

BMJ Open Knowledge of legal rights as a factor of refugee and asylum seekers' health status: a qualitative study

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ABSTRACT

Objectives To examine health behaviours of refugees and asylum seekers, in relation to their knowledge of public benefits and legal rights.

Design Qualitative study, utilising an open-ended, semi-structured interview guide to ensure information-rich data collection. Thematic content was analysed using qualitative research software.

Setting Participants were drawn from the Weill Cornell Center for Human Rights (WCCHR) in New York City, a single-center, human rights clinic with a globally representative patient population. All interviews were conducted at the Weill Cornell Medicine Clinical and Translational Science Center, a multidisciplinary space within an urban academic medical center.

Participants Twenty-four refugees and asylum seekers currently living in the greater New York City area. Eligible participants were 18 years of age or older and had previously sought services from the WCCHR. The recruitment rate was 55%.

Primary and secondary outcome measures Themes and concepts in participants' health, knowledge, perceptions of and experiences with accessing healthcare and public benefits programmes.

Results Twenty-four participants represented 18 countries of origin and 11 primary languages. Several impediments to accessing healthcare and public benefits were identified, including pragmatic barriers (such as prohibitive costs or lack of insurance), knowledge gaps and mistrust of healthcare systems.

Conclusions There is low health engagement by refugees and asylum seekers, as a result of multiple, complex factors impeding the ability of refugee and asylum seekers to access healthcare and other public benefits for which they are eligible—with resultant detrimental health effects. However, there is an opportunity to utilise novel approaches, such as digital technologies, to communicate relevant information regarding legal rights and public benefits to advance the health of vulnerable individuals such as refugees and asylum seekers.

INTRODUCTION

The USA is home to nearly 45 million immigrants, or 14% of the total population.¹ Approximately 3 million people, or 7% of this population, are refugees and asylum seekers.¹

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This qualitative, interview-based work enabled the collection of information-rich data from refugees and asylum seekers on obstacles they experience to accessing healthcare in the USA.
- ⇒ No prior study has, to our knowledge, focused specifically on low healthcare engagement of US refugees and asylum seekers—a distinctly vulnerable group of immigrants.
- ⇒ Novel study developed through multidisciplinary collaboration between clinical and qualitative researchers, physicians and attorneys involved in immigration law and in medical-legal services for asylum seekers and refugees.
- ⇒ This study included a modest sample size of 24 participants; however, this is commensurate with prior guidance regarding the number of participants in qualitative interviews.

By definition, refugees and asylum seekers are forced to flee their homes due to persecution, violence or war; those seeking asylum are awaiting determination on their asylum application and legal recognition of their refugee status.² During all stages of migration and resettling, they experience unique migration stressors, including barriers to healthcare.^{3–5} Among these barriers, restrictive public welfare policies have resulted in widespread low health engagement, contributing to poor mental and physical health among refugees and asylum seekers.⁶

In 2019, the USA's long-standing 'public charge' rule was substantially redefined and expanded, stating that lawful immigrants who use or are likely to need public benefits (e.g., food stamps, housing assistance, Medicaid) could be disqualified from receiving permanent legal status or even be deportable.⁷ The 2019 rule was particularly ambiguous on how 'public charge' was determined and used a proprietary calculation based on the 'totality of circumstances' to make the

legal determination.⁸ Immediately after the announcement of the pending rule, immigrants and refugees decreased their engagement with healthcare providers and other governmental services, including public benefits programmes.^{7 9 10} This healthcare disengagement has resulted in poor health outcomes and increasing health disparities.¹¹ It remains unknown whether the reversal of the rule in 2021 also reversed the low healthcare engagement in these populations. In essence, the sustained impact of policies prohibitive to healthcare access is not well described.

At baseline, immigrants experience delays in medical diagnoses, reduced referrals to treatment services and discontinued or poor management of disease.¹⁰ For example, immigrants such as refugees and asylum seekers are more likely to develop perinatal mental health disorders and pregnancy complications and have increased risks for maternal, neonatal and infant mortality¹²; undocumented immigrants and their children are known to frequently suffer from post-traumatic stress disorder (PTSD), anxiety and depressive disorders¹³; immigrants residing in the USA for more than 10 years have a disproportionately high prevalence of risk factors for cardiovascular disease, including obesity, hypertension and diabetes,^{14 15} along with a greater risk of undiagnosed and uncontrolled hypertension and hyperlipidemia.¹⁶ Immigrants also have higher mortality rates for multiple types of malignancies—the majority of which are infection related and which can be prevented by screening and preventative services.¹⁷ During the ongoing COVID-19 pandemic, data have repeatedly shown that immigrants are more vulnerable to SARS-CoV-2¹⁸ and, after adjusting for age and gender, are two times as likely to die from COVID-19.¹⁹ Healthcare disengagement can compound these issues.²⁰

Healthcare barriers can be categorised into three levels: individual, system and policy.⁴ Individual barriers include lower socioeconomic status,²¹ fear, misinformation and misperception, all of which exacerbate the underutilisation of primary care services.²² System-level barriers include challenges to navigating a complex healthcare system, often compounded by linguistic and cultural differences.^{23 24} Government policies⁹ and moments of heightened enforcement impact the eligibility and accessibility to benefits such as health insurance. While prior studies have demonstrated that immigrant healthcare disengagement is linked to all three factors—individual, system and policy^{4 9 22–24}—to our knowledge, no study has focused on refugees and asylum seekers, a particularly vulnerable category of immigrants: while immigrants generally relocate to improve their livelihoods and can return to their home countries if they wish, refugees and asylum seekers cannot safely return home. This category of immigrants is, by legal definition, forced to flee their homes due to armed conflict, persecution or violence,^{25 26} exposing them to unique stressors and vulnerabilities.^{27 28} Refugees and asylum seekers are at a higher risk for financial insecurity and low social economic status than other

immigrants and the general population in the host country. In general—with significant variations depending on country of origin—immigrants to the USA are more likely to work in lower paying, service-oriented occupations.²⁹ While financial hardship was associated with poor health in refugee populations,^{30 31} a high socioeconomic status did not protect them from negative health conditions experienced after migration.³² Gaps in available diagnostic services, knowledge about available benefits and/or barriers to healthcare services could contribute to reduced healthcare engagement.^{20 33} There is a gap in the current understanding of low healthcare engagement by refugees and asylum seekers, and if such disengagement persists after the reversal of restrictive immigration policies.²⁰ Also lacking are possible solutions to enable stable healthcare utilisation among this vulnerable population within the context of ever-changing political landscapes.

The focus of this study was to examine factors contributing to low healthcare engagement by refugees and asylum seekers. To fill this gap in our current understanding, we conducted semistructured interviews with refugees and asylum seekers focused on healthcare utilisation, their knowledge of public benefits and their understanding of legal rights. This multidisciplinary study was developed through collaboration between physicians, qualitative and clinical researchers, and attorneys all working at the intersection of healthcare, immigration law and medical–legal services for asylum seekers and refugees for over a decade. This collaboration provided us with a deep understanding of the stressors and health outcomes experienced by this population through reviews of the literature as well as findings from our previous studies. The research team was diverse. It included individuals from different cultural, racial and age groups. Half of the team members were first generation immigrants themselves, spoke multiple languages and understood first-hand the participants' experiences. The team was equipped with cultural sensitivity, empathy and was trained in trauma-informed communication. Though the team were experts in the participants' circumstances and conditions, none of the participants were known to any team member. During the informed consent process, the participants were aware that they will neither be receiving any medical care nor any legal guidance. With this in mind, this study is based on the grounded theory framework³⁴ and was driven by a strong common belief in the power of immigrant stories to inform change.

METHODS

The Andersen model of health service utilisation³⁵ served as the conceptual framework for developing a semi-structured open-ended interview guide to examine the factors influencing health engagement, behaviour and healthcare access including predisposing characteristics, enabling resources and health needs. IRB approval was obtained from the Weill Cornell Medicine Institutional Review Board (IRB Protocol #20–07022320). Purposive

sampling techniques were used to identify and recruit refugees and asylum seekers who had previously agreed to be contacted for research. Other inclusion criteria stated participants must be 18 years of age or older and have initially received services at the asylum clinic, the Weill Cornell Center for Human Rights (WCCHR). Recruitment occurred between March 2021 and May 2021 from the WCCHR, which provided study referrals to the research team until data saturation was reached with 24 participants. Individuals previously evaluated at the Center for Human Rights by investigators of this study were ineligible for participation.

The interviews were conducted in-person in English (n=10) or the participant's native language (n=14) using a phone interpretation service offered through Pacific Interpreters, LanguageLine Solutions. All interviews were conducted at the Weill Cornell Medicine Clinical & Translational Science Center. Every participant provided both oral and written informed consent. Participants were informed that their responses will be anonymised, and that any identifying information will not be included in any report or publication. The participants were aware that stored data will be coded and will be unlinked to identifying information. The researchers also described that the study was covered by a Certificate of Confidentiality that prohibits the use or sharing of any identifying information in legal proceedings or groups except designated research members. The method for data collection was adapted from previous health-related qualitative studies with immigrants.^{36–40} Several modules of the study procedure were validated in other studies conducted by the research team.^{41–44} Background demographic information was collected, and participants were asked a series of questions assessing their knowledge of the 2019 public charge rule and available public benefits, how they learnt about these public benefits, any use of public benefits, their health status and recent engagement with healthcare services. Although not obligated to disclose,³⁶ all participants willingly provided their immigration status. Interviews lasted 45–75 min and were audio-recorded. Participants received a \$60 USD gift card for their time and travel on completion of the interview, as has been done previously in our own studies and in multiple qualitative studies with refugees and asylum seekers in high-income countries.^{45–53} The audio-recorded interviews were transcribed verbatim. Identifying information was removed from each transcript and then saved on a secure server.

The interviews were imported into the qualitative analysis software Dedoose (V.8) for coding and analysis.⁵⁴ A thematic coding scheme was created based on (1) the main questions of the interview guide, some of which had clear categorical responses and (2) emergent themes from open-ended qualitative responses. For the non-categorical items, the research team reviewed the transcripts and identified emergent themes in the qualitative responses, and then, through discussion, developed the final set of codes. Two members of the research team coded

each transcript.⁵⁴ Memos were documented throughout. Discrepancies in codes were discussed until consensus was achieved. Following this coding, researchers identified the dominant themes that emerged from these qualitative data.

Patient and public involvement statement

Patients or the public were not involved in the design, conduct or reporting of this particular research endeavour. In the next phase of this project, we aim to include trusted community stakeholders to provide feedback on data collection methods and future directions.

RESULTS

This study had a 55% recruitment rate. 24 foreign-born participants (66% female) participated in this study. Eighteen participants were refugees and asylum seekers, while the remaining participants (6/24) were previous asylum seekers and currently have other immigration statuses. Participants represented 18 countries of origin, 12 ethnic backgrounds and 11 native languages. Ten participants self-identified as Hispanic, and 17 of the participants reported earning a high school degree or above. Sixteen participants were between the ages of 20–39, and 10 self-identified as single. Ten participants lived with their children and 13 of them lived with one or more relatives (table 1).

The average length of residence in the USA was 11 years (range 3–36 years), with 19/24 of the participants residing in the USA for less than 10 years. Nearly half of the participants were employed in the health industry, housekeeping or other jobs at the time of the interview. Five participants had recently lost their jobs due to the COVID-19 pandemic.

Knowledge and utilisation of public benefits

Only one participant had heard about public benefits before coming to the USA, but said, 'I did know that the government will help you with certain stuff, but I didn't know in-depth'.

All but one participant reported receiving at least one benefit. Healthcare insurance was the most common, with 18 participants reporting having Medicaid. Eight of the Medicaid recipients were single family members. Four participants indicated that their child received healthcare coverage through the Child's Health Insurance Program. Fifteen of the 24 participants reported participating in the Supplemental Nutrition Assistance Program (also known as 'food stamps'), the national school lunch programme or receiving support from the Women, Infants and Children nutrition programme. Five participants received assistance with housing costs; four participants were interested in receiving housing support but were unable to. The least known and received public benefits were the Temporary Assistance for Needy Families (TANF), a federally-funded programme providing a variety of social services such as childcare assistance or job preparation,

Table 1 Participant demographics (n=number of participants)

Demographic		n	Demographic		n
Age range	20–29	4	Country of origin	Central America	9
	30–39	13		South America	5
	40–49	6		Caribbean	1
	Over 49	1		Eastern Europe	1
Gender	Female	16	North Africa	1	
	Male	7	West Africa	4	
	Gender non-conforming	1	Southeast Asia	3	
Hispanic	Yes	14	Household members	Spouse or partner only	4
	No	10		Children	6
Relationship status	Single	10		Grandparents	5
	Married or currently in a relationship	11		Other relatives	8
	Divorced, separated or widowed	3		Other household members, no relation	1
Education	Did not complete primary school	2	Employment	Yes	11
	Did not complete middle school	1		No	13
	Did not complete high school	2	Employment Type	Health Industry	6
	Completed primary school	1		Housekeeping	3
	Completed middle school	1		Other	2
	Completed high school	7	Decade of US entry	Not employed or N/A	13
	Associate degree	1		1980s	1
	Some college	2		1990s	1
	Completed college	6		2000s	1
	Postgraduate degree	1	2010s	21	
Primary Language	Spanish	11	Immigration status	Current asylum applicant	9
	English	3		Refugee	9
	French	2		Previous asylum seeker	6
	Arabic	1			
	Other	7			

and Social Security Income, each of which was used by only one participant. Many participants did not know for which types of public benefits they were eligible, and several were interested in learning and applying for these programmes.

Knowledge of the public charge rule

The majority of the participants (19/24) reported that they had heard about the public charge rule through internet sources (6/24), their lawyer (7/24), friends and family members (7/24), news outlets (7/24) and/or other sources (3/24) but lacked clarity on what the policy entailed. Attorneys and healthcare providers themselves were unclear of the implications of the convoluted ruling (e.g., recommending against their client's use of public benefits, when asylum seekers are in fact exempt from the policy). Those who heard about 'public charge' expressed concern about the potential impact using government

services would have on their immigration status. This fear prevented them from seeking public benefits even when needed. A list of pertinent quotes is located in [table 2](#). Multiple participant responses reflected fear and confusion related to changes in the public charge rule as well as accessing healthcare services related to COVID-19. Of particular note, one participant was deterred from completing paternal screening for sickle cell trait, due to misinformation and anxiety surrounding public charge.

Overview of health outcomes and healthcare access

The most common condition reported was seeking care for mental health (12/24). Other typical reasons for seeking care included cancer screenings, high cholesterol and high blood pressure. More than half of the participants (14/24) reported regularly taking medications, but only one stated that the medication cost was a barrier. When asked about having a primary care doctor,

Table 2 Public benefits and public charge

Context	Illustrative participant quotes
Participant viewpoints related to use of public benefits	<ul style="list-style-type: none"> ▶ The attorney said that I can't apply for any public benefits right now so that I won't be like a load for the government...yes a lot of people say it, and the news say it, that we can't receive any rent assistance or food stamps or Medicaid so that we won't be a public charge. ▶ Our lawyer advised us not to go to shelter or to leave, because <i>[sic]</i> going to be a burden on the government. It's gonna affect your case. ▶ I've heard about it in the news about this public charge rule that's helping people with food and all of that, who are not citizens. It causes the government to spend more money on that. And so, to even get documents for residence or citizenship becomes more difficult for us. ▶ Other immigrants told me the same thing: you shouldn't rely on...you shouldn't ask for any benefits from the government, if you want to be a citizen. ▶ I never applied [for a benefit] because as immigrant <i>[sic]</i>...we think that from what the previous administration did, that taking public benefit...could affect our application at the immigration level. ▶ ...It affects the legal cases for people that are asking for asylum and also the people who have immigration cases. So I avoid taking this help from the government because I am afraid it would affect my case... ▶ I have been in situations of need. But because I'm afraid I haven't done it [applied].
Experiences of healthcare disengagement	<ul style="list-style-type: none"> ▶ Because my wife is pregnant... they [doctors] check and they say my wife has some percentage of sickle cell...So they want me to do a blood test to know if I'm also affected... But if I'm not affected, the baby is good...I called my lawyer to find out if I can...He said no, if I do the Medicaid, I will be...a public charge on the government...So for now, I shouldn't do anything. ▶ ...I do not have the money to go and seek medical attention as you know, I have a serious back pain and headache...And you know why I didn't...try to get so much help with the state the government because I seeking asylum <i>[sic]</i>, and I don't want them to feel out <i>[sic]</i> you know, I started depending on the state or in government already. ▶ When I went to the hospital that's where they told me that if I had a case with immigration to not apply or take any public assistance.
Fears surrounding accessing care for COVID-19	<ul style="list-style-type: none"> ▶ When the public charge began I was scared like <i>[sic]</i> I didn't want to go to the doctor I didn't want to hurt my case...I didn't even want to get a food stamps for him [toddler son], and sometimes even today, I feel like I don't want to but it's needed because it's not enough... Sometimes I wouldn't want to because they will <i>[sic]</i> suddenly the law can change and you know here in the United States, a lot can change from one day to the other. ▶ Since I lived here for a long time, I didn't ask for anything...I didn't ask for a healthcare. I pay everything out of my pocket <i>[sic]</i>. But after the COVID...I asked for health benefits and other benefits...I don't know, it was like, not even a week that I just checked the [unintelligible]. They said, oh, we're sending you information. So and then about a week later...I got the letter. It says that...I'm going to get a decision in a month. I waited about two and a half, maybe three months for something...and then finally I heard back...Again, the NO. So I think it is related.

16 participants reported finding a doctor through various healthcare organisations or through family and friends. Most participants reported seeing a doctor more than once a year, either in an office or at urgent care sites. In addition, 10 participants reported receiving care in the emergency room within the past year, but only half reported that the visit was related to an emergent health issue.

Barriers to healthcare access

14 participants reported facing challenges to accessing healthcare, including pragmatic barriers (such as clinic location or conflicting work hours), lack of knowledge of healthcare services and mistrust. Three participants reported that lack of monetary funds was a barrier to seeking healthcare in the first place. The majority

reported knowledge gaps that prevented them from seeking or receiving healthcare services; several reported that they did not know what health benefits were available to them, and others experienced difficulties navigating the healthcare system, preventing them from receiving efficient care or securing timely appointments. Some participants expressed generalised mistrust of the government or the healthcare system (table 3).

Sources of information

When exploring how one might maintain their engagement with health systems, many participants expressed that their favoured sources of information were from official government, academic or hospital institutions. Nine of the 11 participants who sought information on the internet related to public benefits programmes did so

Table 3 Barriers to seeking healthcare

Barrier type	Examples	Illustrative participant quotes
Pragmatic	<ul style="list-style-type: none"> ▶ Prohibitive costs ▶ No insurance ▶ Transportation ▶ Geographic location ▶ Family responsibilities ▶ Work hours conflict with medical clinic hours 	<ul style="list-style-type: none"> ▶ I don't have the money to get there. Even [if] somebody gives me a ride or swipe on the train. To get there it's hard...So, most of the time I've got to reschedule it...I can't go a month or two now because the last thing that I did is the MRI. ▶ I really need a dentist, but I don't have the money so where would I go? I can't chew on it... ▶ Sometimes I don't have time to go to see the doctor. I have to cancel the appointment and make another one. But I have to cancel that again. But I keep trying. That happens sometimes. ▶ So you can't just go to the clinic, and, you know, even the community clinics, you need some money to pay them. You know, when I came in, newly [<i>sic</i>] even if I feel sick, it was really hard for me to go to the clinic, because I wasn't sure which clinic I'm supposed to go to, I have no insurance...there was not a lot of opportunity for me to see a doctor so, you know, my body just I guess, has to try to make this defense mechanism and not get sick.
Knowledge	<ul style="list-style-type: none"> ▶ Difficulty navigating complex systems ▶ Lack of understanding of healthcare system 	<ul style="list-style-type: none"> ▶ [My] visa was denied. And I didn't have like, any authorization to work. I was undocumented. So I was like, experiencing...a lot of anxiety, depression and all of that. And I never sought medical treatment, because I thought there was no access for that. I mean, for example, because I needed like to see a therapist...I thought that I had not no access at all. And if I had, it was gonna be super expensive... ▶ ...My wife told me before I go for a blood test. She said the doctor told her that I can do it. So you went there. And the lady over there said, doctor, then no assistant is there to work...know the system, unless I have the Medicare. And she sent me downstairs to get my appointment for the Medicare...then I called my lawyer to ask if I could apply and she said no. ▶ Other things that have me upset, actually is that for a psychology pill or therapy or support it's really hard to get it even if you have insurance. For example, I came last year because the doctor sent me because of my special case. But I never was able to get a therapist. I went to several places. But I never got to get the therapy that I needed. ▶ I think that the main barrier is the wait that we have to go through in order to have an appointment or to be assisted by the doctor, be seen by the doctor.
Mistrust	<ul style="list-style-type: none"> ▶ Stigma ▶ Mistrust of healthcare system or technology ▶ Lack of understanding of culture 	<ul style="list-style-type: none"> ▶ I was also scared, because I thought that if I wanted to have access to any health provider, I was scared that the government was gonna track what I was doing...I was paranoid thinking that they will have access to my emails, to everything. ▶ They treat you like you're like you're lying at the first place so they're like the interviews goes by that like say you're lying and I'm gonna find why you're lying. ▶ I don't trust the healthcare...I asked him to tell me, how much would it be? I mean, I don't have to say exact price. But I want to know, what is the average price? She's like, 'I don't know, I don't think it's too much.' I don't mind what is too much...just give me a number that I would decide if I wanted to do it or not. She's like, 'No, I can't give you the budget. It's not gonna cost that much.' And then it was like, over \$1000. ▶ When I first came to this country, I didn't know anything. I didn't know about the rights I had...I had always this feeling kind of persecution or sadness.

through government websites. Participants consistently shared a willingness to access reliable digital resources to learn about their legal rights to access healthcare—of the 24 interviewees, only one felt unable to use the internet due to lacking digital literacy. However, some participants noted that information through these sources was not always up-to-date, which impacted trust in all information. Participant quotes illustrating concerns and potential solutions are listed in [table 4](#).

DISCUSSION

Our study found that lacking knowledge of public benefits and legal rights and fear of jeopardising immigration status were primary reasons for low healthcare engagement by refugees and asylum seekers. Prior studies with general immigrant populations indicate that gaps in available diagnostic services, knowledge about available benefits and eligibility and access to healthcare services could contribute to reduced utilisation.^{20 33} From our

qualitative analysis specific to refugees and asylum seekers, a particularly vulnerable subset of immigrants, we found that gaps in knowledge about available benefits and related eligibility were the most common barriers to healthcare utilisation. Participants were often not aware of these benefits; if they were aware, they may have been concerned or confused about their eligibility, or fearful of using the benefits as it may impact their immigration status. Immigration attorneys and healthcare workers contributed to the confusion. Approximately half of the participants were unemployed at the time of this study and were likely to have needed support. However, over three quarters of participants did not use food stamps, ask for housing support, or request TANF or social security benefits.

Migration policies restricting the use of public benefits are enacted based on the idea that the availability of public benefits might incentivise immigration to the USA.⁵⁵ Qualitative data from this study found evidence to

Table 4 Sources of information

Context	Illustrative participant quotes
Participant beliefs related to accessing digital information	<ul style="list-style-type: none"> ▶ It would be to ask [a trusted person] for more precise information because some people say one thing and some people say another, so it will be like better to ask like [sic] somebody that works in a hospital or somebody that works in the government. ▶ Certain New York states [sic] has a website so you can find information. ▶ [IRS site] It's the trusted site. And you don't get wrong information from that ... I am very careful about my source of information on the internet. I mean, I wouldn't just go to read something someone posted... This is from the government themselves... I mean, it kind of makes sense for that to be trustworthy... maybe 'dot-gov' website all of that, you know, [or] BBC News. ▶ Yeah, I also check some government official websites for this particular institution. Maybe... something like an example confirming information about the COVID. If I go to, how do you call it, the CDC website, I believe that it would be more accurate than just taking it [information] from other people... So if it is an official website of an institution, for me is more trustworthy. ▶ Usually Google and then go to the city or to the state website... Yes. That's the only trusted thing to know that information... ▶ ... This is something I learned, like I need to go first to the city website. I think the NYC gov and they have all of the programs that I guess the city provides, we can find. I think [for] the government services, I would go for the city websites. Since there are a lot of different programs it is different than find [sic] the website of organizations ... like they have the CDC website, department websites, if I go to their website and if I found something very useful, then I could, maybe I would follow everything that's there.

the contrary. Nearly all of the participants lacked knowledge of public benefits before arriving in the USA and only one participant had prior knowledge of government assistance programmes. Almost all participants stated that the availability of public benefits was not a factor in their decision to migrate. After residing in the USA, the majority of study participants did not use food stamps, housing benefits or TANF and Social Security Income benefits.

Heightened and erratic enforcement of immigration policies and ambiguity of public charge determination may influence immigrants' health-seeking behaviour. Our study found low engagement with healthcare services was related to both policy ambiguity and lack of knowledge or clarity on current lawful rights. Multiple participants were at risk of worsened health outcomes because they chose not to seek medical attention for their infected gums, recurrent back pain, severe headaches and mental health illness. An expecting father did not undergo screening for sickle cell trait due to fear of impacting his green card application, a decision possibly endangering both his wife and their unborn child.

Studies have shown that beyond the impact on individual health, a lack of engagement with healthcare services poses a threat to public health.^{56–58} The limited use of healthcare services in this population is likely to increase their risks for illnesses such as low birth weight, infant mortality, maternal morbidity, mental health conditions, cancer, diabetes and cardiovascular disease.^{59 60} In addition, studies have shown that immigrants lag behind in vaccination rates for SARS-CoV-2, either due to vaccine hesitancy⁶¹ or other barriers.⁶² Disparities in vaccine coverage against key preventable infections are particularly evident in asylum-seeking children, who are three times less likely to be vaccinated than the local population.⁶³ Optimal individual and public health, such as appropriate health-seeking behaviour and

population-level immunity, can only be achieved if immigrants such as refugees and asylum seekers engage with healthcare systems.^{64 65}

Importantly, while the Public Charge rule was vacated in 2021, immigrants remain confused about what public benefits they can and cannot access. These interviews were conducted almost two years after the revised public charge rule went into effect, and several months after it was reversed. Our findings suggest that the 'chilling effect'⁶⁶ of punitive immigration policy can last beyond implementation and persist even after subsequent reversal, leading to a persistent, detrimental effect.

Restricting public benefits may force refugees and asylum seekers to access disjointed care through more costly means. Rather than seeking regular preventative care, nearly half of the participants in this study reported going to the emergency room for non-medically emergent situations. Participants' lack of knowledge or misunderstanding about the benefits to which they were entitled as well as mistrust of existing information sources were the most commonly reported barriers to primary healthcare service utilisation (table 3). Using the emergency department to address non-urgent medical needs also results in an increased incidence of medical errors and deprives patients of the benefits of preventative care.⁶⁷ Emergency services are often significantly more expensive,^{68 69} and costs for patients at or below the federal poverty level and without health insurance are usually covered by the state and federal governments.⁷⁰ Providing clarity to refugees and asylum seekers about their ability to use primary healthcare services for prevention and early diagnosis could save the government millions.^{68 69}

A potential solution to improving healthcare disengagement among refugees and asylum seekers is to employ digital tools to disseminate accurate information about legal rights. Previous studies with refugees have indicated that over 90% own smartphones regardless of



sociodemographic characteristics, education and immigration status.⁷¹ High rates of smartphone ownership suggest that digital resources could be accessible to refugees and asylum seekers. More than half of the participants in this study used internet sources to learn about their eligibility for public benefits. In a previous study, immigrants found government websites to be difficult to navigate and instead preferred social media for its ease and clarity.⁷² Given the prevalence of misinformation on social media,^{73 74} and its detrimental impact,⁷⁵ there is an opportunity to develop trustworthy, reliable digital resources to provide information about public benefits for refugees and asylum seekers. Such information should be up-to-date with accurate legal information.

There are several limitations to our study. This study included a modest sample size of 24 refugees and asylum seekers. However, this is on par with Creswell's guidance for 30 participants in qualitative interviews,⁷⁶ and recruitment was completed once data saturation was achieved. Recruitment was through purposive sampling through the WCCHR and may have resulted in the inclusion of participants who were more likely to engage in health programmes and research compared with refugees and asylum seekers who were not WCCHR clients and had not sought any medical attention or evaluation from any clinic. While women make up 50% of displaced populations,⁷⁷ the majority of the research participants in this study were women (66%, or 16/24). This observation is consistent with other qualitative research studies with displaced persons.^{36 37 39 40} All participants were provided a gift card to remove any monetary barriers to participation related to missing work obligations and incurring expenses while travelling to the interview site.⁴⁵⁻⁵³ This compensation mechanism could have introduced participation bias. Thus, the characteristics of participants may differ from those who chose not to participate (e.g., age, employment). Having said that, similar compensation mechanisms in health research improved response rates and the representativeness and did not introduce a significant participation bias.⁷⁸

This study complied with the four core components of qualitative research: credibility, dependability, confirmability and transferability (online supplemental table 1).⁷⁹ The researchers are highly experienced with the target population through leadership roles at the WCCHR and Cornell Law School. They have extensive training in trauma and culturally informed research. The investigators are leaders in the field of refugee research and have a track record of conducting qualitative and clinical studies with this population, including those which are federally funded. All research personnel have received human subject and ethics trainings and certificates. The interviewers tested the interview protocol through three independent pilot interviews. Interviews were audio-recorded and stored as deidentified files on a secure server before being transcribed. The research team met weekly and bi-weekly to ensure that the research is conducted according to highest ethical standards. Two types of

triangulation methods were implemented: method and investigator triangulation.⁸⁰ Two purposive techniques, typical case and heterogeneous sampling, were used to capture the heterogeneity of this population and the variations in the responses. Data saturation was measured per interview and throughout the entire data set such that no new codes and concepts emerged through an iterative process.

CONCLUSIONS

This qualitative study enabled the collection of data-rich interviews from refugees and asylum seekers on the obstacles they experience to accessing healthcare in the USA. These barriers included pragmatic barriers, knowledge gaps and mistrust in healthcare systems, which persisted even after the 2019 Public Charge Rule change was reversed. Our findings point to the benefits of exploring a new path forward using digital technology to improve immigrant healthcare access.

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