “What similarities and differences do individuals from these populations present with in treatment compared to other refugee populations?," "Describe your experience working with translators," and "What training are you provided to work with refugees?."

The Refugee Health Screener (RHS-15; Pathways to Wellness, 2011), was also administered to the refugee participants during the interview. The RHS-15 is designed to assess emotional distress common among refugees. The first four items assess PTSD symptoms experienced in the past month, including re-experiencing, emotional numbness, and hyper-vigilance. Another nine items are included to assess other commonly reported symptoms of psychological distress among refugees (e.g., muscle, bone, or joint pain; faintness, dizziness, or weakness; feeling down or sad; feeling helpless). Participants are asked to rate their distress associated with these 13 symptoms on a Likert scale (0 = *not at all distressed* to 4 = *extremely distressed*). The next item is designed to assess the participant's overall ability to cope with his/her life, rated on a 0 to 4 scale such that 0 represents *able to handle (cope with) anything that comes your way* and 4 is *unable to cope with anything*. Finally, the last item is an overall distress thermometer ranging from 0 (*no distress*) to 10 (*extreme distress*), which allows the participant to rate their overall level of distress over the previous week. The current recommendation (RHS-15; Pathways to Wellness, 2011) for interpreting the scores on the RHS-15 is that a total score of 12 or more on the first 14 items or a score of 5 or greater on the distress thermometer is considered to be a positive screen for emotional distress.

Data Analysis

The main goal for data analysis in phenomenological research is to remain connected to participants' stories and conversations. Phenomenological research strives to describe the *lived experience* of a phenomenon (Creswell, 1998). This can take many forms including, written or oral reports and aesthetic expressions (i.e., art, poems). In the current study the participants' oral reports were the sole focus of analysis. Drawing from Creswell's (1998) recommendations for analysis of phenomenological data, the current study employed an emergent strategy that focused on obtaining an understanding of the essential meaning of the healthcare utilization experience. Acknowledging the essential meaning in the data was pivotal to abstracting themes from the initial data. In previous research, essential aspects have been described as components of the data that without which, the phenomenon would not be the same (Waters, 2014). The specific steps of the data analysis process are detailed below.

First, interviews were transcribed and arranged according to the source of information (i.e., refugee, provider). Second, the primary researcher attempted to get a general sense of the data and reflect on its essential meaning, generated through asking such questions as "What general ideas are participants saying?" and "What is the tone of the ideas?" (Creswell, 1998, p. 191). Third, the data was coded by segmenting sentences into meaning units (i.e., ideas). The units were then labeled with a term which was a reflection of the actual language of the participant. Fourth, themes were generated by attempting to capture the essential meaning of the codes that were created in the previous step. The themes display multiple perspectives from individuals which are supported by direct quotations from the participants' narratives. Finally, interpretations of the data were made and are offered in the following sections.

To ensure the trustworthiness of the data, the peer debriefing process was used when creating the codes and themes. This process was intended to develop a technical means for verification similar to inter-rater reliability (Constas, 1992). The goal of peer debriefing is to agree on the codes and themes that best represent the lived experiences of the research participants in relation to the questions that were posed to them in the current study. The process involved the primary investigator first coding the participants' interviews and then sending them to two peer debriefers for their opinion on the accuracy of the codes. The peer debriefers and primary investigator then collaboratively discussed any codes that were discrepant and altered them to reflect a common consensus. Finally, peer debriefers created themes by combining related codes into categories together. A different set of peer debriefers was used for each data set (refugee and medical professionals). All of the debriefers received a two hour training on phenomenological theory, coding, and theme creation by the first author who was trained by a faculty member with extensive experience in qualitative research. The training involved a review of qualitative theories and coding as well as practice exercises in coding and creating themes. The author also engaged in reflective commentary throughout the duration of the study to track personal reactions and consider how they may impact the data interpretation.

After the aforementioned peer debriefing process, a doctoral level psychologist who has extensive training in analyzing qualitative data reviewed all of the codes and themes. She requested clarification of certain codes and advocated revisiting themes to ensure that they reflected the content of the codes. Each data set went through approximately three revision cycles with the psychologist until the themes were mutually agreed upon to reflect the underlying meaning of the codes.

As described in the measures section, gathering quantitative data was attempted with the RHS-15. However, in the current study the RHS-15 was administered in a non-standardized way such that it was read to participants through an interpreter whereas traditionally it is given as a paper and pen measure in the participant's language. The reason for verbal administration is because many of the women were illiterate and some women spoke Sudanese Arabic, for which the RHS-15 has not yet been translated. Due to the unconventional administration, the responses from participants did not always match the numeric scale provided on the RHS-15. Verbal administration of the RHS-15 has not been validated and there is no data to demonstrate its reliability when administered in said manner. Thus, the scoring of the RHS-15 in the present study was only used to enhance the data collected in the primary interview. Specifically, the responses gathered from the RHS-15 helped to guide the remainder of the interview and acted as an additional screen of participants' distress levels. Despite the large number of verbal responses on the RHS-15, there were enough numerical answers from each participant to be classified into one of two categories: high or low distress. The generated themes from the refugee participants were then examined based on their assigned distress category to better understand the experience of participants in the high versus low distress categories.

Results

Seven themes were identified for the refugee participants and six themes for the medical provider participants. Pseudonyms are used to protect confidentiality.

Refugee Participant Themes

Doctors in US effectively treat illness and improve health conditions. The refugee participants expressed a consistent belief that, in the US healthcare system, doctors are effective at treating illness and improving individual's health conditions. Below "DK" elaborates on the involvement of a physician in the improvement of her medical condition:

> But, when I first came the doctor said my blood pressure was very high and what happened was that I had to take blood pressure medication for a little bit. He said that if I come back and my pressure is still high I will continue on the medication because that will drop it. Well, I haven't taken my medication in a while because every time that I go back he says that my blood pressure is better.

Another participant, "BR", spoke about seeing a doctor for the diagnosis and treatment of an acute medical problem:

> I was very sick. I went to the Dr. and he thought my appendix was inflamed or something. So, he sent me to the hospital to do x-rays, but he said no, it's not your appendix. It is your kidney. It's not filtering because you're not drinking water. So, they took care of me and I felt better.

Positive perception of medical care in the US. A clear theme in the data was that refugee participants had a positive perception of their experiences with medical care in the US. One participant, "DK," explained her view of the doctors in the US, "Doctors here [US], of course, are very good in terms of education. They are very educated. They know what they are doing. They are very good with patients." Another participant, "MH", speaks about the positive impression she has about a nurse in the refugee clinic:

> Every Monday we go to the refugee clinic to see the nurse there and I've gotta tell you, she's really good. Actually, all the other refugees that see her say the same thing. They are always raving about how great she is.

Doctors in US are helpful and caring. At several points during the interviews, the participants vocalized their appreciation for personal attributes about doctors. Specifically, they made several comments about the helpful and caring nature of the doctors they had seen. "DK" explained a time immediately after resettling in the US when she experienced doctors as caring:

> I really like doctors here, they care. They go out of their way to make you feel better… when I first came to the country I was very, very sick and I had to go to the ER. When I went to the ER, my husband could not be there with me because he had to stay home with the baby. But, my PCP and his assistants were both at the hospitals and they sat there and waited with me until my husband came which made me feel a lot better.

One participant, "SB" spoke about the experience she had with physicians during her labor and delivery in the US:

> Well, when I first came to the US, I was pregnant. I was pregnant with my son. So, when I came here, a month later I delivered. I was extremely happy that I delivered here in the US. The doctors were very nice and very understanding. They tried to do everything in their power to make me comfortable. At that point I was wishing I had delivered all of my babies here in America. I didn't feel a lot of pain or fatigue during my labor.

Little knowledge and no utilization of mental health professionals. Participants discussed their experience with the mental healthcare system in the US. Overall, most participants had no involvement and limited knowledge with said system. However, they mentioned it frequently enough that they had reasons for and against utilization. "BR" expressed her reservations about visiting a mental health professional:

> Well, the doctors did talk to me the first month that we got here. She talked to me about going to talk to a psychiatrist or counselor. But, I didn't like the idea then because we were new to the country.... I'm still not a fan of the idea. I don't want to get to the point where anything happens and I have to go talk to a psychiatrist because I'm not going to know how to fix my own problems. I don't like that. I like to try to fix my own issues by myself.

Another perspective was provided by "JP" who stated:

> It's not that I decided not to go [to psychiatrist]. I didn't decide that at all. I just hadn't thought about it. Usually when I'm sad or something, I go talk to my friends. But, now what you're saying is right cause there is some things I'm not comfortable talking to my friends about.

Last minute appointment reminders and lack of knowledge about how to schedule appointments increases frustration and canceled appointments. The participants made references to the difficulties with scheduling appointments with medical providers. Overall, they reported that the concept of scheduling was foreign to them, such that in other countries they could walk in to see a provider whenever they had a need. "BR" described her concerns with scheduling appointments:

> To be honest, one of the only things that is very, very difficult for me is having to call and make appointments. I don't know when I should make appointments, when I shouldn't… Cause I think how it's supposed to be is that when I finish with the doctor, the doctor should be like, "Okay, I would like to see you in a couple more weeks" or "Only see you this time and this time," which doesn't happen.

"DK" also discussed her frustration with last minute appointment calls:

> The only issue… they would express how they are really, really frustrated with the organization calling them last minute to tell you about the appointment. That's the only thing that is wrong with the system, is them telling you last minute about the appointment.

Lack of English fluency increases difficulties when interacting with allied health professionals. Participants also reported difficulties in oral communication with their providers. They highlighted that lack of English fluency is a barrier to scheduling appointments, conveying their medical needs, and obtaining information about their medication. "DK" expressed a poignant comment that emphasized several other participants' comments about this situation:

> I went there [physician] and they were like 'Sorry, we can't make you an appointment because we don't make the appointment face to face. You have to go home and call this number.' I'm trying to explain that I do not speak the language so even if I go home it's going to be very, very difficult.

Limited knowledge about health insurance coverage and desire to gain a better understanding of it. Several participants described little to no understanding about health insurance, especially limited knowledge about benefits, coverage dates, and how to communicate with one's insurance company. Most participants that noted having limited knowledge also expressed a willingness to learn about their insurance coverage. One participant, "HG", noted, "Everyone I know tells me that as long as you have insurance you have to call and keep on going to your doctors for follow ups. I don't know when my insurance is going to end." Lastly, "DK", expressed her limited knowledge of insurance by saying, "The only thing I know here about insurance is that when I go to the doctor I can go to any doctor and make an appointment and they will bill the insurance."

Orphan codes. After completing a thematic analysis of the data, there were a few codes where the content could not be accurately reflected in the aforementioned themes. However, they still bear a connection to the current study's research questions and are discussed below.

In US, current insurance would not cover dental procedures. Although the previous code helps to shed light on one refugee's experience utilizing healthcare in the US by detailing the limits of her insurance coverage, it did not fit the theme of limited knowledge about health insurance coverage. In fact, it highlights that this participant knew the restrictions of her dental insurance for certain procedures.

Believes that at the end of a doctor's appointment, doctor should be responsible for scheduling next appointment. Although the previous code provides information about a barrier to care, scheduling appointments, it did not fit a theme. Consideration was made to place the code under the theme addressing limited knowledge about how to scheduling appointments or last minute appointment reminder calls. However, it did not directly reflect that sentiment.

In US, was not worried about dying in delivery, but was scared of staying in the hospital because she didn't know how doctors would treat her. Although the previous code provides information about one refugee's experience utilizing healthcare in the US by detailing her feelings about physicians during her childbirth delivery, it did not fit one of the previously identified themes.

Variability in Refugee Participants' Themes Based on Reported Psychological Distress

As noted, the RHS-15 was administered as an assessment of psychological distress, and refugee participants were divided into two groups: high and low distress. Three participants were classified as high distress, defined by a total score of 12 or more on the first 14 items or a score of five or greater on the distress thermometer; the two other participants were classified as low distress. A qualitative post-hoc examination was conducted to examine differences in the reported themes by the individuals in the high and low distress categories. Individuals in the high distress category had more codes related to barriers to care than those in low distress. Specifically, participants in the high distress category had a greater number of codes under the following themes in comparison to participants in the low distress category: little knowledge and no utilization of mental health professionals, last minute appointment reminders and lack of knowledge about how to schedule appointments increases frustration and canceled appointments, and lack of English fluency increases difficulties when interacting with allied health professionals. In fact, the only codes comprising the theme of "last minute appointment reminders and lack of knowledge about how to schedule appointments increases frustration and canceled appointments" were from members in the high distress category. In the themes that represented positive aspects of care, responses from the low distress group were more prevalent. Of note, there were more participants from the low distress group endorsing statements that supported the following themes: doctors in US effectively treat illness and improve health conditions, positive perception of medical care in the US, and doctors in the US are helpful and caring.

Medical Professional Participant Themes

Reliance on allied health professionals, refugee resettlement agencies and interpreters for coordination of care. At several points during the interviews, the participants discussed how allied health professionals such as social workers and patient service representatives assist in coordinating care for refugees. Specifically, they noted that refugee resettlement agencies tend to be responsible for scheduling initial medical appointments and social workers assist intra-office coordination of care (i.e., connecting with resources and referrals). One nurse participant, Erika, reported:

> Our initial contact is through [Social Service Agency]. They make arrangements for a group of refugees or asylees to be seen on a certain day. They help us by prepping the patient with medical insurance and taking them to the lab so that we can ascertain their immunization status.

One of the physician participants, Dr. Robertson, further explained:

> I have a coordinator who works here full time. So, he'll do a lot of scheduling appointments for people or escorting them to their appointments until they get the hang of

> it to do things like that themselves. We also have a social worker who can help with things along those lines.

Appointments with refugees involve biopsychosocial evaluation of the patient, infectious disease lab work, and orientation to the American healthcare practices. The providers who were interviewed in the current study explained that their initial appointments with refugee patients include several components. There were three primary aspects of the appointment that appeared to be shared across providers. In the biopsychosocial evaluation they reported gathering information about the refugees' past medical/surgical history, past psychological history, current living circumstances, and presenting problem. In addition, the providers reported that in the initial appointment, they spend a significant amount of time reviewing the refugees' lab results for conditions such as tuberculosis, HIV, and certain parasites. Finally, most providers discussed that they educate the refugees about their position as a doctor within the US healthcare system. The following excerpts highlight these aspects of the initial appointment. When describing her initial interactions with refugees, Dr. Tompkins said:

> I take a very detailed history. Where they lived, where they live now, any trauma, anything like that they may have endured, their reason for coming to the US, introduce them to who I am; that I'm a pediatrician, that I take care of children and my purpose is to help with their help.

Dr. Robertson provided another perspective about refugee's initial appointments:

> Essentially you'd get blood work done. Assess if they have any concerns or complaints and you would try to address those. You would do a physical and try to get a full social history and surgical history and then you would finalize the visit based on what you had addressed and the refugee's primary concerns which was usually about lab work and tuberculosis.

Lack of formal training in refugee health and a need to learn from other providers. Most providers denied receiving any formal professional training to work specifically with refugee health concerns before beginning their work in the area. Instead, they described a gradual learning process throughout their careers in which they would gain information about treatment of refugees through peers. Dr. Tompkins described a common training experience:

> The residents, we kinda developed our own resources. But, most stuff came from pre-existing programs. So, for example, Minnesota has a wonderful refugee program and they have a lot of articles on the nuts and bolts of refugee care. And the academic issues like how you treat a certain parasite infection but also on like 'this is how you should run your office.'

Integrated refugee healthcare program and culture specific education noted as ways to facilitate care. One of the areas where there was the greatest consensus in providers' responses was acknowledging that there are areas for improvement in facilitating treatment. Of note, providers discussed how specific trainings for working with refugees would be useful. Further, they noted that systemic reform would improve the quality of care received by refugee patients. A primary component of the proposed integrated healthcare program was the addition of social workers and nurse coordinators. Specifically, the providers discussed how assigning social workers and nurse coordinators solely for refugee patients may increase the team's ability to address the refugees' psycho-social needs. Dr. Hannover expressed his viewpoint on how integrated care could be useful in advancing the field of refugee healthcare:

> You need a dedicated team. It can't be like a random part of healthcare. It needs a true full team approach. Ideally, you'd have multidisciplinary care for that population given their high needs and some of the social things.

Another physician, Dr. Tompkins, addressed cultural specific education:

> Information that is specific to certain groups or patients is really helpful too because there may be some things that are so normal to me as an American....like one of my partners who is middle eastern, she said, you know you should never really ask a middle eastern girl about sex … I never would have thought of that in a million years. So, just little cultural things that can help me to take better medical care of the patient would be good. The best thing is a well-rounded system because you want to make it as easy as possible for people to care for this population.

Experience of significant language barrier when working with refugees, facilitated by professional interpretation services. Similar to an experience mentioned by the refugee participants, the medical professional participants noted language as a barrier to care. Specifically, they noted that the inability to speak the language of their refugee patients, and vice versa, increased difficulties in the provision of medical care. Providers also commented on their use of interpreter services with refugees in session. They spoke about the usefulness of telephone and in-person interpretation as compared to use of a community member to interpret. Further, the providers also spoke about the complications that can arise from both methods. A nurse participant, Anne, explained:

> It's always better to have an in room translator just because for conversation it is much nicer. It's a more natural environment. On the phone, sometimes, it was hard to hear the patient speaking or the translator speaking. Sometimes we would get disconnected and wait a long time to reconnect. Sometimes they don't have the dialect that you're looking for. So, it was usually a last ditch, but necessary because we couldn't speak the languages they were speaking. Usually, the on-site translator was a real medical translator with real training. They were excellent.

Another participant, Erika, expressed a preference for the language line form of interpretation:

> I will say that, from experience, the language line is far superior because a lot of the time the people who are accompanying, you don't really know how reliable these people are. Not only their understanding of medical issues, but also what is the power structure within that community. These are family and you're asking questions and you're not sure if the person is conveying these things accurately.

Engaging in more pre-appointment preparation with refugee patients than non-refugee patients. The providers spoke about the pre-appointment preparation involved in refugee care and how it is usually significantly more than the preparation for appointments with non-refugee patients. Dr. Thrower described an experience that was reflected amongst other participants:

> What we tried to do was get as much of the preliminary work does as possible. So, you'd have a refugee who has a certain number of tests that they are required to get, like

> tuberculosis. Depending on where they are coming from they might get tested for certain parasites, depending on age they might get certain screening tests. So, we would try to get that done before hand.

Orphan codes. After completing a thematic analysis of the data, there were a few codes where the content could not be accurately reflected in the aforementioned themes. However, they still bear a connection to the current study's research questions. Thus, the codes are discussed below.

In hindsight, doctor believes prepping patients in a group would be more effective. This code reflects a possible way to facilitate care; completing pre-session requirements in a group rather than individually. However, as this is one provider's experience with refugee patients and was not reflected by other providers, a theme could not be generated from it.

No strong psychiatric screening process in place for refugees. Although this code helps to answer the research aim of understanding medical professionals' experiences when working with refugees, it was not expressed across the majority of medical professionals in the current study.

Some refugees are reluctant to ask for help, not wanting to bother anybody. Although this code helps to shed light on one provider's perspective of a potential barrier for refugees, it did not fit a theme. Further exploration is necessary to understand if other providers share this same belief.

Discussion

The current study adds to our understanding of refugee's utilization of healthcare by describing the experiences of female, Sudanese refugees receiving medical care in the US. A prominent theme was that Sudanese women were pleased with their healthcare. They perceived physicians and healthcare providers as effective, knowledgeable, and helpful. This theme is highlighted by a participant who compared her childbirth experiences in the US and Sudan:

> If you go into labor [in Sudan] before nine months they still make you go home and make you wait until you are over nine months pregnant. Here [in US], they don't. I wasn't even nine months pregnant and I still got to deliver. The whole entire thing here was more comfortable than I've ever been. People here were very, very kind and that matters a lot when you're delivering.

These positive experience likely contribute to willingness to continue utilizing healthcare services, perhaps even in the face of barriers. It is interesting to consider to what extent these perceptions are shaped by their direct experiences in the US or if Sudanese refugee women hold these positive perceptions prior to seeking healthcare in the host country.

When working with refugee patients, providers may be encouraged to know that the patients likely have a positive view of them. This may be particularly important given that the healthcare providers in this study voiced some frustration about the time commitment involved in pre-appointment preparation. One provider noted, “I hated it. It was a really hard and stressful afternoon. You got so much ahead of time. You had to prep them ahead of time.” Because working with refugee patients has unique stressors that involve additional work on the part of the provider, the provision of high quality care may be facilitated by providers remembering that refugees have a positive perception of them.

In contrast to these noted positive aspects of US healthcare, refugee participants also described encountering a number of difficulties when seeking healthcare. Participants noted barriers detailed in past research (Eckstein, 2011; Kirmayer et al., 2011; Norredam et al., 2005), including problems with scheduling, language barriers, and limited knowledge of insurance and mental healthcare resources. In addition, refugees expressed concerns and difficulties with the practice of scheduling appointments in advance. Interestingly, there appears to be a discrepancy between refugees' experiences when scheduling appointments and the reported effort exerted by healthcare providers and resettlement agencies in facilitating scheduling. Providers reported that resettlement agencies work very closely with refugees to schedule their medical appointments, especially the initial appointment. A consistent report amongst providers was that a representative from the resettlement agency would accompany the refugee to her first appointment. However, refugee participants expressed a concern that when asked to schedule appointments without the help of the agency they do not know what to do. Future intervention may involve educating refugees about how to schedule appointments once the resettlement agency's services are decreased or removed. Further, absence of fluency in English was noted by refugees as a barrier to scheduling. Thus, different approaches to scheduling refugee patients may be useful. For instance, an interpreter could be available by phone as the first point of contact for refugee patients who wish to schedule an appointment and then the interpreter could act as a liaison between the refugee and the medical provider's office for future scheduling and questions.

Additionally, incorporating community healthcare workers (CHW) may help to overcome identified barriers. CHW are individuals who are native members of specific refugee communities who have a more developed understanding of the US healthcare system. CHW also understand their native culture which can assist in bridging the cultural and medical divide. Further, they can also serve as an ambassador from their community to healthcare professionals. Past research (Viswanathan et al., 2009) has noted that CHW interventions can improve participant knowledge, behavior change, and health outcomes. A CHW could be used as a liaison between resettlement organizations or healthcare providers to provide education to newly settled refugees about scheduling appointments, insurance, and available healthcare services. Further, due to their developed understanding of the healthcare system and high likelihood that they speak the same language as individuals within their community, CHW could assist in interpretation when a professionally trained interpreter is unavailable (e.g., in emergency care or daily encouragement of compliance to medical regimes and follow-up care).

Previous literature has found that refugees may be hesitant to report mental health symptoms to physicians because they are afraid that their concerns will not be understood or will be deemed inappropriate for a medical setting (Schoevers et al., 2009; Whitley et al., 2006). These specific concerns were not discovered in the current study. However, refugee participants expressed a reluctance to seek mental healthcare because of a fear that use of mental health services may decrease their own ability to problem-solve and cope with their emotional experiences. In contrast to this concern, several refugee participants expressed an interest in obtaining more information about the mental health options available to them, suggesting that limited knowledge of resources may be a more significant barrier than fears or concerns. For instance, one refugee participant expressed her interest in seeing a psychologist "cause there is [*sic*] some things I'm not comfortable talking to my friends about." Further, distressed participants made comments about how they benefited from the study interview because it gave them a chance to talk about their concerns (e.g., "the fact that I can find someone to talk to relieves some of the stress and some of the negative feelings that I have and makes me feel better"). As mentioned above, employment of a CHW to assist in this area of education may facilitate refugees' use of mental healthcare options. Use of a CHW may also reduce the stigma that is sometimes associated with seeking mental healthcare.

Further highlighting the importance of addressing mental healthcare services, the refugee participants in the current study expressed several mental health concerns and pre-migration traumas. They also reported that they present to their medical doctor for concerns such as "thinking too much." This is similar to past research demonstrating that refugees with PTSD report increased visits to medical doctors rather than a mental health provider (Tempany, 2009; Tipping et al., 2007; Schweitzer et al., 2006). Future interventions and policy could consider ways to facilitate mental healthcare between refugees and providers. A first step may be to educate CHW specifically about mental health (i.e., what it is, how it can be identified, and what to do if someone in their community is suffering from a mental health concern).

The comparisons of individual in the high and low distress categories on the RHS-15 are also relevant. For instance, the description of quality of life pre- and post-resettlement differed between participants in the high and low distress groups. Individuals in the high distress group expressed thoughts about life being harder in the US than they had expected (i.e., "Life here is very hard and expensive. You know, stuff you dream about, you come here and you find it very hard and it turns into a problem."). Also, they also described experiencing more mental health symptoms (i.e., anxious, restless, "too many thoughts," sadness, etc.) and more physical health ailments (i.e., body aches, muscle pain, headaches, etc.) after resettlement in the US than individuals in the low distress group. The low distress group described their quality of life being worse before they resettled in the US and experiencing improvements after resettling. These findings may be informative to healthcare providers in considering specific warning signs of mental health concerns. Providers may need to listen for the sentiments expressed by the distressed women in this study and then further explore mental health symptoms and concerns. Better detection may lead to greater referrals to mental health services within the community.

Similar to the refugees, healthcare providers noted both positive and negative aspects of refugee healthcare. Similar to previous research (e.g., Burnett & Peel, 2001), providers in the present study reported obstacles to care involving language barriers and time constraints, and they also noted unique difficulties such as intensive pre-session preparation and limited training about refugee health concerns. The medical providers also reported believing that professionally trained interpreters can facilitate good clinical care. Moreover, the providers reported frequent consultations with community organizations like refugee resettlement agencies to increase the quality of care. These practices are consistent with research suggesting that both the use of trained interpreters and consulting with refugee resettlement agencies facilitates a higher quality of care (Kirmayer et al., 2011).

Integration of the services involved in refugee healthcare was a concept that many providers discussed when contributing suggestions on how to improve the quality of care available to refugees. One physician noted:

> The best way [to improve care] would be to have a very integrated program that could address whole person's needs … That's the most important thing that I would want to convey if I was talking to somebody who actually had the power to do something.

Several providers commented on ways to address the "whole person's needs." A common suggestion was increasing accessibility of care through physical integration. Specifically, providers discussed that, ideally, a refugee patient could come to their primary care appointment and walk down the hall to receive specialty medical services, dental care, mental healthcare, and pharmacy services. Patient centered medical homes (PCMH) provide one model of such integrated care and research indicates that medical homes can lead to higher quality and lower costs, and can improve patients' and providers' experience of care (National Committee for Quality Assurance, 2015). Further, the PCMH model would likely improve follow-up care and access to referral services, and could help to eliminate the scheduling barrier that refugees mentioned.

The current study's strengths include examining the issue of refugee healthcare from a qualitative perspective. The qualitative nature of the study allowed for a deeper analysis of the participants' experiences as compared to a quantitative study. In addition, the study explored the perspective of female refugees after resettlement, whereas past research has focused primarily on men and children. The current study also adds to a limited research base about a marginalized and sizeable population in the US. This not only validates the experience of individuals who identify as refugees, it also adds to our understanding of the concerns of a group that is often ostracized within the US. Further, this study examined both refugees' and healthcare providers' views of healthcare utilization in a refugee population, which encourages a more holistic view of the healthcare system than has been documented in past research in this area. This expansion may help to address some larger, systemic issues within the healthcare system that are best addressed by policy reform.

The current study was limited in that it did not sample until saturation which likely omitted some themes and codes that would have presented themselves within a larger sample. This study also provided no triangulation of the data collected which decreases the credibility and trustworthiness of the data. Use of the RHS-15 data was originally planned to support the validity of the qualitative data analysis, but unfortunately this quantitative data was unable to be used due to problems in administration. However, the study employed a peer-debriefing process in creating codes and themes in an attempt to increase the credibility and trustworthiness of the data. The author also engaged in reflective commentary throughout the duration of the study to track personal reactions and consider how they may impact the data interpretation. Finally, the research attempted to bolster the trustworthiness of the data by engaging in tactics meant to increase honest responding from the participants. For example, in the informed consent process, participants were told that their responses would be kept confidential such that their identities would be protected through the use of pseudonyms in the final document.

In summary, the current study explored Sudanese refugees' experiences utilizing healthcare in the US as well as specific barriers and/or facilitating factors that impact their healthcare utilization. It also detailed the experiences of healthcare providers who work with these refugees while highlighting common barriers to providing medical services. Future interventions may include revising the appointment scheduling system with refugees, continued inclusion of community organizations, community liaisons, and trained interpreters, creation of an integrated health system, and further exploration of barriers specific to mental healthcare.

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