

Healthcare Barriers for Congolese Refugee Children in Louisville, KY: Parental Perception and Narratives through Focus Group Discussions

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Abstract

Background: There are up to 3500 refugees who resettle in Kentucky annually with 66% of refugee children originating from the Democratic Republic of the Congo. Little is known about the barriers to healthcare perceived by Congolese parents. This information can direct interventions to improve the care of these children.

Methods: Focus group discussions (FGD) were used to allow families to share personal anecdotes, compare experiences, and encourage discussion between group members. Between August 2018 to May 2020, three FGDs were conducted with Congolese parents who have at least one child ≤18 years old. An interpreter was utilized for each session to allow participants to communicate in their preferred language. FGDs were recorded, transcribed, and analyzed by three research members using qualitative content analysis to generate frequent themes.

Results: A total of 3 focus groups were performed with a total of 13 participants. Majority of the participants were female (85%), have lived in Louisville for less than 2 years (54%) and are currently unemployed (38%). Content analysis of the three focus groups discussions reveal three major themes of healthcare barriers: transportation, language, and provider-related factors. Sub-themes include heavy reliance on public transportation despite access to cars, confusion about emergency service utilization, language barriers outside of the traditional healthcare space, long wait times, and re-traumatization during encounters with providers.

Conclusion: Although parents report a wide variety of obstacles for their children, future interventions in Louisville should focus on improving transportation, language barriers, and parental experiences with providers.

Introduction

Children from refugee families are a growing underserved population in the United States (US) with a complex array of health care needs. Children alone accounted for 43.4% of newly settled refugees across the US in 2018. [1] In Louisville specifically, this population comprises a significant proportion of our foreign-born population. In 2018, the largest countries of origin of refugee children based on health screenings were the Democratic Republic of the Congo (66%), Burma/Myanmar (11%), Afghanistan (5%), Bhutan (4%), and Ukraine (4%). [2] This heterogeneity makes it challenging to identify unifying characteristics that can be applied across these different communities. Nevertheless, there are some unique features that make caring for this patient population unique and challenging. For example, refugee families in Louisville speak at least 77 different languages and are more likely to have limited English proficiency. [3] Refugee families are also more likely to belong to low-income households and more likely to be underinsured or uninsured despite being eligible for Medicaid. [3] This diversity complicates the design of research studies and can cause results to be overgeneralized and poorly specific to any one group.

Despite their heterogeneity, one commonality these children share is that they are at risk

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of health conditions such as anemia, intestinal parasites, lead poisoning, and communicable infectious diseases such as TB and HIV. [2] Many of these are further mitigated by the presence of toxic stress and adverse childhood events such as violence, abuse, torture, and neglect which places them at an increased risk of chronic medical problems. [4,5] Despite the increase need for medical care, refugees utilize healthcare resources less frequently, are less likely to be appropriately vaccinated, and less likely to attend preventative health services, suggesting that they face significant barriers in obtaining care. [6,7] Recognizing barriers to healthcare has justifiably been recommended by the American Academy of Pediatrics in their most recent policy statement on the care of immigrant children. [8]

Healthcare barriers among refugees have been the focus of several studies that have identified a wide array of themes related to language barriers, lack of transportation, insurance access, medical expenses, acculturation and cultural factors, poor health literacy, medical mistrust, perceived discrimination, stigmatization of mental health, and complexity of the U.S. health system. [6,9-16] Many of these factors persist despite high levels of satisfaction with the existing health care facilities or the perceived availability of a solution. [9,10] For example, translators are often available but not utilized at all levels of interaction including appointment scheduling or filling medicines. [11] This reflects the complexity of interaction between healthcare users, providers, and the healthcare system and tackling these barriers will likely involve a multi-systems approach.

As refugees have immensely diverse backgrounds, studies conducted at different countries, cities, and even institutions may not always be applicable to Louisville's distinct population. Most of the existing research that examined healthcare barriers are based in Europe and Australia and among those performed in the US, only two are from the state of Kentucky. Of these, one was limited to the Bhutanese and Karen population prior to the adoption of the Affordable Care Act (ACA) and the other examined barriers from the perspective of healthcare providers. [9,16] Given the changing context of the US healthcare system including the passage of the ACA, there exists a need for an updated assessment of the major barriers of care for refugee children in Louisville, especially from the Democratic of Congo, which is the largest proportion of newly arrived refugee children in the city.

Our aim is to elucidate potential barriers to health care for Congolese children who have been resettled in Louisville through a qualitative study design to inform and guide future interventions that address these barriers.

Methods

Study Design and Methodology

The primary study method utilized to determine major barriers to healthcare among refugee children was focus group discussions. Focus groups were chosen as the research design because they allow families to share personal anecdotes, compare experiences and attitudes, and encourage discussion between group members. Another intent of the study is to demonstrate the feasibility and ease of conducting focus group discussions in assessing barriers of care for other refugee populations. Other studies that utilize questionnaires reported limitations in those methods as they were unable to explore issues and themes that were identified with follow up questions. [10]

This study is approved by the University of Louisville Institutional Review Board (IRB no. 17.1290). Focus groups were conducted from August 2018 to May 2019 and each focus group session ran for approximately 21-41 minutes. An independent third-party interpreter was utilized for every session to allow participants to communicate in their preferred language. All participants were reminded at the start of each session about the confidential nature of their conversation and reminded that they may withdraw from participation at any time.

The methodology, analysis, and reporting strategies for this study are based on the Consolidated Criteria for Reporting Qualitative Research (Appendix A). [17]

Study Population and Recruitment

Based on the most recent 2018 refugee arrival data in Kentucky, the largest estimated source of pediatric refugees originates from the Democratic Republic of the Congo (66%). [2] We specifically target parents of children from the Democratic Republic of Congo to prevent over-generalizable data given the diversity and heterogeneity of Louisville's refugee population. This data allows better prioritization of resources so that future interventions can target the most prevalent or detrimental barriers for this group, which in turn can improve health outcomes for our patients.

Inclusion criteria includes refugees who originate from the Democratic Republic of Congo with at least one child who is aged 18 years or less. They must reside in the US for greater than 12 months as many barriers are less apparent during the initial resettlement process. Finally, they must be willing to provide voluntary informed consent and must be willing to have their conversation tape-recorded. Participants are identified by community leaders within the Congolese refugee community.

Statistical Analysis

Data collected through audio files were reviewed and transcribed by ZT. Three research members (ZT, BA, AR) then independently read the transcript and analyzed the data using qualitative content analysis. Each member generated themes according to a pre-specified schematic designed by the study team based on categorization by Health People 2020 to capture different social determinants of health. Baseline demographic data were also obtained to characterize the study population.

Results

A total of 3 focus groups were performed with a total of 13 participants. Baseline demographic data as well as social determinants were obtained from participants and represented in **Table 1**. Most participants are female (85%), have lived in Louisville between 1-2 years (54%), and have 1-2 children (38%)..

Content analysis of the three focus groups discussions reveal three major themes of healthcare barriers: Transportation, Language, and Provider-related factors.

Theme 1: Transportation

Transportation to clinics and hospitals are the most frequently cited barrier including reliance on public transport such as buses. Participants report delays with public transportation that could lead them to miss appointments.

“So, for me, I go downtown and my WIC office is downtown. The main issue I face every time I go there is transportation because I have to ride the bus and I have three children and whether the medical or WIC appointment, it is very hard to ride the bus with three at once”

“We only have one bus ... and you have to wait a whole hour for the bus.”

“So you can't find anybody to help you among your friends or relatives, what we do, we just try to ride the bus, we get there when we are late, the hospital they send us back that we are late...”

Availability and access to a car does not eliminate transportation as a barrier to healthcare. Although majority of participants report that their principal mode of transportation was a car (62%), mothers were often unable to drive themselves and shared a car between the whole household.

“... the big issue she has is because she doesn't know how to drive. They have a car. But her husband works all night so when the children have appointment in the morning, he just come in the house from work ... and you know he should sleep but he doesn't have choice because he has to take the children.”

“Because, like when they get us here, they give us two days of teaching the rules of the road, but that is not teaching how to drive.”

Utilization of emergency services such as calling for an ambulance also presents unique challenges for parents, who report confusion on the appropriateness of utilizing emergency services.

“... the challenge is, we're told that you call an ambulance when someone is dying, so a child may be very sick, but they don't think the child is dying.”

“Ya, what I can say about the ambulance, by the time they reach here, they told us you need ambulance when you are like, you are almost dying. So, you don't need ambulance all the time.”

“ And one more thing, some other new people, they do scare to call the ambulance. If everything is 911... they called the police, 911, call the ambulance 911. So they do scare to call 911 and you have to pay the ambulance when they came here.”

A solution proposed by one participant was for hospitals/clinics to provide transportation. This has previously been trialed by several institutions using rideshare-based transportation, resulting in variable degrees of success. [18,19]

“She says, like if the hospital could have a car, and then, give to the new patient, a number, a telephone number and let them know if your child is sick, just call this number, we'll send our car to come pick you up and your children”

Theme 2: Language

Although participants report that clinics and hospitals consistently utilized interpreters during in-person appointments, their use was limited over the phone. Similarly, use of written instructions that were translated also presents a barrier to parents.

“The problem for the appointment, sometimes when you have already one, it’s good because before you leave the hospital, they give you the appointment for the next. The problem, sometimes it’s in English, then we try to look around for people who can interpret, who can help us”

“He says that it’s 911...The problem then it will be the language after calling 911”

Language issues can even be apparent with the availability of an interpreter.

[Moderator] Do you find it hard understanding what the doctor says even with an interpreter?

[Participant via Interpreter] Yes, sometimes I got some people who interpret [for] me, and they [still do not] understand. I don’t know if it’s because it’s English or what. Sometimes they put mistakes [in] which I don’t understand.

[Moderator] So even with an interpreter, sometimes it’s still confusing?

[Participant via Interpreter] Yes

Theme 3: Provider-related Factors

Even when parents can bring their children to a clinic or hospital, they report frustration in their interaction with the healthcare system. Parents report difficulty in physically locating medical buildings as a new immigrant, long wait times in both clinic and emergency settings, and concerns with their interactions with healthcare providers.

“So, when you are new, all the buildings look the same, you can’t tell if this is a hospital or not. Unless they tell you and take you there”

“Oh she says, what makes them uncomfortable is when they take the child to the doctor, you see the nurse first, and then they tell you to wait, and then they make you wait more than an hour, she is wondering why they have to do that when you have an appointment”

“So the most problem we have, it’s when we take like children to emergency, so we meet with the nurse, but to get the doctor takes many many hours and sometimes we go there, calling it emergency, expecting to get like help really soon within a short period, but we spend there hours and hours without help yet we are in the emergency”

“... they have an issue with many doctors, when you go in, she says I’m not the only one because we talk about it. When you go to see the doctor but then the doctor comes see, he or she is not welcoming, just look at you like you know, look down at you. He doesn’t know what is going on with you but you just froze.”

One mother expresses the feeling of re-traumatization whenever she is asked by healthcare providers about her experiences in the Congo.

“Some of us, they came, it’s only the one person. Everybody else was killed. So to keep on repeating that same thing, it’s not easy for the person. Like me, I’m the only one left. My husband is the only one in his family. We are just the two of us. So we want peace. When you start reminding us the past, you are not taking us in the right place. And another person is here with his family. That is normal. Yea, they may have gone through some problems but not as much. They may have problems that they are totally different problems.”

Table 1. Socioeconomic Characteristics of Participants

	n	%
Gender		
Female	11	85%
Male	2	15%
Years Living in Louisville		
1-2	7	54%
3-5	2	15%
6-10	3	23%
No answer	1	31%
Resettlement Sponsor		
Catholic Charities	5	38%
Kentucky Refugee Ministries	4	31%
No answer/other	4	31%
Number of Children		
1-2	5	38%
3-5	3	23%
5-6	4	31%
No answer	1	8%
Highest Level of Education		
Did not complete high school	5	38%
High school diploma	5	38%
College	1	8%
Post-Bachelor/Higher Education	1	8%
No answer	1	8%
Employment Status		
Unemployed	5	38%
Employed	2	15%
Part-time employed	1	8%
No answer	5	38%
Principle Mode of Transportation		
Car	8	62%
Bus	3	23%
Walking	1	8%
No answer	2	15%
Food Insecurity Screening		
Presence of Food Insecurity	2	15%
Absence of Food Insecurity	9	69%
No answer	2	15%
Income Insecurity Screening		
Presence of Income Insecurity	3	23%
Absence of Income Insecurity	7	54%
No answer	3	23%

Discussion

Congolese parents in Louisville report a wide variety of obstacles in obtaining medical care for their children but three main themes are evident during this analysis. Transportation is often the first barrier identified by parents, who express difficulties utilizing public transportation which are slow and burdensome as well as difficulty driving cars despite their availability. Although parents readily knew the method for calling emergency services, many reports being reprimanded for calling 911 and are confused about the appropriateness of when to call for an ambulance. For Congolese parents in Louisville, this collectively means missed or cancelled appointments and delayed care for their children with unknown implications on their child's health. A systematic review examining transportation barriers among the general population reports transportation difficulties are implicated in missed clinic appointments, ability to fill prescriptions, and medication non-compliance leading to hospital admissions. [20] Congolese children are likely to be similarly affected but further studies are needed to specifically detail these effects.

Language and provider-related factors are also reported as barriers by parents across all groups, citing various issues related to their encounter with healthcare providers. For example, parents report that interpreters are readily available during an in-person visit but are unavailable over the phone when making an appointment or when calling 911. One participant interestingly reported that emergency services overcame this issue by bringing an in-person interpreter to their location after she called 911. Another example frequently raised by parents are the long wait times for a clinic appointment or an emergency room visit with parents raising frustration with the lack of communication from staff while waiting to see a provider. However, the direct impact this has on their child's medical care is unclear including whether this leads to early termination of a child's visit or a reluctance in using medical services in the future. Interestingly, participants from all groups frequently deny health insurance, medication access, and perceived discrimination or racism as healthcare barriers for their children.

Overall, this is a hypothesis generating study and further studies targeting specific barriers and their relation to health outcomes may be helpful. Focus group discussions are a feasible method in obtaining qualitative data on healthcare barriers among refugee parents and could be similarly implemented in other refugee groups to examine similarities or differences in their experiences. Transportation difficulties are widely reported by Congolese parents and may be appropriate as initial targets for intervention. Potential areas identified by this study include transportation assistance for healthcare visits, improved education on use of emergency medical services, and increased access to interpreters during phone conversations. A family-focused community-based intervention should serve as a model to ensure refugee families are incorporated in the design and implementation of any proposed intervention. [21]

Limitations of this study include small sample size and potential sampling bias given the reliance of community members to identify participants. Findings of this study are not generalizable to Congolese families in different cities or different refugee groups in Louisville. However, the dialogues derived from the focus groups are still valuable and provide insight into the experiences of Congolese parents navigating the healthcare system in Louisville.

In conclusion, Congolese parents report a wide variety of obstacles in obtaining medical care for their children but frequently identify transportation, language, and parental experiences with providers as barriers. Further studies and interventions related to these three themes may be helpful in improving the healthcare experience for Congolese children in Louisville. Focus group discussions are a useful tool in elucidating narrative experiences of refugee families and could be similarly implemented for other refugee groups.

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