

Note: “Fear is Grounded in Reality”: The Impact of the COVID-19 Pandemic on Refugees’ Access to Health and Accessibility Resources in the United States

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ABSTRACT

The COVID-19 pandemic continues to have a significant impact on people’s lives worldwide. Research has shown that these impacts are distinct for different populations and often exasperate existing inequities and challenges. Within this landscape, the experiences of refugees with disabilities and mental health challenges are understudied. There is a need to better understand the challenges that refugees with disabilities and their families face in host countries during the pandemic and investigate strategies used to overcome them to inform future inclusive pandemic preparedness efforts. In this paper, we report findings from interviews conducted during the first year of the COVID-19 pandemic with four experts who serve refugees in the US. Participants described the impact of the pandemic on refugees, explained challenges that the prevailing political conditions of the time added to refugees’ experiences, and identified several strategies for resilience they experienced in the communities they serve.

CCS CONCEPTS

• **Human-centered computing** → Human computer interaction (HCI); Empirical studies in HCI.

KEYWORDS

Refugees, People with Disabilities, Accessibility, Assistive Technology

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1 INTRODUCTION

The number of forced migrants worldwide has doubled in the past decade and according to the United Nations Refugee Agency (UNHCR), currently more than 79 million people are forcibly displaced worldwide [45]. There are distinct factors that impact this diverse

population at times of crises, including pandemics. In a recent survey of 30,000 refugees and migrants, the World Health Organization (WHO) participants reported lack of financial means and fear of deportation as important factors, among others, in making them not seek medical help when experiencing COVID-19 symptoms [49]. Furthermore, at least 50% of respondents had reported increased feelings of depression, anxiety, and loneliness since the COVID-19 pandemic began. These findings are even more alarming considering that these populations are already more likely to experience mental health challenges, such as post-traumatic distress (PTSD), and acquired disabilities due to increased chance of exposure to adverse pre-displacement, displacement, and post-displacement events [9] [38]. Finally, research has shown that low-cost technologies such as cell phones and social networks can provide practical means for forced migrants and refugees to sustain and develop relationships, find resources and opportunities, and navigate new languages or cultural contexts [24]. Given this landscape, we sought to better understand the experience of refugees and forced migrants, especially those with disabilities and their families, during the COVID-19 pandemic with a view of how sociotechnical interventions may support their access to resources and services in future crises.

In this paper, we present findings from an exploratory interview study with four experts in the state of Maryland in Eastern United States that provide services to refugees with a focus on understanding their experiences during the first year of the COVID-19 pandemic, especially with respect to access to accessibility and health services. The US is one of the most prominent resettlement destinations for refugees and forced migrants who currently represent about 10% of the annual immigration flow into the US [32]. Our findings outline how the co-existence of the pandemic with a turbulent political environment in the US contributed to exacerbating existing inequities that are faced by refugees.

2 RELATED WORK: DESIGNING INTERACTIVE TECHNOLOGIES WITH AND FOR REFUGEES

Studies focusing on designing technologies for refugees have explored different contexts, including (1) refugee camps (e.g., [21]), (2) when traveling to a new host country (e.g., [17]), and (3) in the process of settling into a host country (e.g., [7] [36]). The goal of many of these studies has been understanding the impact of different barriers on the experience and transition of refugees to overcome them through new sociotechnical solutions. For example, Almohamed and Vyas conducted a series of interviews with refugees in Australia and found that many of them experienced

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social isolation and challenges due to cultural differences [2]. Participants identified the design of specialized digital technologies as promising for overcoming some of these issues.

Previous research has resulted in exploration of a range of technologies such as translating platforms [11], dietary tracking devices [20], mapping technologies [21], Interactive Voice Response (IVR) radios [39], and mobile applications [7] and phones [48] for refugees. These projects have often been motivated by the need for refugees to overcome barriers of social isolation, language and cultural difficulties, and accessing health and wellbeing resources. From a methodological perspective, a significant portion of existing HCI research with refugees has been focused on the development of participatory design approaches to understand and create technologies with refugee input and feedback [4] [21] [19]. 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 [21]. The project resulted in a better understanding of the challenges refugee youth face in accessing educational and informational resources in a refugee camp setting. The research team conducted several similar workshops with immigrant youth in the United States and found the approach effective [23] [8]. Other similar projects have taken an assets-based approach to designing with refugees. 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 as a basis to build a community-commissioned database of household assets that were available for sharing [21]. Al-mohamed et al. also found that using speculative design approaches, such as Magic Machine workshops [6], can encourage refugees to have a strong voice and offer new perspectives on the design of future technologies [5].

Despite this growing body of research, few papers have explored the experience of refugees and forced migrants with disabilities or mental health challenges. In a recent study, Hamidi and Karachiwalla conducted interviews with experts who provide health services to refugees in the US and found that while a number of resources exist to support resettlement, there are structural, socio-cultural, and technological barriers to effectively accessing them for these populations and their families [27]. On a related note, and in the context of technology development in support of mental health in Low and Middle-Income Countries (LMICs), Pendse et al. argued for adopting an aspirations-based approach that takes into account how individuals or communities envision change [35]. Among other recommendations, they advocated for considering multiple factors, including social (e.g., stigma), biological, and environmental ones when creating interventions, taking into account the impact of interventions on both families and individuals, and designing for use in low-income setting.

Several papers have studied the impact of the COVID-19 pandemic on people with disabilities. For example, in an analysis of Twitter data, Gleason et al. found that people with disabilities faced numerous barriers in accessing information and basic services when social distancing measures were enforced during the pandemic [25]. In an interview study with special education teachers and therapists, Long et al. found that children with disabilities and their families experienced challenges in accessing remote learning resources during the pandemic and identified a need to develop pandemic

preparedness plans that are responsive to the needs of people with disabilities [30]. To our knowledge, research has not yet studied the impact of COVID-19 on refugees with disabilities.

Other work has studied the impact of the COVID-19 pandemic on refugees and found that it has exacerbated existing inequities and challenges for them (e.g., [30] [43]). While this research provides insight into barriers faced by refugees with disabilities (including those during the COVID-19 pandemic), it is not focused on technology use and opportunities for design of future interactive technology systems that may improve the accessibility of services and resources for refugees with disabilities.

3 METHODS

3.1 Participants

We conducted interviews with four employees of governmental and non-governmental organizations that serve refugees in Maryland in the Eastern United States. Table 1 below provides a summary of information about the participants. 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. One of the participants (P4) arrived in the United States as refugees themselves and drew 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 member with disabilities. All participants work with multiple refugee and forced migrant populations, including those from the Middle East and Central America.

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. We conducted the interviews remotely since the study took place during the first year of the COVID-19 pandemic. At that time, vaccines were not available and social distancing measures were largely in effect in most parts of the world. 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. 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). Subsequent questions were divided into three categories: the impact of disability on refugee families, the accessibility of disability services and health resources, and the impact of the COVID-19 pandemic. In the

Table 1: Participant Information

Participant ID	Age range	Gender	Ethnic Background	Years in Service	Organizational Role
P1	40's	Male	African American	10+ years	Program Coordinator
P2	30's	Female	White	8 years	Mental Health Coordinator
P3	40's	Female	Native American and White	14 years	Mental Health Coordinator
P4	20's	Male	African	7+ years	Youth Fitness Coordinator

current paper, we will focus on the last category of questions and discuss our other findings elsewhere.

We audio-recorded the interviews, which we then stored in an encrypted online location before being sent to an online service for transcription. We asked and received all participants' consent to record the interviews. The second author independently conducted inductive thematic analysis on the transcripts which was followed by the first author reviewing and refining the themes.

4 FINDINGS

Our analysis resulted in three broad themes, including how the pandemic has exacerbated obstacles already faced by refugees, the impactful role of remote technology in overcoming COVID-related challenges, and how government programs and non-government organizations are approaching the needs of refugees during the pandemic. We will discuss these in detail next.

4.1 Obstacles Caused by COVID-19

P1, P2, P3, and P4 emphasized how the COVID-19 pandemic amplified preexisting challenges for vulnerable populations, including the people they work with. P2 stated that:

"COVID has really sort of skewed everything. It's added all of these other challenges and barriers. . . . Because I'm like, transportation is hard now because of COVID, but that's not a main concern. But yeah, I think training and understanding for schedulers and people working at offices understanding working with different backgrounds and also how to kindly, gently, and patiently help someone who doesn't speak English [can be helpful]."

Similarly, P4 explained that:

"They already had minimal access to . . . [available] help and the medical care. The pandemic has made that even worse, where parents were only taking their children to seek medical help if it was something horribly serious. The priority of everything that wasn't life-threatening was just put on the back burner. So, stuff like mental health and cognitive and physical disabilities got put on the back burner because we're in a pandemic, and we have to stay at home. So, no one is going to the hospital, especially because hospitals are seen as dangerous places now."

P3 further described how the pandemic added to already existing stress points for many of her clients: "now [refugees] have to worry about COVID-19 on top of [everything else] . . . People who are already coming here dealing with adjustment disorder, leaving their

family behind, losing their support system, dealing with destitution in the first place, people are worried more because now they also have to think about this little bug getting them sick."

P1, P3, and P4 also expanded on how COVID-19 created both physical and virtual distance between people. For example, P3 described the importance of physical touch in her practice and how it is limited due to social distancing:

"It's been difficult for me because I'm a people person and a therapist, and I touch. And touch is very important... So just talking to people on the phone or on video, it takes away from what I can offer to clients... And it takes more time too. When I'm talking with clients on the phone—using a telephonic interpreter does slow you down a little bit, but now I spend much more time explaining things because I can't use as much body language."

Similarly, P4 shared that spending in-person time with refugees is limited because of social distancing:

"We used to do lots of home visits. We couldn't do that for a big chunk of time, where we'd actually go spend time with a family at dinner. Now we have to do it outside."

P1 and P4 specifically identified isolation as a major issue during the pandemic. For example, P1 said: "I know isolation is a big thing . . . it's hard because [of] having family members that might be stuck somewhere else." P3 described how this added isolation can lead to other serious challenges, including increased risk of domestic violence or child abuse: "In mental health and social services, we know that anytime there is a quarantine event, the number of child abuse and domestic abuse cases skyrockets. So, now we've got families who are new in the country, isolated, impoverished, and in some cases, there's child abuse or domestic violence going on in the family, so those things are spiking."

Participants' observations about how challenges such as isolation and decreased access to in-person services has impacted refugees with disabilities are similar to much (e.g., [30] [43]) that emerged on the impact of the pandemic on vulnerable populations and showed that challenges are exacerbated by multiple dimensions of vulnerability (e.g., ability and socioeconomic conditions). In the case of refugees, decreased social capital in host countries and lack of access to a range of social relationships seem to have particularly contributed to the isolating aspects of the pandemic. These issues are even more amplified for refugees with disabilities and their families because they may need access to more health and accessibility

resources than refugees without disabilities which requires navigating complex information systems with reduced opportunities to receive in-person support in these tasks from experts.

4.2 Lack of Trust During COVID-19

P3 and P4 described how confusing messaging about the pandemic and medical advice on how to protect oneself can cause paranoia and other specific difficulties for refugees. P3 described:

“I talked to families who are trying to keep their family healthy, but they’re not getting outside to go for walks with their family. So, it’s overdoing it to the other extreme. And I think again, all this would be aided if there were better— if language access was broader. There are a lot of myths going around in English about COVID-19, right? . . . I mean, it’s really hard to get to what is actually true? Is there a cure for it or not? Is there a vaccine for it or not? Am I supposed to wear a mask or not? . . . And those things are even more muddy for refugees because there are a lot of myths going around, but the news isn’t translated into Arabic. To get to the CDC site where everything is translated into every language, I mean, it’s my job and I couldn’t even tell you exactly what website to go to.”

In the above quote, P3 is describing the difficulty of navigating online information resources even for herself as a service provider, let alone her clients who may have less experience with the system. P4 also mentioned the existence of limited multilingual information resources and how this impacted his clients:

“There could have been more education towards the risks and what each family should do. There were a few flyers and information that was circulated by the government about what COVID was, and how you could stay safe, and stuff like that. But I feel like there needed to be more information and more help, at least to the different language groups.”

P1 described how this disconnect can go both ways and is impacted by historical and political dynamics that led to Western-trained medical professionals look down on traditional healing methods:

“There are cultural stigmas around CBD (Cannabidiol), around the use of medical marijuana and other alternatives to be able to treat certain medical issues. But because if Eurocentric, anti-Black health care system, and anti-Native health care system that looked at things like natural herbs as a way to treat things, we take on those cultural norms as well, and we make it religious.”

P1 further pointed to specific governmental policies and practices that distilled fear in refugee populations making it more difficult to communicate with them directly:

“But an extremely racist government over the last four years that’s been actively xenophobic and attacking refugee populations has just made it difficult to work with folks, because there’s a lot of fear. Fear is

grounded in the reality of where we’re at with . . . an extremely racist administration . . . [Federal agents] actually were knocking on people’s doors. I think it was what, 2017, 2018. You just saw agents going from door-to-door knocking on people’s doors . . . It makes people less wanting to report [health or disability information] because now you have an active person that was hunting them down like criminals for wanting to come to the United States to live a better life...That affected our work directly.”

In the above quotes participants are describing the challenges of navigating confusing and harmful rhetoric in the form of both misinformation and xenophobic messages disseminated through both official and unofficial channels. These findings show that while these issues cause difficulties for everyone, they can cause amplified confusion and paranoia in newly arrived forced migrants who have left their home countries, often under stressful and traumatic conditions, to avoid danger and hardship,

4.3 Strategies in Overcoming COVID-19 Obstacles

Participants described several strategies in place in Maryland to help refugees during the pandemic, both by governmental and non-governmental organizations. P3 described how their non-governmental organization has established protocols for dealing with increased need and difficult circumstances:

“We’re also educating caseworkers at the resettlement centers, just kind of have your eyes open for this...If you suspect abuse called this number, if you suspect domestic abuse, call this number, if the person is in need of mental health referrals, call me. I think just sort of expanded communications and making ourselves available. And the clinics that we contract at the FQHC is to do behavioral health. They had language access capabilities before, but now they’re able to do phone and video sessions with clients.”

P3 discussed how the city and state governments are putting inclusive pandemic response measures relevant to refugees: “Baltimore City, for example, I think they’re the ones who have made testing available for free to everybody. . . . I think Maryland organizations are working really hard to make sure if anybody needs coverage pertaining to COVID, it’s going to be taken care of, but this state is not the norm [compared to other parts of the US].”

P4 further described how they adapted to the pandemic through staying in touch with families while observing social distancing:

“We’d all have modified practices... where we’ll still interacting with the parents and the families, but just outside. Because it was still warmer during the summer, everyone would come outside to the neighborhood park, and we’d just talk and enjoy the day and speak to the parents and find out what they needed. . . . I will say that it wasn’t the same, because some families became hyper-vigilant and hyper-cautious, in that they wouldn’t go for these things, or they

wouldn't allow their kids anywhere near any programming, which in itself has become a challenge. Because we've lost our touch or constant communication with those families."

He further described how they responded to the immediate needs of refugee families that had arisen as a result of the pandemic:

"During the pandemic, there was a rent forgiveness program, or rent assistance, that we were helping a lot of our families navigate... We were trying to help all our families because a lot of them lost jobs. Stay away from eviction or navigate that... Another assistance that some of the organizations we work with is just providing food and supplies to the families during that time . . . And I think those were the two main ones, mostly around rent and food. There wasn't that much to do with medical or healthcare."

P3 discussed the challenge of low funding to support effective communication during the pandemic:

"I think communication is sort of a theme of this whole thing. And I think that the bottom line is that the dollars for refugees are less in this political environment [referring to the 2020 US administration]. . . . We should all be communicating better and making every dollar stretch as far as we possibly can so that we can help the most amount of people."

She further explained how often expertise on specific types of services provided to refugees is scattered across multiple organizations and connecting them in a centralized way can support better access:

"I'm trying to put together a refugee mental health sort of task force or coalition statewide so that we can literally sit down at the same table and one program can say, 'I'm doing this, and this, and this for this client, but we don't do this. And that's what they really need.' And another person at the table can say, 'Wait, we do that. We can do that for that client,' and try to fill in those gaps together. So many great things being done in so many great organizations, but we rarely know what each other is doing. We just need to communicate better."

4.4 Impact of technology during COVID-19

Despite challenges, P2 and P3 emphasized the positive role that technology has had in helping refugees access resources during the pandemic. P2 described the use of telehealth services, "A number of places are doing telehealth services because of COVID...there are challenges with certain clients and families in being able to access these services, but when they've been able to, they've been really helpful". P3 additionally emphasized the impact of service moving online during the pandemic:

"So, we were using telephonic and in-person interpreters before across all programming, but now the video interpretation has taken a bigger role. Zoom communications, WhatsApp, because not everybody

has good Internet. So, I think usually when I'm talking to people, it's on WhatsApp... And our health and mental health orientations have gone virtual now, so we're sending more documents. I send a PowerPoint through WhatsApp. I can have the client's whole family joined me for a refugee mental health orientation on Zoom or Google Meet. Yeah, I think the clinics of course are doing virtual services. Dietary therapy, medical appointments, just not just about everything, but so much can be done on a virtual platform."

P3 generally saw this as a positive movement that may provide more opportunities to serve more people: "We are moving our mental health orientations. . . to a WhatsApp platform during COVID-19. And I think we're going to reach more people than when we do the sessions in person."

P4 also emphasized the benefits of technology during the pandemic, describing that having access to connectivity and devices has been crucial: "Especially with the schools giving the kids laptops, that's been very helpful. I feel like usually, the parents have phones and there's usually one or two phones for the kids. But mostly, they've been using their laptops." P4 described how having access to devices and connectivity has allowed the populations they serve to access beneficial online educational or health services:

"Zoom is a major one in that now, instead of one-on-one academic time at school, now we do Zoom sessions for academic help every day from four to six, where students now go into breakout rooms with college volunteers and get help with their homework. It's also looked like having Zoom Fitness, where everyone logs on, on their phone or on their laptop, and, in their bedrooms, do a short, quick fitness session for an hour . . . the [main technologies] during this time has massively been Zoom and Messenger and WhatsApp."

The overall positive observations our participants made towards the role of technology in supporting some continuity in refugee families accessing learning and social interaction opportunities during the pandemic, including staying connected with service providers, point to implications for future technology design that prioritize solutions that are affordable, inclusive, and distributed equitably among stakeholders. These observations also underline the importance of having access to basic services that enable online access, such as broadband connectivity and affordable internet-enabled devices.

5 DISCUSSION: IMPROVING PANDEMIC-PREPAREDNESS MEASURES FOR REFUGEES

In line with previous research [30] [43], participants described how the COVID-19 pandemic had exacerbated many existing issues for refugees, such as social isolation and difficulty navigating health and wellness resources. These results point to several possibilities for future improvement, such as building more capacity to provide online social support and informational resources to refugees, especially resources in multiple languages and with high-quality and

culturally sensitive translations. More importantly, our findings provide a window into issues related to the socio-political aspects of the lives of refugees with disabilities and mental health challenges during the pandemic. Specifically, participants described that during COVID-19, refugees encountered not only cultural or language barriers in accessing information on how to stay safe or avoid social isolation but also political pressure due to racist and xenophobic political rhetoric that placed the blame of the spread of the disease, and even its genesis, on foreigners.

Another challenge observed by the participants was in the cognitive dissonance that refugees experienced in seeking medical help from a government that they feared would deport themselves or others in similar situations. We argue that challenges with trusting authority may also be present in the case of refugees encountering medical entities and negatively impact their interactions with them. This points to an opportunity for design that acknowledges that not all entities within a government (or governing body) can be trusted equally by marginalized communities and aims to help users identify and build bridges with entities that either because of legislation, mission, or other factors are committed to the well-being of everyone in a social context, regardless of their immigration status or ethnicity.

6 CONCLUSION AND FUTURE WORK

The COVID-19 pandemic has, and is continuing to, impact different communities and individuals differently. The challenges that refugees with disabilities and their families faced during the pandemic were amplified by a range of factors including compromised social support networks due to moving to a new context and the need to navigate a complicated and unfamiliar network of resources and services in the host country. We conducted interviews with experts who work with refugees to better understand some of the challenges they encountered and observed refugees experience during the first year of the pandemic. Our findings show that refugees with disabilities and mental health challenges faced exacerbated difficulties during the pandemic due to language and cultural differences, especially with respect to how navigating public health announcements and guidance proved overwhelming and not tailored to meet the needs of these populations. Perhaps more importantly, some of the major difficulties that refugee communities experienced during the pandemic arose from a need for them to trust authorities that at the same time as providing guidance on how to stay safe, also posed the threat of deportation or other persecution. Finally, participants described how using remote communication technologies such as Zoom or WhatsApp helped people stay connected and, after initial adjustment, helped service providers share services and documents with their clients. These findings show that considering refugees, and in particular those with disabilities and their families, should be a consideration for pandemic preparedness. The needs of this population, while distinct, have much in common with those of other vulnerable populations. These include prioritizing communication mechanisms that are accessible to people with diverse language and cultural backgrounds and in a way that supports trust, for example by explicitly prioritizing privacy and safety.

An important limitation of our paper is that refugees themselves were not directly involved in the research. In this exploratory phase,

we worked with experts to capture their perspectives about the experience of refugee populations during the early phases of the pandemic. We wanted to both gain a better understanding of the issues facing refugees before working with them directly and also avoid burdening them with research activities during this time. In the future, we plan to work directly with refugees to better understand their first-hand lived experiences and verify and complement our current findings.

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