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Structural Accessibility Barriers and Service Gaps Facing Refugees with Disabilities in the United States

Abstract

Purpose – *The purpose of our scoping study was to understand the experiences of refugees with disabilities and their families in the US from expert service-provider perspectives, including gaps in resources and services. We also investigated challenges and opportunities for technology intervention in this space.*

Design/methodology/approach - *We conducted semi-structured interviews with six experts who serve refugees in the United States. We asked them about the experiences of refugees with disabilities and their families and inquired into challenges and opportunities for technology access for this population.*

Findings – *We found that refugees and their families are significantly impacted by disabilities and mental health challenges. Additionally, while refugees have access to resources and services, they face a number of structural barriers, including the need to navigate a complex healthcare system, geographic placements that sometimes make it difficult to access employment or healthcare services, and issues with accessing public transit.*

Practical Implications - *We offer several directions for practical improvements based on our findings, including improving structural support for refugees with disabilities and incentivizing health care providers utilizing more culturally aware language services.*

Limitations - *The main limitation of our current study is that we did not collect data directly from refugees with disabilities.*

Originality/value - *While the number of refugees worldwide has doubled in the past decade and there is consensus that a significant number of refugees experience disabilities and mental health challenges, few projects have looked into the technology needs of refugees with disabilities. Our exploratory study provides population-level insights on the experiences and accessibility barriers of refugees with disabilities in the United States.*

1 INTRODUCTION

The worldwide number of forced migrants, including refugees, has doubled in the past decade (United Nations High Commission for Refugees (UNHCR), 2019). Additionally, recent efforts by the United Nations Refugee Agency (UNHCR) that have focused on recognizing the prevalence and impact of physical and cognitive disabilities, and mental health challenges in refugee populations have shown that significant numbers of individuals and communities are impacted (United Nations High Commissioner for Refugees, 2017). These statistics and ongoing effort underline the importance of pursuing appropriate strategies and resources to support these vulnerable and diverse populations in different phases of their journeys and resettlements processes. From an accessibility and assistive technology design perspective, it is crucial to investigate the sociocultural,

structural, and technological barriers that refugees with disabilities and their families face in different contexts in order to move towards sociotechnical systems to support their inclusion and empowerment.

We conducted an exploratory interview study with 6 experts service providers in Eastern United States (Maryland) who work with refugees to better understand the impact of disabilities, including mental health challenges, on refugees and recent migrants, and the structural service and accessibility gaps that they face in their everyday lives. We chose to work with experts, rather than refugees themselves, since we were interested in population-level perspectives to inform the next steps in our research program that will involve working directly with refugees with disabilities and their families. We found that disability and mental health impact the lives of refugees significantly and while a range of supportive resources exist, structural barriers such as the need to navigate a complex healthcare system, distance from employment and health locations, limited access to public transit to reach them, and gaps and delays in receiving insurance coverage makes it difficult for refugees to access them effectively. These findings have implications for the future design of technological and educational programs and resources, specifically designed to meet the needs of these underserved populations. In the following sections, we first present an overview of related work in this area, followed by a description of our methods, including participant demographics and interview protocol. This paper extends and complements our previous conference paper in which we focused on the socio-cultural aspects of the experiences of refugees with disabilities and their families with accessibility and assistive technology (Hamidi and Karachiwalla, 2022). We follow with a presentation of our findings along the major themes we identified in the data, and a discussion of our findings that includes practical implications. We conclude with a summary and ideas for future research directions.

2 RELATED WORK: DESIGNING INTERACTIVE TECHNOLOGIES WITH AND FOR REFUGEES

Previous research on technology design has addressed several application areas related to refugees, including navigating new language and cultural resources (Brown and Grinter, 2016; Duarte et al., 2018), finding resources upon arriving a new country (Noyman et al., 2017), and accessing health care (Talhok, Mesmar, et al., 2016). Three recent international workshops focused on human-computer interaction and refugees identified areas where digital technology design can make contributions, including access to healthcare and education services specifically for refugees, supporting refugees during their journeys to safety, and their integration into host countries (Sabie et al., 2021; Talhok, Ahmed, et al., 2016; Talhok et al., 2018). Furthermore, the workshops resulted in a set of design guidelines that include continuously re-evaluating research scope, contributing to broader refugee agenda at the local, national, and international levels, and building in flexibility and time for trust-building into the research plan (Talhok et al., 2018).

Studies have been conducted in three different contexts: (1) refugee camps (e.g., (Fisher et al., 2016; Talhok et al., 2019), (2) when traveling to a new host country (e.g., Dekker et al., 2018), and (3) in the process of settling into a host country (e.g., Baranoff et al., 2015; Coles-Kemp et al., 2018; Irani et al., 2018). While each of these contexts has its unique characteristics, the goal of many of these studies has been understanding the impact of different barriers such as cultural competency, language understanding, healthcare, and social inclusion on the experience and transition of refugees, to overcome them through new solutions. For example, Almohamed and Vyas conducted a series of interviews with refugees in Australia and found that many of them experienced social isolation and challenges due to cultural differences (Almohamed and Vyas, 2016a). Participants identified the design of specialized digital technologies as promising for overcoming some of these

issues. In another study of the impact of relocation and forced migration on refugees' or asylum seekers' social capital, Almohamed et al. investigated the impact of migration on refugees' mental health and found that refugees who lack social ties in the host community have a significantly higher risk of depression compared to other community members in the same context (Almohamed and Vyas, 2016b). They further found that digital communication technologies can have a positive impact on the social inclusion of refugees. Finally, using a set of participatory design activities with refugees, Almohamed et al. identified three factors, cultural adjustment, organizational support, and social activities that contribute to newly arrived refugees' social capital (Almohamed et al., 2017).

Several other studies investigated how refugees negotiate digital technology use when arriving in a new land and what barriers or challenges they face in doing that (Coles-Kemp et al., 2018; Coles-Kemp and Jensen, 2019). For example, in workshops with 70 newcomers in Sweden, Coles-Kemp et al. found that newcomers used mobile phones to find security and capitalize on resources when arriving in a new land but also that their usage may expose them to new threats and vulnerabilities (Coles-Kemp et al., 2018). In another study with refugees in Sweden, Jensen et al. found that while digital technologies and services facilitate and make efficient some aspects of integration, important components needed to make authentic connections to the host country's culture and society are missing from current designs (Jensen et al., 2020). Outside of Europe, Sadie and Ahmed looked at the challenges faced by refugees in accessing Canadian digital services (Sabie and Ahmed, 2019). They identified a series of challenges including the need to navigate complex informational systems, ensuring online security, and managing gender dynamics when accessing resources as areas that could benefit from future digital intervention. In addition to striving for more accessible, flexible, and available online resources, the researcher also recommended supporting the formation of intercultural communities to increase empathy and social technology learning (Sabie and Ahmed, 2019).

In a recent paper, Almohamed et al. developed a theoretical framework to conceptualize the challenges that refugees and asylum seekers face in accessing social capital in host countries (Almohamed et al., 2022). They identified cultural backdrops (e.g., religion, language), displacement-related stressors (e.g., mistrust, family fragmentation), and host country's social resources (e.g., neighbors, stereotypes towards refugees and asylum seekers) as key interacting factors that need to be considered in design, policy, and theory-building in this space. In relation to technology design, they argued for accounting for the diversity of these populations, including a consideration of their different religions and cultural practices, and experiences of trauma and mental health challenges. They stressed the importance of acknowledging that often technology is not enough, and it has to be complemented with other social, political, and cultural efforts to support communities effectively.

From a methodological perspective, a significant portion of existing HCI research with refugees has used participatory design approaches to understand and create technologies with refugee input and feedback (Almohamed et al., 2017; Duarte et al., 2018; Fisher et al., 2016). For example, Fisher et al. conducted a series of participatory design workshops with 144 young people to create paper prototypes of visionary devices to help their community (Fisher et al., 2016). The project resulted in a better understanding of the challenges refugee youth face in accessing educational and informational resources in a refugee camp setting. Furthermore, the work shed light on how much refugee youth support others in navigating resources at refugee camps, showing opportunities for involving them in co-designing innovative systems in the future. The research team conducted several similar workshops with immigrant youth in the United States and found the approach effective in understanding their perspectives and coming up with innovative solutions (Brown and Grinter, 2016; Fisher et

al., 2017). Other similar projects have taken an assets-based approach to designing with refugees (Fisher et al., 2016; Irani et al., 2018). For example, in a project conducted at a Syrian refugee camp, Fisher et al. collected and analyzed data on how families gather information about available assets in the community and used it to build a community-commissioned database of household assets that were available for sharing (Fisher et al., 2016).

A range of technologies such as translating platforms (Brown and Grinter, 2016), dietary tracking devices (Fisher et al., 2017), mapping technologies (Fisher et al., 2016), Interactive Voice Response (IVR) radios (Talhok et al., 2017), and mobile applications (Baranoff et al., 2015; Irani et al., 2018) have been created to overcome specific barriers of social inclusion, language competency, and improving health. For example, building on the knowledge that many refugees have access to low-cost mobile phones, Baranoff et al. designed a cost-efficient mobile service to help refugees navigate their surroundings and get specialized services by using a combination of mobile phones and Near Field Communication (NFC) tags that can be placed in different locations to provide contextualized translated information to users (Baranoff et al., 2015). Another project conducted in a Syrian refugee camp in Lebanon utilized an IVR mobile-based radio show to provide health information specifically curated by and for refugees for camp residents (Talhok et al., 2017). In the context of refugee camps, several projects have adapted Western models of informal learning and access to digital resources, such as MIT's Computer Clubhouses (Sawhney, 2009) and the German Computer Club (Aal et al., 2014), for use in long-term refugee camps in Palestine and the West Bank. In both of these projects, researchers identify rich opportunities for camp members to engage in digital media production and storytelling (Sawhney, 2009), and also emphasize the importance of conducting situated research that is aware of the particular characteristics of each setting and using participatory approaches in building bottom-up information infrastructures and resources to ensure they are relevant to the real desires and needs of refugees (Aal et al., 2014).

Of particular relevance to our work is a small and growing body of research that investigates supporting refugees' mental health and well-being using digital technologies. For example, Ertl et al. interviewed 5 refugees, and 3 psychologists and 3 volunteers working with refugees, to explore the possibilities of future system designs to support refugees seeking mental health support (Ertl et al., 2020). They found an opportunity for developing culturally-sensitive self-help tools that can complement more intensive therapies and interventions and support individuals build their self-resilience upon arriving in a host county. Other projects have focused on understanding how to support the mental health of a particularly vulnerable subgroup of refugees, unaccompanied migrant youth (UMY). Using interviews and workshops with 18 professional and volunteer support workers and 5 UMYs, Tachtler et al. investigated ways to support the psychological resilience and well-being of UMY when they arrive in a European host county (Tachtler et al., 2020). They recognized the importance of the role of adult mentors and argued for approaches to support them better support the youth. Drawing on a social-ecological model of resilience (Ungar, 2012), the authors argued for helping mentors find relevant mental health resources in a changing and scattered landscape, apply the resources effectively when found, and coordinate better with other peer and expert support workers (Tachtler et al., 2020).

In another study with UMYs, Tachtler et al. used a similar social-ecological lens to understand how multiple factors impact youth's use of digital mental health interventions (i.e., existing apps) and how to design future applications effectively (Tachtler et al., 2021). Drawing on three workshops where youth commented on existing apps and imagined future ones, the researchers identified a series of important design characteristics such as

accounting for both social encounters in youth's everyday lives and supporting their physically distanced social contacts. Furthermore, the researchers found that designers should also specifically consider youth's mentors and how to best support them provide resources to the youth. The researchers also pointed out that future interventions should consider the changes that happen in youths' lives (e.g., frequent change of accommodation) and their evolving learning process. The researchers found that macro-system factors such as policies and legal structures impact all other factors, thereby making it necessary to strive for social transformations at these levels in addition to pursuing individual or community level interventions (such as new technologies).

Other research outside HCI, in refugee and forced migration studies, have looked at the experience of refugees with disabilities. For example, in a study with 44 service providers, Choi and Wynn found that communication barriers and lack of knowledge about mainstream health services were major barriers to accessing services for developmental disabilities for Asian refugees in the US (Ellen, 2000). Other studies have identified additional factors such as inadequate community outreach and cultural differences and misunderstanding as posing barriers in this space as well (Hasnain, 2010; Trinh-Shevrin et al., 2009). A study by Mirza and Heinemann used a series of interviews, focus groups, surveys, and participant observations with both refugees and service providers to find that refugees with disabilities have several unmet disability-related needs, including service providers' limited awareness of disability rights and resources and a medical understanding of disability (Mirza and Heinemann, 2012). They identified other factors including refugees being disconnected from disability service systems, lack of communication and trust between different organizations serving refugees, and limited cross-cultural understanding in disability services. Similarly, using interviews with service providers and refugees in California, Morris et al. found that the majority of refugees do not regularly access health services, and language and cultural differences impact all stages of access to healthcare services, from making appointments to filling prescriptions (Morris et al., 2009). This research did not focus on technology design opportunities that can improve the accessibility of services and resources for refugees with disabilities.

This overview of previous research shows that while research in this area is growing, to date few efforts have focused on understanding the needs of refugees with disabilities with a view to inform future technology design. More research is needed to investigate the specific needs and desires of refugees with disabilities, including those experiencing mental health issues, to inform the design of future interactive systems specifically for them.

3 METHODS

3.1 Participants

We conducted interviews with six employees of governmental and non-governmental organizations that serve refugees in the Eastern United States' state of Maryland. Table 1 below provides a summary of information about the participants, including their roles. We contacted community organizations, and local, and state government programs to recruit participants and used snowball sampling to find new participants. All participants, except P2, work at non-profit organizations that provide services to refugees, and P2 works at a government agency that does the same. All participants work with multiple refugee and forced migrant populations, including those from the Middle East and Central America. Three of the participants (P1, P4, and P5) arrived in the United States as refugees themselves and draw on their personal experiences as refugees during interviews. We decided to interview experts because we wanted to ensure that for this initial phase of

the project, we collect population-level data reflected in the perspective of experts who have worked with multiple individuals, and also to decrease the burden of participation on refugee families with a family member with disabilities. When recruiting participants, we reached out via email and LinkedIn to all organizations in Maryland that we could find and provided services to refugees and forced migrants. We stopped recruiting when we could not recruit additional participants after multiple inquiries.

Table 1: Participant Information

Identifier	Age range	Gender	Ethnic Background	Years in refugee service	Role in Organization
P1	60's	Male	Middle Eastern	Five years	Program analyst
P2	30's	Female	White	Eight years	Program coordinator
P3	40's	Female	Native American/White	Fourteen years	Program director
P4	40-50	Male	Middle Eastern	Four years	Social services coordinator
P5	20's	Male	African	Seven+ years	Youth fitness activities coordinator
P6	40's	Male	African American	Ten+ years	Program coordinator

3.2 Data Collection and Analysis

We conducted remote semi-structured interviews through either Google Meets or by phone. We decided to use semi-structured interviews since they provide an opportunity to gather detailed qualitative information about participants' experiences (Merriam and Tisdell, 2015). We conducted the interviews remotely since the study took place during the COVID-19 pandemic. Interviews lasted on average 60 minutes. All Participants except P2 received a \$25 gift card upon participation. P2 chose to opt out of receiving the gift card. The study protocol was reviewed and approved by our university's institutional review board (IRB).

We developed an interview protocol based on a preliminary literature review. We piloted the interview with two students to refine terminology and timing before using it in interviews. Both students had previous experience conducting research in health care setting and working with service providers (although not with providers specifically to refugees). In the interviews, participants were first asked about their backgrounds and experiences with the refugee population in Maryland (the Eastern United States State in which the study took place). We then asked participants about the impact of disability on refugee families and the accessibility of disability services and health resources in the US.

We audio-recorded the interviews, which we then stored in an encrypted online location before being sent to an online service for transcription. The second author independently coded the transcripts using an inductive thematic analysis approach (Braun and Clarke, 2006) which was followed by the first author reviewing and refining the themes. Sample codes included medical care for refugees, insurance for refugees, barrier to reaching medical care, impact of disability on family members, impact of disability on individual, among others. We grouped the codes based on how they captured different aspects of multifaceted theme with the process resulting in three overarching themes that we present next.

4 FINDINGS

Our analysis resulted in three themes that we present next. First, in Section 4.1, we will discuss participants' perspectives on the impact of different disabilities on refugees and their families, including an emphasis on the

significant impact of cognitive disabilities and increased chances of a family unit experiencing economic and other hardships. Next, in Section 4.2, we discuss the types of health and accessibility resources and services available to refugees in the study context. Finally, in Section 4.3, we discuss some of the structural barriers to accessing these resources, including the need for navigating a complex healthcare system, and distance from and lack of adequate public transport access to resources.

4.1 Impact of Different Disabilities on Refugees and Their Families

Participants emphasized the acute and lingering effects of physical and cognitive disabilities on refugees. P1 described how injuries sustained from adverse experiences had long-lasting impacts: “The impact to [refugees’] lives is quite great ... They were constantly going to the doctor. They were constantly needing or requiring access to medical care.” In P1’s view, this ongoing need for care adds an additional layer of demand on refugees’ time and resources. A demand that may be more pronounced in the case of cognitive disabilities. Similarly, P2 shared how people with cognitive disabilities “need caretaking,” in which case “usually, a parent can’t work because they have to be a caretaker which affects the family’s income.”

These difficulties are not only limited to parents caring for a child with disabilities. P2 described how mental health problems in parents can also cause problems for children by increasing household instability: “I’ve seen (parent’s mental health issues) affect families and how much they’re able to, sort of, trust their kids in [encountering the new country] or ... feel safe and stable and, sort of, that can affect the children’s mental health as well.”

P5 additionally reflected on the impact of disabilities on children’s academic performance which is amplified when children are isolated and are not connected to a community upon arrival in a new context:

“These mental health concerns impact their lives in that the students we work with before they join [extracurricular activities organization that P5 works at], are shy and reserved, and some may say that...they were very lonely before they found this sense of community.... A lot of our students, especially the boys, a few boys in my team, have had issues with processing anger and feelings in healthy ways. That just comes from not learning how to cope with those different things, and not learning how to channel your frustrations in more positive ways. So, a lot of outbursts, a lot of complete shutdowns.”

In this quote, P5 identifies a goal of their non-profit organization to address this need for community and mentorship for youth. The importance of supporting refugee youths’ mental health and well-being is identified in previous research (Fisher et al., 2016; Hynie et al., 2013) and needs to be supported by both developing resources for youth and their mentors (Tachtler et al., 2020).

P6 described longer-term impacts that having a family member with disabilities may have on youth in refugee families:

“If a parent had a disability, the young child, meaning if you had a boy that was 16 or 17, could not complete high school because his responsibility was to work for the family. So, a lot of times [this can result in] lack of education or lack of a degree which will then impact their upward mobility within the US because they’re not able to acquire a high school ... they have to work. So, unfortunately, they then are behind again because they don’t have the education, they’re not able to provide for their family, so it becomes a cycle.”

P2 and P6 emphasized that in the case of cognitive disabilities and mental health issues, the impact can touch every member of the family and also limit family members' availability for employment, impacting overall family income and well-being. P1 also emphasized this point:

"Not only did these injuries require time and resources but also impacted the ability for refugees to work, and in turn impact the amount of support they provide for their families. Not only did these physical injuries/disabilities impact the individual but also has great impact on the entire family."

P2 also echoed these views on the difficulties of maintaining a job in the presence of mental health challenges, such as "certain paranoia disorders or certain anxiety, depression." P3 discussed another aspect of the relationship between disability, health, and job opportunity:

"Refugees getting jobs and being self-supporting [is important]. I think the higher level of health access, the higher probability that [refugees] are going to be able to be self-sufficient, able to hold down a job, able to go to school, get better jobs as a result... But the issue is access [to health resources]."

P1 described how for refugees difficulties caused by the presence of disabilities or health conditions exist on top of a lot of other factors related to a drastic change in life as a result of becoming refugees:

"We need to understand that these refugees before being refugees, they actually had their own lives. ... Most of them, they were very successful before they became refugees.... Transitioning into a new country, a new environment with a new language to learn, it's so much pressure on them. And, also, the fact that some of them experienced some type of torture [before being] resettled or witnessing someone being tortured has created significant mental health concerns on them."

Thus, P1, P2 and P3 draw a link from access to healthcare services and accessibility to economic stability and long-term success for refugees.

4.2 Health and Disability Resources for Refugees

In the United States, refugees generally receive Medicare health insurance for the first year and some also qualify for Medicaid health insurance that in combination can include more resources. According to P3 refugees undergo physical and mental health assessment both overseas and again upon arrival, a process that slightly differs according to the state. According to P1, for three months following arrival, refugees also receive financial aid, cultural lessons, and some language training. P3 described that part of their role included equipping healthcare providers with resources helpful to communicate and aid refugees, as well as connecting refugees with good providers:

"A big part of my job is training mental health providers that work at [federally qualified health centers], how to serve different refugee populations. I train on how to work with interpreters and mental health settings ... My program funds interpretation for those interpreters-- or for those mental health providers to do therapy with professional mental health interpreters."

For individuals with disabilities or adverse health conditions, specialized resources often in the form of specialized or intensive case management (ICM) that encompasses social and medical support to deal with

specific mental or physical health challenges is provided (Coles, 2018). To illustrate, P4 reflected on the case of a child who needed ICM:

"I'm going to bring a case of an eight-year-old female [who] was having—I mean, is still having issues to actually read a three-letter word. So, this child can actually articulate everything correctly, but if, [they have] to actually write it down or to spell it out or even to [identify] the word on a piece of paper ... [they would] have such a difficult challenge even to come up with the first letter pronunciation...I had recommended the school to do an assessment evaluation for her ... and I believe that's still ongoing."

P4 also described another scenario where ICM was used and described it as:

"a little bit more catered towards the needs of the person... They make sure that this person gets a visitation from the case manager in terms of either twice a week, and they just make sure that the parents are on the same page."

Organizations such as non-profits, religious centers, and community support organizations also provide support for refugees. P1 discussed how religious houses acted as a gateway for refugees to access information and support, "the mosques and churches and synagogues also helped. The houses of worship for the three great monotheistic religions tended to act as the gateway to accessing healthcare and refugee support." P2 also observed several local and national non-profit organizations as offering ICM programs but also witnessed that these programs have limited capacity. P5 also mentioned that they work with other local non-profit organizations that have some capacity in this area. However, P3, P4, and P5 did discuss that to their knowledge there were not any organizations that specifically focused on providing accessibility services or assistive technologies to refugees with disabilities or mental illness.

4.3 Systematic Factors Affecting Access

4.3.1 Gaps in Health Insurance Coverage and Delays in Receiving Support

Participants described how health insurance provided to refugees has several gaps where services are not covered or comprehensive. Examples include the temporary nature of support that only lasts for a short amount of time before refugees have to pay for insurance and healthcare (P6), many dental care procedures not being covered (P1, P2), and a lack of comprehensive mental health coverage, depending on what each family might qualify for and receive (P1, P4, P6). P1 and P4 described a need for more comprehensive mental healthcare and counseling coverage.

When asked how they would rate current insurance coverage for refugees, P1 described:

"I gave it a mark, out of 10, of only a five. Or maybe even a four. Four or five maximum. It's still lacking... We need universal healthcare. And the population that most need it are the vulnerable ones including, among other, refugees who are recent arrivals and need every help that they can get."

In addition to gaps in coverage, there is a delay in receiving care especially for refugees who need mental health services and/or have existing medical concerns. According to P2:

"It takes a long time (to get disability) for anybody regardless of how long [they have been] here ... the delays are just exacerbated [for refugees with existing disabilities] ... And I think that it causes additional complications like in resettlement."

In addition to delays in receiving coverage, P2 also described how refugees face barriers and delays in making appointment and receiving mental health services:

"In my experience for refugee appointments, mental health in Baltimore City, there are huge waiting lists and wait times to get into places. And then people also, depending on the provider, can just fall off the radar. If they miss an appointment, they miss an appointment. That's it... [a healthcare provider] relies on the client to call themselves, which isn't necessarily going to happen depending on the client without assistance if they're not having case management support."

These results are similar to previous research that also identified similar barriers in refugees accessing common healthcare services (Morris et al., 2009).

4.3.2 Difficulty Navigating a Complex Healthcare System

P1 described that systematic barriers to accessing healthcare and disability services extend beyond gaps in coverage and delays in receiving service to how the entire healthcare system is difficult to access for new refugees:

"For [refugees] to access this very labyrinthine and complicated US healthcare delivery system is very, very challenging... With less education, little or no English, newcomers to the country. Oh, man. You add all those layers which are obstacles, those layers, and that's a challenge. So, the kind of support they need is to better access the healthcare system. And the government needs to pony-up the kind of support to resettle them properly.."

In the previous quote, P1 is alluding to multiple barriers, including lack of familiarity with a system, limited language skills, and access to social support that add up to make it difficult for refugees to access services they need. P5 similarly described how helping families navigate the health system and insurance is needed:

"There's a [need to help refugees with] not understanding the coverage and the policies and stuff like that. I feel like from personal experience, interacting with a lot of the families ... helping them navigate especially the insurance, and helping them understand the different places and how they can seek that help and support, or helping them, pointing them in the right direction when it comes to either navigating their insurance or navigating the healthcare assistance [is needed]."

P2 saw potential in simplifying processes needed to access healthcare services, stating that, "The American health system is incredibly confusing for me ... [The US healthcare system] is far from simplified, and I think whatever we can try to simplify it for this population would just make everything a lot more accessible and easier." While P2 was optimistic that efforts in system simplification would reduce barriers to access, they also acknowledged the challenge of working with a system that is already complicated: "but we're working within a very flawed framework anyway."

4.3.3 *Difficulties Arising from Geographic Placement*

Another systemic barrier described by our participants included the geographic placement of refugees in the Eastern US state of Maryland where our study took place. Difficulty with accessing public transport, cost of transportation, and difficulty communicating with transportation workers created challenges for refugees traveling to medical facilities to receive treatment. P4 described how referring refugees to a facility that is far from where they are settled can pose a barrier to access:

“Most of the cases that I know, they were referred to [local facility providing healthcare and special education service]. They [i.e., the refugees] live about 50 miles away Transportation is always a challenge, and if transportation is available in this case at times the parents are not available, either they have jobs to attend to, and they don't have the time to take their kids or their child through the service. So, geographic residential location is really important to also accessing these kind of services.”

Similarly, P2 described that while when agencies try to place refugees in central locations when they are being resettled, using public transportation to get to work is slow and complicated to navigate. P5 also echoes these concerns, identifying limited public transportation options as a barrier to receive health services. P1 described how this issue is especially present at the beginning when refugees arrive and do not have access to transportation alternatives that can cause barriers even if they are given access to high-quality healthcare services:

“There generally was-- they were well-served with healthcare facilities, physical therapy facilities, etc., but the problem was getting access. Getting transportation there. Sometimes that was a problem until they all bought cars...And had money to put gas in the tank.”

Issues with accessing public transportation were amplified in specific locations that are historically underserved. When asked about systemic barriers to accessing services, P3 went so far as to say:

“[Most refugees] are not placed in the rural settings, although if we expand refugee to include migrant workers, they are in rural settings, so there are some possibilities of it. Public transportation, I mean, in some cities it's great. And I think refugees do better with it there.”

P4 also referred to the difficulty of using public transit to get to the city from the suburbs for work or to access services. P1 agreed that “public transit was very cumbersome in the Baltimore City area.” They also added that even in the presence of acceptable public transit options, the level of language skills needed to navigate a complex system of buses, trains, and subway cars can be challenging for refugees. P3 described this in more detail:

“For instance, they'll want to see a therapist, but they don't have two hours to get there, and they don't have two hours to get back. And the Medicaid transport that is supposed to be available for people with Medicaid, logistically, it's such a pain in the butt to schedule, and the schedulers on the Medicaid lines rarely use an interpreter.”

The above quote shows that issues with using public transport can intersect with language barriers and that multiple relevant ways to access this resource are not implemented. The issue of limited public transportation

causing barriers to accessing healthcare services for refugees and forced migrants resonates with previous research conducted in the US context (Vais et al., 2020).

5 DISCUSSION

In this section, we synthesize our findings into a series of discussion points with a view to identify design and practice opportunities for improving refugees' access to services and resources. Given the multiple factors that impact the experiences of refugees with disabilities in new settings, we see it necessary for issues to be addressed from multiple directions (e.g., policy, education, and technology design). For example, the barriers that refugees are facing because of language and immigration policies is not created solely by limited English language skills, but also by the shortcomings of current technologies and the immigration laws of the USA. Our findings point to several implications for policy, education, and technology design that we offer next. We first present implications that relate to both policy and education, followed by implication for the design of future technologies.

Improving Structural Support for Refugees: Similar to previous research that has recommended considering legal and policy changes in supporting refugees' health (e.g., (Almohamed et al., 2022; Tachtler et al., 2021)), participants identified several directions for more structural changes to support refugees with disabilities and health concerns and their families. For example, P1, P2, and P4 emphasized the need for more comprehensive insurance especially for mental health support and dental care. During P1's interview, he even described current health insurance for refugees as "lacking" and ranked it as four or five out of ten. Participants described that though Medicaid does cover some forms of mental health care, it is only provided for refugees that qualify based on income and sometimes refugees will qualify for counseling support only for a short time as they are resettling. This challenge combined with delays in receiving care can cause what P2 described as "additional complications in resettlement."

According to our participants, another area of possible improvement is a simplification of navigating the current American health care system. P1 and P2 both emphasized that at the root of many of the challenges refugees face is a healthcare system that is complex, intimidating, and hard to navigate. Further, P2 described the system as "confusing," "labyrinthine, and complicated." While completing changing a healthcare system to make it more accessible and inclusive is a considerable undertaking, we believe that this recommendation points to an opportunity for service design that can draw on well-used models and principles in the accessibility community, such as Universal Design (UD) (Story, 2001; Zimmer, 2012), to develop a more inclusive and accessible portal to this complicated system that would help all community members navigate it more easily and efficiently. We anticipate that such a system may be useful not only to the refugee communities but also to anyone who currently has difficulty navigating health and disability services.

Incentivizing health care providers utilizing more culturally aware language services: Some of the participants (e.g., P3) described that even though health care professionals are legally required to offer language support services, these laws are generally not enforced. P3 stated that sometimes providers are not even aware of these laws. Therefore, participants recommended that more enforcement by the government is needed to protect and serve these vulnerable communities. This component also involves telling refugees and serving organization about existing laws and how violations may be reported. Beyond enforcement participants also suggested an increased use of interpreter services, hiring and training more multilingual providers, and developing and updating more multilingual information resources. Participants were also quick to clarify that in

developing these services, it is important to recognize the diversity of refugee interpretive service needs with respect to multiple dialects, cultural norms, and regional values or shared histories that may exist within one linguistic group (e.g., within the Arab-speaking refugee population in Maryland). These points echo findings from the work of others (Almohamed et al., 2022) that emphasize the need to take into account both the diversity of refugees and the impact of their culture and religion in envisioning future solutions.

Implications for the Design of Future Technologies: Our findings point to several opportunities for future design intervention. First, there are opportunities for developing interactive systems to help refugees navigate complex information about health and accessibility resources. Given the success of participatory and co-design approaches used with refugees in the past (e.g., (Almohamed et al., 2017; Bustamante Duarte et al., 2021; Duarte et al., 2018)), we envision that using similar methods can result in systems that are relevant and useful specifically for this population. Previous research has shown that engaging refugees of different ages in the design process can lead to innovative solutions and that creating safe spaces are highly important to fostering creativity and openness (Bustamante Duarte et al., 2021; Talhouk et al., 2019).

Similarly, better systems can be designed for service-providers to provide them with culturally sensitive resources and motivation through engaging content to better fit their services to the needs of refugees. Improving the quality and quantity of multilingual resources, and online or in-person interpretation services can be promising directions. To highlight and recognize the cultural value of refugee perspectives, we recommend adopting assets-based approaches (Fisher et al., 2016; Irani et al., 2018) to develop these resources and use them as an opportunity to both enable and educate service providers.

Finally, there are multiple opportunities to address the challenge of accessing public transit in several directions. The lack of robust public transit infrastructure is a well-known problem in the United States, where in many contexts, especially outside of major metropolitan areas, the majority of transportation infrastructure (e.g., highways, roads, etc.) is designed and built for people who own cars (Cass et al., 2005; Lichtenwalter et al., 2006). Recent research has argued for considering all stakeholders when designing accessible and affordable transit infrastructure (e.g., (Dillahunt et al., 2017)). Including refugees, their families, and service providers in the design of solutions to better access public transit can offer opportunities to make this essential service more accessible. Similar to existing efforts to bridge inequity gaps in access to transit, we envision a combination of new ride-sharing apps and services, specifically designed to meet the needs of refugees with disabilities and their families.

6 CONCLUSION AND FUTURE WORK

There is an increasing awareness of the prevalence of invisible disabilities and mental health difficulties in refugee populations worldwide. As the worldwide number of refugees around the world is increasing, we need to better understand the challenges that refugees with disabilities and their families face in host countries to inform supportive policy, service, and technology solutions. In this paper, we reported findings from interviews with six expert service providers to diverse groups of refugees in the Eastern United States. Participants described the impact of disability on refugees with disabilities and their families, the resources available to them in the United States, and barriers to accessing these resources. We concluded with a discussion of potential future directions for interactive technology design in this space.

The main limitation of our study is that refugees themselves were not directly involved in the research. In the future, we plan to conduct a series of culturally sensitive workshops with refugee families and translators that

focus on understanding their perspective towards accessibility, access to healthcare services, and assistive technology in the United States. Diversity within refugee populations is a point that was emphasized in the current paper, and we plan to incorporate in any future study design to include diverse representation, not only in the case of immigration status or disability, but also cultural background, socioeconomic status, and gender identify among others.

Another limitation is the small number of participants who are all concentrated in the Eastern United States. We conducted the study during the COVID-19 crisis which provided us with an opportunity to record a snapshot of expert perspectives during this unprecedented time (especially about the impact of the pandemic itself). However, the pandemic also made recruitment and data collection particularly challenging since a lot of the experts were facing increased demands for services. In the future, we plan to expand the study to include perspectives from different parts of the United States, since we imagine that perspectives, possibilities, and challenges would be different depending on local infrastructure and conditions.

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