OREGON CENTER FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH NEEDS

Unmet Expectations

Swahili-speaking immigrants and refugees discuss getting care for their children with special health care needs

2021

Introduction

The Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) and the Sickle Cell Anemia Foundation of Oregon (SCAFO) collaborated in 2020 to collect data about the needs and experiences of families with Black children and youth with special health care needs (CYSHCN). The aims of this study were to learn about Black CYSHCN's health and support needs, and their family experiences with: access to care and services; cultural and linguistic responsiveness of the care and services; and youth transition from pediatric to adult health care.

After collecting data from English-speaking families of Black CYSHCN across the state, SCAFO partnered with the African Family Holistic Health Organization (AFHHO) to conduct an additional facilitated discussion with Swahili-speaking families of Black CYSHCN (hereafter referred to as simply as "families" or "family members"). AFHHO serves the African immigrant and refugee community in the Portland, Oregon metropolitan area.

Methods

In March 2020 (before the COVID 19 pandemic), AFHHO conducted a discussion with ten Swahili-speaking family members of Black CYSHCN. The discussion was held at the AFHHO office in Portland, Oregon. It was facilitated by AFHHO's native Swahili-speaking Community Health Specialist. Families were asked questions about their CYSHCN's needs, accessing care for their CYSHCN, and the cultural and linguistic responsiveness of that care. AFHHO staff translated the transcript into English, and OCCYSHN's research staff analyzed it.

Findings

OCCYSHN's research staff used a thematic approach to analyzing the discussion's transcript. The following six overarching themes were identified from the experiences of immigrant and refugee Swahili-speaking family members of Black CYSHCN.

1. *Language barriers*

Family members described frequently experiencing language barriers with their children's care providers. For example, when they requested interpretation services, they said it was not uncommon to get an interpreter who was fluent in an African language other than Swahili. Families also described interpreters not interpreting what they were saying to the provider correctly, resulting in confusion. One parent said:

> *"…They usually ask what language we speak but yet they still send an interpreter that does not speak my language… The second thing is sometimes you get to your appointment and the interpreter is not there, then they request a virtual interpreter who is far away…"*

Some family members described receiving mail and phone calls in English from providers' offices. They said it was important to use interpreters when calling families. They also said it was important to have the same interpreter at every visit. Family members emphasized that language matters more than the race of the provider when it comes to getting good care for their CYSHCN.

2. *Unmet health care expectations*

Families had expectations about their child getting medical tests and prescription medications that were not realized. Family members perceived that their child's care providers did not adequately test or treat their children's illnesses. They reported that their children were not prescribed medication, even when they were ill.

OCCYSHN
Oregon Center for Children and Youth with Special Health Needs

OHSU

Unmet health care expectations (continued)

> *"… As for us refugees, we are used to, when you are sick, you go to the hospital, get tested and get medications. But here, they will just look at the baby and say, 'the baby is fine.' How will I know if my baby is fine? I am not a doctor. How would you know if your child is sick or not? If I go back home with a sick child, will he be fine without any medication?"*

Some family members reported that it was easier for them to get health care at refugee camps than it is in the United States. Health care was provided at no cost in the refugee camps. One family member said that medications that were free in the refugee camps are expensive here. Another family member reported that refugee health insurance benefits ended after one year. They were still adjusting to life in the U.S., and expected those benefits to last longer.

3. Challenges getting to health care providers

Family members described difficulty getting to hospitals or clinics for their children's care. One family member reported they live far from their child's clinic, and taking public transportation there is time-consuming and expensive. A couple parents described seeking care for their child at a hospital or clinic, only to be redirected to the emergency department. One parent said this was not what they wanted, because getting care at the emergency department is difficult.

4. Financial hardship

Family members reported problems affording basic needs like clothing, housing, rent, and utilities. A couple parents described the difficulty of juggling the employment required to pay bills with the time they need to care for their CYSHCN.

> *"[Housing] is so hard to get; it took me six years to get into affordable housing. I used to pay $1400 in rent by myself as a single parent with sick kids, and I am also sick. I did that for six years. It was so hard."*

5. Parental separation

Family members described the challenges of single parenting CYSHCN. Some parents were separated from their spouses upon establishing refugee status in Oregon. One said she needed help to bring her child's other parent to the US to help care for the child. Family members described difficulty meeting CYSHCN's needs without the support of a spouse.

6. Parent health care experience

Family members shared negative experiences with their own health care. They especially focused on inadequate interpretation services. One parent recalled that when she specifically requested a female interpreter for an appointment focused on women's health issues, the clinic provided a male interpreter.

Conclusion

African immigrants and refugees in Oregon face significant challenges, such as finding employment and affordable housing, having limited English proficiency, and securing health insurance.[1,2] A lack of understanding about the complexities of the U.S. health care system can exacerbate these challenges.

Family members in this discussion expected to have an easier time getting care for their CYSHCN in the U.S. Their experiences also highlight the need for culturally responsive care among *all* immigrant and refugee families of CYSHCN. Better interpretation services are clearly required. Their experiences suggest that Swahili-speaking immigrants and refugee families of CYSHCN need better support navigating health care systems, such as when to make an urgent office care appointment versus going to the emergency department. Family Navigators or Community Health Workers who speak the same language can coach families on navigating the exceedingly complex U.S. health care system.

---

[1] Curry-Stevens, A. & Coalition of Communities of Color (2013). *The African immigrant and refugee community in Multnomah county: An unsettling profile*. Portland, OR: Portland State University. Retrieved from https://www.portlandoregon.gov/oehr/article/713236.

[2] Bikele, F. (2017). *African migrants in Oregon: Healthcare preferences and the importance of worldviews.* [Master's thesis, University of Oregon]. University of Oregon Scholars' Bank. Retrieved from https://scholarsbank.uoregon.edu/xmlui/bitstream/handle/1794/22779/Bikele_oregon_0171N_11776.pdf?sequence=1&isAllowed=y.

Our sincere thanks to the families who participated in this facilitated discussion. We are grateful for their candor, emotion, time, and information.

- **Oregon Center for Children and Youth with Special Health Needs**
  occyshn@ohsu.edu www.occyshn.org
- **African Family Holistic Health Organization**
  info@afhho.org www.afhho.org
- **Sickle Cell Anemia Foundation of Oregon**
  info@sicklecelloregon.org www.sicklecelloregon.org