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Knowledge of Legal Rights as a Determinant of Refugee and Asylum-Seekers' Healthcare Utilization: A Qualitative Analysis

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TITLE

Knowledge of Legal Rights as a Determinant of Refugee and Asylum-Seekers' Healthcare Utilization: A Qualitative Analysis

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SUMMARY

What is already known on this topic:

- Greater than eighty-two million people worldwide have been forcibly displaced as a result of increasing global conflict: approximately three million are refugees and asylum seekers living in the United States.
- Immigrants of low socioeconomic status face substantial barriers to medical care which worsen by income and legal status.
- Refugee and immigrant populations in the United States are decreasing their engagement with healthcare providers and systems, resulting in deepening healthcare disparities.

What this study adds:

- Our study suggests that practical, knowledge-related, and trust barriers impact how refugees and asylum seekers interact with the healthcare system.
- The use of novel approaches such as digital technologies offers an opportunity for enhanced individual and public health.

ABSTRACT

Objectives: To identify actionable, causative factors for decreased healthcare engagement of refugees and asylum seekers, and examine whether this disengagement is related to a lack of knowledge of public benefits and legal rights.

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 multi-disciplinary space within an urban academic medical center.

Participants: 24 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 Weill Cornell Center for Human Rights (WCCHR). The recruitment rate was 48% with a retention rate of 77%.

Primary and Secondary Outcome Measures: Themes and concepts in participants' knowledge, perceptions of, and experiences with accessing healthcare and public benefits programs.

Results: 24 participants represented 18 countries of origin and 11 primary languages. Several impediments to accessing healthcare were identified, including pragmatic barriers (such as prohibitive costs or lack of insurance), knowledge gaps, and mistrust in healthcare systems. Public narrative suggests that immigrants arrive to the U.S. with the intention of seeking public benefits; however, only a single participant in our study had heard about public benefits programs before arriving to the U.S.

Conclusions: Several factors impede 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 utilize novel approaches, such as digital technologies, to communicate relevant information regarding legal rights to care to ensure individual and population health.

INTRODUCTION

The United States 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. Refugees and asylum seekers are forced to flee their homes due to persecution, violence, or war. During all stages of migration and resettling, they experience unique migration stressors, including barriers to healthcare.²⁻⁴ Among these barriers, restrictive public welfare policies have resulted in widespread and decreased health engagement, contributing to poor mental and physical health among refugees and asylum seekers.⁵

A 2019 “public charge” rule by the United States Government stated that lawful immigrants who use or are likely to need public benefits (e.g., food stamps, housing assistance, or Medicaid) might be disqualified from receiving permanent legal status or could even be deportable.⁶ 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.⁷ Immediately after the announcement of the pending rule, immigrants and refugees decreased their engagement with healthcare providers and services.^{6,8,9} This healthcare disengagement has resulted in poor health outcomes and increasing health disparities.¹⁰

At baseline, immigrants experience delays in medical diagnoses, reduced referrals to treatment services, and discontinued or poor management of disease.⁹ 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 mortality.¹¹ Undocumented immigrants and their children are known to frequently suffer from PTSD, anxiety, and depressive disorders.¹² Immigrants residing in the United States for more than 10 years have a disproportionately high prevalence of risk factors for cardiovascular disease, including obesity, hypertension and diabetes,^{13,14} along with a greater risk of undiagnosed and uncontrolled hypertension and hyperlipidemia.¹⁵ Immigrants also have higher mortality rates for multiple types of malignancies—the majority of which are infection-related and which can be

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3 prevented by screening and preventative services.¹⁶ During the ongoing COVID-19 pandemic, data have
4 repeatedly shown that immigrants are more vulnerable to SARS-CoV-2¹⁷ and, after adjusting for age and
5 gender, are twice as likely to die from COVID-19.¹⁸ Healthcare disengagement compounds these issues.¹⁹
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11 Healthcare barriers can be categorized into three levels: individual, system, and policy.³ Individual
12 barriers include fear, misinformation, and misperception, all of which exacerbate the underutilization of
13 primary care services.²⁰ System level barriers include challenges to navigating a complex healthcare
14 system, often compounded by linguistic and cultural differences.^{21,22} Government policies⁸ and moments
15 of heightened enforcement impact the eligibility and accessibility to benefits such as health insurance.
16
17 While prior studies have demonstrated that immigrant healthcare disengagement is linked to all three
18 factors—individual, system, and policy^{3,8,20-22}—to our knowledge, no study has focused on refugees and
19 asylum seekers, a particularly vulnerable category of immigrants: while immigrants generally relocate to
20 improve their livelihoods and can return to their home countries if they wish, refugees and asylum seekers
21 cannot safely return home. This category of immigrants are, by legal definition, forced to flee their homes
22 due to armed conflict, persecution, or violence,^{23,24} exposing them to unique stressors and
23 vulnerabilities.^{25,26} Gaps in available diagnostic services, knowledge about available benefits, and/or
24 barriers to healthcare services could contribute to reduced healthcare engagement.^{19,27} There is a gap in
25 the current understanding of healthcare disengagement by refugees and asylum seekers, and why such
26 disengagement persists after the reversal of restrictive immigration policies.¹⁹ Also lacking are possible
27 solutions to enable stable healthcare utilization among this vulnerable population within the context of
28 ever-changing political landscapes.
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50 We hypothesized that a lack of knowledge regarding legal rights to public benefits contributes to
51 healthcare disengagement in refugees and asylum seekers in the United States. To fill this gap in our
52 current understanding, we conducted semistructured interviews with refugees and asylum seekers focused
53 on healthcare utilization, their knowledge of public benefits, and their understanding of legal rights.
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METHODS

The Andersen model of health service utilization²⁸ served as the conceptual framework for developing a semi-structured open-ended interview guide. 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 (age 18 and older) who had previously agreed to be contacted for research. Recruitment occurred between March 2021 and May 2021 from the Weill Cornell Center for Human Rights (WCCHR), which provided study referrals to the research team until data saturation was reached with 24 participants.

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. 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 learned about these public benefits, any use of public benefits, their health status, and recent engagement with healthcare services. Although not obligated to disclose, all participants willingly provided their immigration status. Interviews lasted 45-75 minutes and were audio-recorded. Participants received a \$60 gift card for their time upon completion of the interview. 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 (Version 8) for coding and analysis. 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

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3 emergent themes in the qualitative responses, and then, through discussion, developed the final set of
4 codes. Two members of the research team coded each transcript. Memos were documented throughout.
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6 Discrepancies in codes were discussed until consensus was achieved. An inter-rater reliability coefficient
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8 of 90% was achieved. Following this coding, researchers identified the dominant themes that emerged
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10 from these qualitative data.
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15 **Patient and Public Involvement Statement:** Patients or the public were not involved in the design,
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17 conduct, or reporting of this particular research endeavor. In the next phase of this project, we aim to
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19 include trusted community stakeholders to provide feedback on data collection methods and future
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21 directions.
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24 25 26 **RESULTS**

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28 This study had a 48% recruitment rate and a 77% retention rate. Twenty-four foreign-born participants
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30 (58% female) participated in this study. 75% (18/24) of participants were refugees and asylum seekers,
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32 while the remaining participants (6/24) were previous asylum seekers and currently have other
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34 immigration statuses. Participants represented 18 countries of origin, 12 ethnic backgrounds, and 11
35
36 native languages. Ten participants self-identified as Hispanic, and 17 of the participants reported earning
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38 a high school degree or above. Sixteen participants were between the ages of 20 to 39, and 10 self-
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40 identified as single. Ten participants lived with their children and 13 of them lived with one or more
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42 relatives (**Table 1**).
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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		Not employed or N/A	13
	Associate degree	1	DECADE OF U.S. ENTRY	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			

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3 The average length of residence in the United States was 11 years (range 3-36 years), with 80% (19/24) of
4 the participants residing in the U.S. for less than 10 years. Nearly half of the participants (46%) were
5 employed in the health industry, housekeeping, or other jobs at the time of the interview. Five participants
6 had recently lost their jobs due to the COVID-19 pandemic.
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11 12 13 14 15 **Knowledge and utilization of public benefits.**

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17 Only one participant had heard about public benefits before coming to the U.S., but said, “I did know that
18 the government will help you with certain stuff, but I didn’t know in-depth.”
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23 All but one participant reported receiving at least one benefit. Healthcare insurance was the most
24 common, with 18 participants reporting having Medicaid. 44% (8/18) of the Medicaid recipients were
25 single family members. Four participants indicated that their child received healthcare coverage through
26 the Child’s Health Insurance Program (CHIP). 15 of the 24 participants reported participating in the
27 Supplemental Nutrition Assistance Program (SNAP, also known as “food stamps”), the national school
28 lunch program, or receiving support from the Women, Infants, and Children (WIC) nutrition program.
29
30 Five participants received assistance with housing costs; 4 participants were interested in receiving
31 housing support but were unable to. The least known and received public benefits were the Temporary
32 Assistance for Needy Families (TANF), a federally-funded program providing a variety of social services
33 such as childcare assistance or job preparation, and Social Security Income, each of which were used by
34 only one participant. Many participants did not know for which types of public benefits they were
35 eligible, and several were interested in learning and applying for these programs.
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51 **Knowledge of the public charge rule.**

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53 The majority of the participants (19/24) reported that they had heard about the public charge rule through
54 internet sources (6/24), their lawyer (7/24), friends and family members (7/24), news outlets (7/24), or
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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 utilizing 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.

Table 2. PUBLIC BENEFITS AND PUBLIC CHARGE

Context	Illustrative Participant Quotes
Participant beliefs 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

- When the public charge began I was scared like *[sic]* 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 [4-year-old 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 *[sic]* 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 *[sic]*. 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.

Utilization of healthcare services.

When asked about having a primary care doctor, 16 participants reported finding a doctor through various healthcare organizations 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 was related to an emergent health issue.

Overview of health outcomes.

The most common condition reported was seeking care for mental health (12/24). Other reasons for seeking care included cancer screenings and high cholesterol (7/24), and high blood pressure (6/24). More than half of the participants (14/24) reported regularly taking medications, but only one stated that the medication cost was a barrier. Fourteen 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 the efficient care or securing timely appointments. None of the participants reported

poor communication as a barrier to receiving healthcare. However, some participants expressed generalized mistrust of the government or the healthcare system (Table 3).

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 	<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.

- Lack of understanding of culture
- 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 \$1,000.
- 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.

Sources of information.

When exploring how one might maintain their engagement with health systems, many participants expressed that their favored sources of information were from official government, academic, or hospital institutions. 9 of the 11 participants who sought information on the internet related to public benefits programs did so 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 were not always up-to-date which decreased trust in all information. Participant quotes illustrating concerns and potential solutions are listed in **Table 4**.

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 <i>[sic]</i> somebody that works in a hospital or somebody that works in the government. • Certain New York states <i>[sic]</i> 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.

DISCUSSION

Our study found that lacking knowledge of public benefits and legal rights was a primary reason for healthcare disengagement. The focus of this study was to identify actionable causative factors for decreased healthcare engagement of refugees and asylum seekers. Prior studies with general immigrant populations indicated that gaps in available diagnostic services, knowledge about available benefits and eligibility, and access to healthcare services could contribute to reduced utilization.^{19,27} 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 utilization. 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. 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, 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 incentivize immigration to the U.S.²⁹ Qualitative data from this study found evidence to the contrary. Nearly all of the participants lacked knowledge of public benefits before arriving in the U.S. and only one participant had prior knowledge of government assistance programs. Almost all participants stated that the availability of public benefits was not a factor in their decision to migrate. After residing in the U.S., the majority of study participants did not use food stamps, housing benefits, or TANF and Social Security Income benefits.

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5 Importantly, while the Public Charge rule was vacated in 2021, immigrants remain confused about what
6 public benefits they can and cannot access. These interviews were conducted almost two years after the
7 revised public charge rule went into effect, and several months after it was reversed. Our findings suggest
8 that the “chilling effect”³⁰ of punitive immigration policy can last years after implementation and persist
9 even after subsequent reversal.
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18 Heightened and erratic enforcement of immigration policies and ambiguity of public charge determination
19 may influence immigrants’ health-seeking behavior. Our study found decreased engagement with
20 healthcare services was related to both policy ambiguity, and lack of knowledge or clarity on current
21 lawful rights. Multiple participants were at risk of worsened health outcomes because they chose not to
22 seek medical attention for their infected gums, recurrent back pain, severe headaches, and mental health
23 illness. An expecting father did not undergo screening for sickle cell trait due to fear of impacting his
24 green card application, a decision possibly endangering both his wife and their unborn child.
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35 Studies have shown that beyond the impact on individual health, decreased engagement with healthcare
36 services poses a threat to public health.³¹⁻³³ The limited use of healthcare services in this population is
37 likely to increase their risks for illnesses such as low birth weight, infant mortality, maternal morbidity,
38 mental health conditions, cancer, diabetes, and cardiovascular disease.^{34,35} In addition, studies have shown
39 that immigrants lag behind in vaccination rates for SARS-CoV-2, either due to vaccine hesitancy³⁶ or
40 other barriers.³⁷ Disparities in vaccine coverage against key preventable infections was particularly
41 evident in asylum-seeking children, who were three times less likely to be vaccinated than the local
42 population.³⁸ Optimal individual and public health, such as appropriate health-seeking behavior and
43 population-level immunity, can only be achieved if immigrants such as refugees and asylum seekers
44 engage with healthcare systems.^{39,40}
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3 Restricting public benefits may force refugees and asylum seekers to access disjointed care through more
4 costly means. Rather than seeking regular preventative care, nearly half of the participants in this study
5 reported going to the emergency room for non-medically emergent situations. Participants' lack of
6 knowledge or misunderstanding about the benefits to which they were entitled, as well as mistrust of
7 existing information sources were the most commonly reported barriers to primary healthcare service
8 utilization (**Table 3**). Using the emergency department to address non-urgent medical needs also results in
9 an increased incidence of medical errors and deprives them of the benefits of preventative care.⁴¹
10
11 Emergency services are often significantly more expensive,^{42,43} and costs for patients at or below the
12 federal poverty level and without health insurance are usually covered by the state and federal
13 governments.⁴⁴ Providing clarity to refugees and asylum seekers about their ability to use primary
14 healthcare services for prevention and early diagnosis could save the government millions.^{42,43}
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28 A potential solution to improving healthcare disengagement among refugees and asylum seekers is to
29 employ digital tools to disseminate accurate information about legal rights. Previous studies with refugees
30 have indicated that over 90% own smartphones regardless of sociodemographic characteristics, education
31 and immigration status.⁴⁵ High rates of smartphone ownership suggests that digital resources could be
32 accessible to refugees and asylum seekers. More than half of the participants in this study used internet
33 sources to learn about their eligibility for public benefits. In a previous study, immigrants found
34 government websites to be difficult to navigate and instead preferred social media for its ease and
35 clarity.⁴⁶ Given the prevalence of misinformation on social media,^{47,48} and its detrimental impact,⁴⁹ there
36 is an opportunity to develop trustworthy, reliable digital resources to provide information about public
37 benefits for refugees and asylum seekers. Such information should be up-to-date with accurate legal
38 information.
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53 There are several limitations to our study. This study included a modest sample size of 24 refugees and
54 asylum seekers. However, this is on par with Creswell's guidance for 30 participants in qualitative
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3 interviews,⁵⁰ and recruitment was completed once data saturation was achieved. Recruitment was through
4
5 convenience sampling through WCCHR, and may have resulted in the inclusion of participants who were
6
7 more likely to engage in health programs and research compared to refugees and asylum seekers who
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9 were not WCCHR clients and had not sought any medical attention or evaluation from any clinic. Further,
10
11 while WCCHR sees a globally representative population of patients, this sample of 24 participants did not
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13 represent individuals from every country. However, 4 continents and 7 sub-continents were represented
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15 in the sample.
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20 **CONCLUSIONS**

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22 This qualitative study enabled the collection of data-rich interviews from refugees and asylum seekers on
23
24 the obstacles they experience to accessing healthcare in the United States. These barriers included
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26 pragmatic barriers, knowledge gaps, and mistrust in healthcare systems. Our findings point to the benefits
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28 of exploring a new path forward using digital technology to improve immigrant healthcare access.
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3 **Data availability statement.** All data used and analyzed in this study are available from the
4
5 corresponding author upon reasonable request.
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38
39 and take responsibility for the integrity of the data and the accuracy of the data analysis.
40

41 *Concept and design:* Pilato, Yale-Loehr, Powers, Bazarova, Kaur.

42
43 *Acquisition, analysis, or interpretation of data:* All authors.

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45 *Drafting of the manuscript:* Taki, Pilato, Kaur.

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47 *Critical revision of the manuscript for important intellectual content:* All authors.

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49 *Statistical analysis:* Purington, Maley, Powers.

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51 *Obtained funding:* Taki, Yale-Loehr, Powers, Bazarova, Kaur.

52
53 *Administrative, technical, or material support:* Pilato, Sbröllini.

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55 *Supervision:* Yale-Loehr, Powers, Bazarova, Kaur.
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5 **Ethics Statement.** This study involved human participants and was conducted in accordance with the
6 ethical standards of the institutional research committee and with the Helsinki declaration. IRB approval
7 was obtained from the Weill Cornell Medicine Institutional Review Board (IRB Protocol #20-07022320).
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11 Written informed consent was obtained from all individuals who participated in this study.
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TITLE

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 behaviors of refugees and asylum seekers, in relation to their knowledge of public benefits and legal rights.

Design: Qualitative study, utilizing an open-ended, semi-structured interview guide to ensure information-rich data collection. Thematic content was analyzed 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 multi-disciplinary 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 Weill Cornell Center for Human Rights (WCCHR). The recruitment rate was 48%.

Primary and Secondary Outcome Measures: Themes and concepts in participants' health, knowledge, perceptions of, and experiences with accessing healthcare and public benefits programs.

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 utilize 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.

ARTICLE SUMMARY

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 United States.
- No prior study has, to our knowledge, focused specifically on low healthcare engagement of United States refugees and asylum seekers – a distinctly vulnerable group of immigrants.
- Novel study developed through multi-disciplinary collaboration between clinical and qualitative researchers, physicians, and attorneys involved in immigration law and experts in medical-legal work for asylum seekers and refugees.
- This study included a modest sample size of 24 subjects; however, this is commensurate with prior guidance regarding the number of participants in qualitative interviews.

INTRODUCTION

The United States 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 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 United States' long-standing "public charge" rule was substantially re-defined 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 programs.^{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 mortality;¹² undocumented immigrants and their

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3 children are known to frequently suffer from PTSD, anxiety, and depressive disorders;¹³ immigrants
4 residing in the United States for more than 10 years have a disproportionately high prevalence of risk
5 factors for cardiovascular disease, including obesity, hypertension and diabetes,^{14,15} along with a greater
6 risk of undiagnosed and uncontrolled hypertension and hyperlipidemia.¹⁶ Immigrants also have higher
7 mortality rates for multiple types of malignancies—the majority of which are infection-related and which
8 can be prevented by screening and preventative services.¹⁷ During the ongoing COVID-19 pandemic, data
9 have repeatedly shown that immigrants are more vulnerable to SARS-CoV-2¹⁸ and, after adjusting for age
10 and gender, are twice as likely to die from COVID-19.¹⁹ Healthcare disengagement can compound these
11 issues.²⁰

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24 Healthcare barriers can be categorized into three levels: individual, system, and policy.⁴ Individual
25 barriers include lower socioeconomic status,²¹ fear, misinformation, and misperception, all of which
26 exacerbate the underutilization of primary care services.²² System level barriers include challenges to
27 navigating a complex healthcare system, often compounded by linguistic and cultural differences.^{23,24}
28 Government policies⁹ and moments of heightened enforcement impact the eligibility and accessibility to
29 benefits such as health insurance. While prior studies have demonstrated that immigrant healthcare
30 disengagement is linked to all three factors—individual, system, and policy^{4,9,22-24}—to our knowledge, no
31 study has focused on refugees and asylum seekers, a particularly vulnerable category of immigrants:
32 while immigrants generally relocate to improve their livelihoods and can return to their home countries if
33 they wish, refugees and asylum seekers cannot safely return home. This category of immigrants are, by
34 legal definition, forced to flee their homes due to armed conflict, persecution, or violence,^{25,26} exposing
35 them to unique stressors and vulnerabilities.^{27,28} Refugees and asylum seekers are at a higher risk for
36 financial insecurity and low social economic status than other immigrants and the general population in
37 the host country. In general – with significant variations depending on country of origin – immigrants to
38 the United States are more likely to work in lower-paying, service-oriented occupations.²⁹ While financial
39 hardship was associated with poor health in refugee populations,^{30,31} a high socioeconomic status did not

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3 protect them from negative health conditions experienced after migration.³² Gaps in available diagnostic
4 services, knowledge about available benefits, and/or barriers to healthcare services could contribute to
5 reduced healthcare engagement.^{20,33} There is a gap in the current understanding of low healthcare
6 engagement by refugees and asylum seekers, and if such disengagement persists after the reversal of
7 restrictive immigration policies.²⁰ Also lacking are possible solutions to enable stable healthcare
8 utilization among this vulnerable population within the context of ever-changing political landscapes.
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18 The focus of this study was to examine factors contributing to low healthcare engagement by refugees and
19 asylum seekers. To fill this gap in our current understanding, we conducted semi-structured interviews
20 with refugees and asylum seekers focused on healthcare utilization, their knowledge of public benefits,
21 and their understanding of legal rights. This multi-disciplinary study was developed through collaboration
22 between physicians, qualitative and clinical researchers, and attorneys all working at the intersection of
23 healthcare, immigration law and medical-legal services for asylum seekers and refugees.
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33 **METHODS**

34 The Andersen model of health service utilization³⁴ served as the conceptual framework for developing a
35 semi-structured open-ended interview guide to examine the factors influencing health engagement,
36 behavior, and healthcare access including predisposing characteristics, enabling resources, and health
37 needs. IRB approval was obtained from the Weill Cornell Medicine Institutional Review Board (IRB
38 Protocol #20-07022320). Purposive sampling techniques were used to identify and recruit refugees and
39 asylum seekers who had previously agreed to be contacted for research. Other inclusion criteria stated
40 participants must be 18 years of age or older, and have initially received services at the asylum clinic, the
41 Weill Cornell Center for Human Rights (WCCHR). Recruitment occurred between March 2021 and May
42 2021 from the WCCHR, which provided study referrals to the research team until data saturation was
43 reached with 24 participants. Individuals previously evaluated at the Center for Human Rights by
44 investigators of this study were ineligible for participation.
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5 The interviews were conducted in-person in English (n=10) or the participant's native language (n=14)
6 using a phone interpretation service offered through Pacific Interpreters, LanguageLine Solutions. All
7 interviews were conducted at the Weill Cornell Medicine Clinical & Translational Science Center. Every
8 participant provided both oral and written informed consent. The method for data collection was adapted
9 from previous health related qualitative studies with immigrants.³⁵⁻³⁹ Background demographic
10 information was collected, and participants were asked a series of questions assessing their knowledge of
11 the 2019 public charge rule and available public benefits, how they learned about these public benefits,
12 any use of public benefits, their health status, and recent engagement with healthcare services. Although
13 not obligated to disclose,³⁵ all participants willingly provided their immigration status. Interviews lasted
14 45-75 minutes and were audio-recorded. Participants received a \$60 gift card for their time and travel
15 upon completion of the interview, as has been done previously in our own studies and in multiple
16 qualitative studies with refugees and asylum seekers in developed countries.⁴⁰⁻⁴⁸ The audio-recorded
17 interviews were transcribed verbatim. Identifying information was removed from each transcript and then
18 saved on a secure server.
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37 The interviews were imported into the qualitative analysis software Dedoose (Version 8) for coding and
38 analysis.⁴⁹ A thematic coding scheme was created based on 1) the main questions of the interview guide,
39 some of which had clear categorical responses, and 2) emergent themes from open-ended qualitative
40 responses. For the non-categorical items, the research team reviewed the transcripts and identified
41 emergent themes in the qualitative responses, and then, through discussion, developed the final set of
42 codes. Two members of the research team coded each transcript.⁴⁹ Memos were documented throughout.
43 Discrepancies in codes were discussed until consensus was achieved. An inter-rater reliability coefficient
44 of 90% was achieved. Following this coding, researchers identified the dominant themes that emerged
45 from these qualitative data.
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Patient and Public Involvement Statement: Patients or the public were not involved in the design, conduct, or reporting of this particular research endeavor. 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 48% recruitment rate. Twenty-four foreign-born participants (66% female) participated in this study. 18 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 to 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**).

Demographic	n	Demographic	n		
AGE RANGE	20-29	4	COUNTRY OF ORIGIN		
	30-39	13			
	40-49	6			
	Over 49	1			
GENDER	Female	16		Central America	9
	Male	7		South America	5
	Gender non-conforming	1		Caribbean	1
HISPANIC	Yes	14		Eastern Europe	1
	No	10		North Africa	1
Single	10	Yes		West Africa	4
			Southwest Asia	3	
HOUSEHOLD MEMBERS	11	11	Spouse or partner only	4	
			Children	6	
			Grandparents	5	
			Other relatives	8	
			Other household members, no relation	1	

RELATIONSHIP STATUS	Married or currently in a relationship	11	EMPLOYMENT	No	13
	Divorced, separated or widowed	3			
EDUCATION	Did not complete primary school	2	EMPLOYMENT TYPE	Health Industry	6
	Did not complete middle school	1		Housekeeping	3
	Did not complete high school	2		Other	2
	Completed primary school	1		Not employed or N/A	13
	Completed middle school	1	DECADE OF U.S. ENTRY	1980s	1
	Completed high school	7		1990s	1
	Associate degree	1		2000s	1
	Some college	2	2010s	21	
	Completed college	6	IMMIGRATION STATUS	Current asylum applicant	9
	Postgraduate degree	1		Refugee	9
Spanish	11	Previous asylum seeker		6	
English	3				
French	2				
PRIMARY LANGUAGE	Arabic	1			
	Other	7			

The average length of residence in the United States was 11 years (range 3-36 years), with 19/24 of the participants residing in the U.S. 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 utilization of public benefits.

Only one participant had heard about public benefits before coming to the U.S., 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 (CHIP). Fifteen of the 24 participants reported participating in the Supplemental Nutrition Assistance Program (SNAP, also known as "food stamps"), the national school lunch program, or receiving support from the Women, Infants, and Children (WIC) nutrition program. Five participants received assistance with housing costs; 4 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 program providing a variety of social services such as childcare assistance or job preparation, and Social Security Income, each of which were 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 programs.

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), 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 utilizing 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.

Table 2. PUBLIC BENEFITS AND PUBLIC CHARGE

Context	Illustrative Participant Quotes
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<p>Participant viewpoints related to use of public benefits</p>	<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].
<p>Experiences of healthcare disengagement</p>	<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.
<p>Fears surrounding accessing care for COVID-19</p>	<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.

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, 16 participants reported finding a doctor through various healthcare organizations 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 was related to an emergent health issue.

Barriers to healthcare access.

Fourteen 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 generalized mistrust of the government or the healthcare system (**Table 3**).

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 \$1,000. • 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.

Sources of information.

When exploring how one might maintain their engagement with health systems, many participants expressed that their favored 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

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3 programs did so through government websites. Participants consistently shared a willingness to access
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5 reliable digital resources to learn about their legal rights to access healthcare—of the 24 interviewees,
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7 only one felt unable to use the internet due to lacking digital literacy. However, some participants noted
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9 that information through these sources were not always up-to-date which impacted trust in all
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11 information. Participant quotes illustrating concerns and potential solutions are listed in **Table 4**.

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16 **Table 4. SOURCES OF INFORMATION**

Context	Illustrative Participant Quotes
Participant beliefs related to accessing digital information	<ul style="list-style-type: none"> <li data-bbox="440 667 1481 772">• 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 [<i>sic</i>] somebody that works in a hospital or somebody that works in the government. <li data-bbox="440 779 1481 810">• Certain New York states [<i>sic</i>] has a website so you can find information. <li data-bbox="440 816 1481 982">• [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. <li data-bbox="440 989 1481 1155">• 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. <li data-bbox="440 1161 1481 1234">• Usually Google and then go to the city or to the state website... Yes. That's the only trusted thing to know that information... <li data-bbox="440 1241 1481 1444">• ... 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 [<i>sic</i>] 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.

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45 **DISCUSSION**

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47 Our study found that lacking knowledge of public benefits and legal rights and fear of jeopardizing
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49 immigration status were primary reasons for low healthcare engagement by refugees and asylum seekers.
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51 Prior studies with general immigrant populations indicate that gaps in available diagnostic services,
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53 knowledge about available benefits and eligibility, and access to healthcare services could contribute to
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55 reduced utilization.^{20,33} From our qualitative analysis specific to refugees and asylum seekers, a
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3 particularly vulnerable subset of immigrants, we found that gaps in knowledge about available benefits
4 and related eligibility were the most common barriers to healthcare utilization. Participants were often not
5 aware of these benefits; if they were aware, they may have been concerned or confused about their
6 eligibility, or fearful of using the benefits as it may impact their immigration status. Immigration
7 attorneys and healthcare workers contributed to the confusion. Approximately half of the participants
8 were unemployed at the time of this study and were likely to have needed support. However, over three
9 quarters of participants did not use food stamps, ask for housing support, or request TANF or social
10 security benefits.
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22 Migration policies restricting the use of public benefits are enacted based on the idea that the availability
23 of public benefits might incentivize immigration to the U.S.⁵⁰ Qualitative data from this study found
24 evidence to the contrary. Nearly all of the participants lacked knowledge of public benefits before arriving
25 in the U.S. and only one participant had prior knowledge of government assistance programs. Almost all
26 participants stated that the availability of public benefits was not a factor in their decision to migrate.
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28 After residing in the U.S., the majority of study participants did not use food stamps, housing benefits, or
29 TANF and Social Security Income benefits.
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39 Heightened and erratic enforcement of immigration policies and ambiguity of public charge determination
40 may influence immigrants' health-seeking behavior. Our study found low engagement with healthcare
41 services was related to both policy ambiguity, and lack of knowledge or clarity on current lawful rights.
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43 Multiple participants were at risk of worsened health outcomes because they chose not to seek medical
44 attention for their infected gums, recurrent back pain, severe headaches, and mental health illness. An
45 expecting father did not undergo screening for sickle cell trait due to fear of impacting his green card
46 application, a decision possibly endangering both his wife and their unborn child.
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3 Studies have shown that beyond the impact on individual health, a lack of engagement with healthcare
4 services poses a threat to public health.⁵¹⁻⁵³ The limited use of healthcare services in this population is
5 likely to increase their risks for illnesses such as low birth weight, infant mortality, maternal morbidity,
6 mental health conditions, cancer, diabetes, and cardiovascular disease.^{54,55} In addition, studies have shown
7 that immigrants lag behind in vaccination rates for SARS-CoV-2, either due to vaccine hesitancy⁵⁶ or
8 other barriers.⁵⁷ Disparities in vaccine coverage against key preventable infections is particularly evident
9 in asylum-seeking children, who are three times less likely to be vaccinated than the local population.⁵⁸
10 Optimal individual and public health, such as appropriate health-seeking behavior and population-level
11 immunity, can only be achieved if immigrants such as refugees and asylum seekers engage with
12 healthcare systems.^{59,60}
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26 Importantly, while the Public Charge rule was vacated in 2021, immigrants remain confused about what
27 public benefits they can and cannot access. These interviews were conducted almost two years after the
28 revised public charge rule went into effect, and several months after it was reversed. Our findings suggest
29 that the “chilling effect”⁶¹ of punitive immigration policy can last beyond implementation and persist
30 even after subsequent reversal, leading to a persistent, detrimental effect.
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39 Restricting public benefits may force refugees and asylum seekers to access disjointed care through more
40 costly means. Rather than seeking regular preventative care, nearly half of the participants in this study
41 reported going to the emergency room for non-medically emergent situations. Participants’ lack of
42 knowledge or misunderstanding about the benefits to which they were entitled, as well as mistrust of
43 existing information sources were the most commonly reported barriers to primary healthcare service
44 utilization (**Table 3**). Using the emergency department to address non-urgent medical needs also results in
45 an increased incidence of medical errors and deprives patients of the benefits of preventative care.⁶²
46 Emergency services are often significantly more expensive,^{63,64} and costs for patients at or below the
47 federal poverty level and without health insurance are usually covered by the state and federal
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3 governments.⁶⁵ Providing clarity to refugees and asylum seekers about their ability to use primary
4 healthcare services for prevention and early diagnosis could save the government millions.^{63,64}
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9 A potential solution to improving healthcare disengagement among refugees and asylum seekers is to
10 employ digital tools to disseminate accurate information about legal rights. Previous studies with refugees
11 have indicated that over 90% own smartphones regardless of sociodemographic characteristics, education
12 and immigration status.⁶⁶ High rates of smartphone ownership suggests that digital resources could be
13 accessible to refugees and asylum seekers. More than half of the participants in this study used internet
14 sources to learn about their eligibility for public benefits. In a previous study, immigrants found
15 government websites to be difficult to navigate and instead preferred social media for its ease and
16 clarity.⁶⁷ Given the prevalence of misinformation on social media,^{68,69} and its detrimental impact,⁷⁰ there
17 is an opportunity to develop trustworthy, reliable digital resources to provide information about public
18 benefits for refugees and asylum seekers. Such information should be up-to-date with accurate legal
19 information.
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35 There are several limitations to our study. This study included a modest sample size of 24 refugees and
36 asylum seekers. However, this is on par with Creswell's guidance for 30 participants in qualitative
37 interviews,⁷¹ and recruitment was completed once data saturation was achieved. Recruitment was through
38 convenience sampling through WCCHR, and may have resulted in the inclusion of participants who were
39 more likely to engage in health programs and research compared to refugees and asylum seekers who
40 were not WCCHR clients and had not sought any medical attention or evaluation from any clinic. While
41 women make up 50% of displaced populations,⁷² the majority of the research participants in this study
42 were females (66%, or 16/24). This observation is consistent with other qualitative research studies with
43 displaced persons.^{35,36,38,39} All participants were promised a gift card to remove any monetary barriers to
44 participation related to missing work obligations and incurring expenses while traveling to the interview
45 site.⁴⁰⁻⁴⁸
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5 This study complied with the four core components of qualitative research: credibility, dependability,
6 confirmability, and transferability (**Supplementary Table 1**).⁷³ The interviewers are highly experienced
7 with the target population through leadership roles with the Weill Cornell Center for Human Rights. They
8 have extensive training in trauma and culturally informed research. The investigators are leaders in the
9 field of refugee research and have a track record of conducting qualitative and clinical studies with this
10 population, several of which are federally funded. All research personnel have received human subject
11 and ethics trainings and certificates. The interviewers tested the interview protocol through three
12 independent pilot interviews. Interviews were audio-recorded and stored as de-identified files on a secure
13 server before being transcribed. The research team met weekly and bi-weekly to ensure that the research
14 is conducted according to highest ethical standards. Two types of triangulation methods were
15 implemented: method and investigator triangulation.⁷⁴ Two purposive techniques were used to capture the
16 heterogeneity of this population and the variations in the responses.
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33 **CONCLUSIONS**

34 This qualitative study enabled the collection of data-rich interviews from refugees and asylum seekers on
35 the obstacles they experience to accessing healthcare in the United States. These barriers included
36 pragmatic barriers, knowledge gaps, and mistrust in healthcare systems, which persisted even after the
37 2019 Public Charge Rule change was reversed. Our findings point to the benefits of exploring a new path
38 forward using digital technology to improve immigrant healthcare access.
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3 **Data availability statement.** All data relevant to the study are included in the article or uploaded as
4 supplementary information. All data used and analyzed in this study are available from the corresponding
5 author upon reasonable request.
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12
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3 Sbrollini gave administrative, technical, and material support; Yale-Loehr, Powers, Bazarova, Kaur
4 supervised the entirety of the study.
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10 ethical standards of the institutional research committee and with the Helsinki declaration. IRB approval
11 was obtained from the Weill Cornell Medicine Institutional Review Board (IRB Protocol #20-07022320).
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Written informed consent was obtained from all individuals who participated in this study.

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Supplementary Table 1: Four Components for Trustworthiness in Qualitative Research

Research component	Research element	Study detail
Credibility	Engagement with the participants	The interviewers hold leadership roles in the Weill Cornell Center for Human Rights & the Human Rights Impact Lab. They have engaged with asylum seekers for numerous hours in the setting of providing pro-bono forensic evaluations. Prof Yale-Loehr is a leader in immigration law and oversees a pro-bono law clinic that assists hundreds of asylum seekers in their immigration applications. Drs. Bazarova and Powers have extensive experiences in conducting qualitative research with disadvantaged groups.
	Interviewing process and techniques	The interview guide was developed through extensive research and review of the available literature, a process that took over six months. The interview protocol was tested using a pilot interview, and was intentionally open-ended, and minimally structured to ensure gathering of information-rich data.
	Establishing investigators' authority	The investigators have several IRB-approved, NIH-funded protocols with displaced populations, and have extensive experience with conducting qualitative surveys and collecting sensitive clinical information from this population. All research personnel have taken human subject training and research ethics certificate. The study has a certificate of confidentiality from the NIH. Medical and legal experts on the research protocol participated in development of the interview guide.
	Collection of referential adequacy materials	All interviews were audio-recorded. The recordings were stored on a secure server. All recordings were de-identified before being transcribed.
	Peer debriefing	Weekly and bi-weekly meetings were held with the research personnel and collaborators to ensure that all research was conducted with the utmost ethical standards.
Dependability	Description of the study methods	A detailed description of the development and conceptualization of our interview guide was provided. Inclusion and exclusion criteria were clearly defined.
	Reproducibility	Coding accuracy and inter-coder reliability were measured and reported.

Confirmability	Reflexivity & triangulation	<p>Two types of triangulation methods were used: method and investigator.</p> <p>Method triangulation: interviews were used in this study. Prior observations and field notes were based on 400+ affidavits from clients who received forensic evaluations from the Weill Cornell Center for Human Rights and 50+ clients of the pro-bono clinic of the Cornell Law schools representing this population.</p> <p>Investigator triangulation: this study was led by four lead investigators: medical lead investigator (Gunisha Kaur), law lead investigator (Stephen Yale-Loehr), and 2 qualitative research investigators (Jane Powers and Natalie Bazarova) who have decades of experience working with this population. The study design and findings were discussed in bi-weekly meetings.</p>
Transferability	Purposive sampling and data saturation	<p>Two purposive sampling methods were used: typical case and heterogenous sampling. Data saturation was measured per interview and throughout the entire dataset such that no new codes and concepts emerged through an iterative process.</p>

SRQR Checklist for Reporting of Qualitative Research:

SRQR	
Title	Pg 1
Abstract	Pg 3
Problem Formulation	Introduction, pg 4-5
Purpose or research question	Introduction, pg 5
Qualitative approach and research paradigm	Methods, pg 5
Researcher characteristics, reflexivity	Methods, pg 5; Discussion, pg 17
Context	Methods, pg 5-6
Sampling strategy	Methods, pg 5
Ethical issues pertaining to human subjects	Methods, pg 5-6
Data collection methods	Methods, pg 6
Data collection instruments/technologies	Methods, pg 6
Units of study	Methods, pg 6
Data processing	Methods, pg 5-6
Data analysis	Methods, pg 6
Techniques to enhance trustworthiness	Methods, pg 5-6; Supplementary Table
Synthesis and interpretation	Results, pg 7-13
Links to empirical data	Results, pg 7-8; Table 1
Integration with prior work, implications, transferability, and contribution(s)	Discussion, pg 15
Limitations	Discussion, pg 16
Conflicts of interest	Pg 19
Funding	Pg 18

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TITLE

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 behaviors of refugees and asylum seekers, in relation to their knowledge of public benefits and legal rights.

Design: Qualitative study, utilizing an open-ended, semi-structured interview guide to ensure information-rich data collection. Thematic content was analyzed 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 multi-disciplinary 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 Weill Cornell Center for Human Rights (WCCHR). The recruitment rate was 48%.

Primary and Secondary Outcome Measures: Themes and concepts in participants' health, knowledge, perceptions of, and experiences with accessing healthcare and public benefits programs.

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 utilize 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.

ARTICLE SUMMARY

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 United States.
- No prior study has, to our knowledge, focused specifically on low healthcare engagement of United States refugees and asylum seekers – a distinctly vulnerable group of immigrants.
- Novel study developed through multi-disciplinary collaboration between clinical and qualitative researchers, physicians, and attorneys involved in immigration law and experts in medical-legal work for asylum seekers and refugees.
- This study included a modest sample size of 24 subjects; however, this is commensurate with prior guidance regarding the number of participants in qualitative interviews.

INTRODUCTION

The United States 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 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 United States' long-standing "public charge" rule was substantially re-defined 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 programs.^{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 mortality;¹² undocumented immigrants and their

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3 children are known to frequently suffer from PTSD, anxiety, and depressive disorders;¹³ immigrants
4 residing in the United States for more than 10 years have a disproportionately high prevalence of risk
5 factors for cardiovascular disease, including obesity, hypertension and diabetes,^{14,15} along with a greater
6 risk of undiagnosed and uncontrolled hypertension and hyperlipidemia.¹⁶ Immigrants also have higher
7 mortality rates for multiple types of malignancies—the majority of which are infection-related and which
8 can be prevented by screening and preventative services.¹⁷ During the ongoing COVID-19 pandemic, data
9 have repeatedly shown that immigrants are more vulnerable to SARS-CoV-2¹⁸ and, after adjusting for age
10 and gender, are twice as likely to die from COVID-19.¹⁹ Healthcare disengagement can compound these
11 issues.²⁰

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24 Healthcare barriers can be categorized into three levels: individual, system, and policy.⁴ Individual
25 barriers include lower socioeconomic status,²¹ fear, misinformation, and misperception, all of which
26 exacerbate the underutilization of primary care services.²² System level barriers include challenges to
27 navigating a complex healthcare system, often compounded by linguistic and cultural differences.^{23,24}
28 Government policies⁹ and moments of heightened enforcement impact the eligibility and accessibility to
29 benefits such as health insurance. While prior studies have demonstrated that immigrant healthcare
30 disengagement is linked to all three factors—individual, system, and policy^{4,9,22-24}—to our knowledge, no
31 study has focused on refugees and asylum seekers, a particularly vulnerable category of immigrants:
32 while immigrants generally relocate to improve their livelihoods and can return to their home countries if
33 they wish, refugees and asylum seekers cannot safely return home. This category of immigrants are, by
34 legal definition, forced to flee their homes due to armed conflict, persecution, or violence,^{25,26} exposing
35 them to unique stressors and vulnerabilities.^{27,28} Refugees and asylum seekers are at a higher risk for
36 financial insecurity and low social economic status than other immigrants and the general population in
37 the host country. In general – with significant variations depending on country of origin – immigrants to
38 the United States are more likely to work in lower-paying, service-oriented occupations.²⁹ While financial
39 hardship was associated with poor health in refugee populations,^{30,31} a high socioeconomic status did not

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3 protect them from negative health conditions experienced after migration.³² Gaps in available diagnostic
4 services, knowledge about available benefits, and/or barriers to healthcare services could contribute to
5 reduced healthcare engagement.^{20,33} There is a gap in the current understanding of low healthcare
6 engagement by refugees and asylum seekers, and if such disengagement persists after the reversal of
7 restrictive immigration policies.²⁰ Also lacking are possible solutions to enable stable healthcare
8 utilization among this vulnerable population within the context of ever-changing political landscapes.
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18 The focus of this study was to examine factors contributing to low healthcare engagement by refugees and
19 asylum seekers. To fill this gap in our current understanding, we conducted semi-structured interviews
20 with refugees and asylum seekers focused on healthcare utilization, their knowledge of public benefits,
21 and their understanding of legal rights. This multi-disciplinary study was developed through collaboration
22 between physicians, qualitative and clinical researchers, and attorneys all working at the intersection of
23 healthcare, immigration law and medical-legal services for asylum seekers and refugees for over a
24 decade. This collaboration provided us with a deep understanding of the stressors and health outcomes
25 experienced by this population through reviews of the literature as well as findings from our previous
26 studies. The research team was diverse. It included individuals from different cultural, racial and age
27 groups. Half of the team members were first generation immigrants themselves, spoke multiple
28 languages, and understood first-hand the participants' experiences. The team was equipped with cultural
29 sensitivity, empathy and was trained in trauma-informed communication. Though the team were experts
30 in the participants' circumstances and conditions, none of the participants were known to any team
31 member. During the informed consent process, the participants were aware that they will neither be
32 receiving any medical care nor any legal guidance. With this in mind, this study is based on the grounded
33 theory framework³⁴ and was driven by a strong common belief in the power of immigrant stories to
34 inform change.
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56 **METHODS**

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3 The Andersen model of health service utilization³⁵ served as the conceptual framework for developing a
4 semi-structured open-ended interview guide to examine the factors influencing health engagement,
5 behavior, and healthcare access including predisposing characteristics, enabling resources, and health
6 needs. IRB approval was obtained from the Weill Cornell Medicine Institutional Review Board (IRB
7 Protocol #20-07022320). Purposive sampling techniques were used to identify and recruit refugees and
8 asylum seekers who had previously agreed to be contacted for research. Other inclusion criteria stated
9 participants must be 18 years of age or older, and have initially received services at the asylum clinic, the
10 Weill Cornell Center for Human Rights (WCCHR). Recruitment occurred between March 2021 and May
11 2021 from the WCCHR, which provided study referrals to the research team until data saturation was
12 reached with 24 participants. Individuals previously evaluated at the Center for Human Rights by
13 investigators of this study were ineligible for participation.
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28 The interviews were conducted in-person in English (n=10) or the participant's native language (n=14)
29 using a phone interpretation service offered through Pacific Interpreters, LanguageLine Solutions. All
30 interviews were conducted at the Weill Cornell Medicine Clinical & Translational Science Center. Every
31 participant provided both oral and written informed consent. Participants were informed that their
32 responses will be anonymized, and that any identifying information will not be included in any report or
33 publication. The participants were aware that stored data will be coded and will be unlinked to identifying
34 information. The researchers also described that the study was covered by a Certificate of Confidentiality
35 that prohibits the use or sharing of any identifying information in legal proceedings or groups except
36 designated research members. The method for data collection was adapted from previous health related
37 qualitative studies with immigrants.³⁶⁻⁴⁰ Several modules of the study procedure were validated in other
38 studies conducted by the research team.⁴¹⁻⁴⁴ Background demographic information was collected, and
39 participants were asked a series of questions assessing their knowledge of the 2019 public charge rule and
40 available public benefits, how they learned about these public benefits, any use of public benefits, their
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3 health status, and recent engagement with healthcare services. Although not obligated to disclose,³⁶ all
4 participants willingly provided their immigration status. Interviews lasted 45-75 minutes and were audio-
5 recorded. Participants received a \$60 gift card for their time and travel upon completion of the interview,
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7 as has been done previously in our own studies and in multiple qualitative studies with refugees and
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9 asylum seekers in developed countries.⁴⁵⁻⁵³ The audio-recorded interviews were transcribed verbatim.
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11 Identifying information was removed from each transcript and then saved on a secure server.
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18 The interviews were imported into the qualitative analysis software Dedoose (Version 8) for coding and
19 analysis.⁵⁴ A thematic coding scheme was created based on 1) the main questions of the interview guide,
20 some of which had clear categorical responses, and 2) emergent themes from open-ended qualitative
21 responses. For the non-categorical items, the research team reviewed the transcripts and identified
22 emergent themes in the qualitative responses, and then, through discussion, developed the final set of
23 codes. Two members of the research team coded each transcript.⁵⁴ Memos were documented throughout.
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25 Discrepancies in codes were discussed until consensus was achieved. Following this coding, researchers
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27 identified the dominant themes that emerged from these qualitative data.
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37 **Patient and Public Involvement Statement:** Patients or the public were not involved in the design,
38 conduct, or reporting of this particular research endeavor. In the next phase of this project, we aim to
39 include trusted community stakeholders to provide feedback on data collection methods and future
40 directions.
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47 RESULTS

48 This study had a 48% recruitment rate. Twenty-four foreign-born participants (66% female) participated
49 in this study. 18 participants were refugees and asylum seekers, while the remaining participants (6/24)
50 were previous asylum seekers and currently have other immigration statuses. Participants represented 18
51 countries of origin, 12 ethnic backgrounds, and 11 native languages. Ten participants self-identified as
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Hispanic, and 17 of the participants reported earning a high school degree or above. Sixteen participants were between the ages of 20 to 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).

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
					Grandparents	5
			Other relatives		8	
RELATIONSHIP STATUS	Single	10	EMPLOYMENT TYPE	Other household members, no relation	1	
	Married or currently in a relationship	11		Yes	11	
	Divorced, separated or widowed	3		No	13	
EDUCATION	Did not complete primary school	2		EMPLOYMENT TYPE	Health Industry	6
	Did not complete middle school	1	Housekeeping		3	
	Did not complete high school	2	Other		2	
	Completed primary school	1	DECADE OF U.S. ENTRY	Not employed or N/A	13	
	Completed middle school	1		1980s	1	
	Completed high school	7		1990s	1	
	Associate degree	1		2000s	1	
	Some college	2	IMMIGRATION STATUS	2010s	21	
	Completed college	6		Current asylum applicant	9	
Postgraduate degree	1	Refugee		9		
PRIMARY LANGUAGE	Spanish	11	IMMIGRATION STATUS	Previous asylum seeker	6	
	English	3				
	French	2				

Arabic	1
Other	7

The average length of residence in the United States was 11 years (range 3-36 years), with 19/24 of the participants residing in the U.S. 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 utilization of public benefits.

Only one participant had heard about public benefits before coming to the U.S., 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 (CHIP). Fifteen of the 24 participants reported participating in the Supplemental Nutrition Assistance Program (SNAP, also known as “food stamps”), the national school lunch program, or receiving support from the Women, Infants, and Children (WIC) nutrition program. Five participants received assistance with housing costs; 4 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 program providing a variety of social services such as childcare assistance or job preparation, and Social Security Income, each of which were 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 programs.

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), 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 utilizing 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.

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.

	<ul style="list-style-type: none"> • ...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 [sic], and I don't want them to feel out [sic] 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.
<p>Fears surrounding accessing care for COVID-19</p>	<ul style="list-style-type: none"> • When the public charge began I was scared like [sic] 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 [sic] 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 [sic]. 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.

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, 16 participants reported finding a doctor through various healthcare organizations 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 was related to an emergent health issue.

Barriers to healthcare access.

Fourteen 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 generalized mistrust of the government or the healthcare system (**Table 3**).

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

- Stigma
- 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.
- Mistrust of healthcare system or technology
- They treat you 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.
- Lack of understanding of culture
- 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 \$1,000.
- 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.

Sources of information.

When exploring how one might maintain their engagement with health systems, many participants expressed that their favored 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 programs did so 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 were not always up-to-date which impacted trust in all information. Participant quotes illustrating concerns and potential solutions are listed in **Table 4**.

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 <i>[sic]</i> somebody that works in a hospital or somebody that works in the government. • Certain New York states <i>[sic]</i> 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

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3 makes sense for that to be trustworthy... maybe 'dot-gov' website all of that, you know, [or]
4 BBC News.

- 5 • Yeah, I also check some government official websites for this particular institution. Maybe...
6 something like an example confirming information about the COVID. If I go to, how do you
7 call it, the CDC website, I believe that it would be more accurate than just taking it
8 [information] from other people... So if it is an official website of an institution, for me is
9 more trustworthy.
- 10 • Usually Google and then go to the city or to the state website... Yes. That's the only trusted
11 thing to know that information...
- 12 • ... This is something I learned, like I need to go first to the city website. I think the NYC gov
13 and they have all of the programs that I guess the city provides, we can find. I think [for] the
14 government services, I would go for the city websites. Since there are a lot of different
15 programs it is different than find *[sic]* the website of organizations ... like they have the CDC
16 website, department websites, if I go to their website and if I found something very useful,
17 then I could, maybe I would follow everything that's there.

21 22 **DISCUSSION**

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24 Our study found that lacking knowledge of public benefits and legal rights and fear of jeopardizing
25 immigration status were primary reasons for low healthcare engagement by refugees and asylum seekers.
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27 Prior studies with general immigrant populations indicate that gaps in available diagnostic services,
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29 knowledge about available benefits and eligibility, and access to healthcare services could contribute to
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31 reduced utilization.^{20,33} From our qualitative analysis specific to refugees and asylum seekers, a
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33 particularly vulnerable subset of immigrants, we found that gaps in knowledge about available benefits
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35 and related eligibility were the most common barriers to healthcare utilization. Participants were often not
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37 aware of these benefits; if they were aware, they may have been concerned or confused about their
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39 eligibility, or fearful of using the benefits as it may impact their immigration status. Immigration
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41 attorneys and healthcare workers contributed to the confusion. Approximately half of the participants
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43 were unemployed at the time of this study and were likely to have needed support. However, over three
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45 quarters of participants did not use food stamps, ask for housing support, or request TANF or social
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47 security benefits.
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3 Migration policies restricting the use of public benefits are enacted based on the idea that the availability
4 of public benefits might incentivize immigration to the U.S.⁵⁵ Qualitative data from this study found
5 evidence to the contrary. Nearly all of the participants lacked knowledge of public benefits before arriving
6 in the U.S. and only one participant had prior knowledge of government assistance programs. Almost all
7 participants stated that the availability of public benefits was not a factor in their decision to migrate.
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11 After residing in the U.S., the majority of study participants did not use food stamps, housing benefits, or
12 TANF and Social Security Income benefits.
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20 Heightened and erratic enforcement of immigration policies and ambiguity of public charge determination
21 may influence immigrants' health-seeking behavior. Our study found low engagement with healthcare
22 services was related to both policy ambiguity, and lack of knowledge or clarity on current lawful rights.
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24 Multiple participants were at risk of worsened health outcomes because they chose not to seek medical
25 attention for their infected gums, recurrent back pain, severe headaches, and mental health illness. An
26 expecting father did not undergo screening for sickle cell trait due to fear of impacting his green card
27 application, a decision possibly endangering both his wife and their unborn child.
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37 Studies have shown that beyond the impact on individual health, a lack of engagement with healthcare
38 services poses a threat to public health.⁵⁶⁻⁵⁸ The limited use of healthcare services in this population is
39 likely to increase their risks for illnesses such as low birth weight, infant mortality, maternal morbidity,
40 mental health conditions, cancer, diabetes, and cardiovascular disease.^{59,60} In addition, studies have shown
41 that immigrants lag behind in vaccination rates for SARS-CoV-2, either due to vaccine hesitancy⁶¹ or
42 other barriers.⁶² Disparities in vaccine coverage against key preventable infections is particularly evident
43 in asylum-seeking children, who are three times less likely to be vaccinated than the local population.⁶³
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45 Optimal individual and public health, such as appropriate health-seeking behavior and population-level
46 immunity, can only be achieved if immigrants such as refugees and asylum seekers engage with
47 healthcare systems.^{64,65}
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5 Importantly, while the Public Charge rule was vacated in 2021, immigrants remain confused about what
6 public benefits they can and cannot access. These interviews were conducted almost two years after the
7 revised public charge rule went into effect, and several months after it was reversed. Our findings suggest
8 that the “chilling effect”⁶⁶ of punitive immigration policy can last beyond implementation and persist
9 even after subsequent reversal, leading to a persistent, detrimental effect.
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18 Restricting public benefits may force refugees and asylum seekers to access disjointed care through more
19 costly means. Rather than seeking regular preventative care, nearly half of the participants in this study
20 reported going to the emergency room for non-medically emergent situations. Participants’ lack of
21 knowledge or misunderstanding about the benefits to which they were entitled, as well as mistrust of
22 existing information sources were the most commonly reported barriers to primary healthcare service
23 utilization (**Table 3**). Using the emergency department to address non-urgent medical needs also results in
24 an increased incidence of medical errors and deprives patients of the benefits of preventative care.⁶⁷
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26 Emergency services are often significantly more expensive,^{68,69} and costs for patients at or below the
27 federal poverty level and without health insurance are usually covered by the state and federal
28 governments.⁷⁰ Providing clarity to refugees and asylum seekers about their ability to use primary
29 healthcare services for prevention and early diagnosis could save the government millions.^{68,69}
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43 A potential solution to improving healthcare disengagement among refugees and asylum seekers is to
44 employ digital tools to disseminate accurate information about legal rights. Previous studies with refugees
45 have indicated that over 90% own smartphones regardless of sociodemographic characteristics, education
46 and immigration status.⁷¹ High rates of smartphone ownership suggests that digital resources could be
47 accessible to refugees and asylum seekers. More than half of the participants in this study used internet
48 sources to learn about their eligibility for public benefits. In a previous study, immigrants found
49 government websites to be difficult to navigate and instead preferred social media for its ease and
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3 clarity.⁷² Given the prevalence of misinformation on social media,^{73,74} and its detrimental impact,⁷⁵ there
4 is an opportunity to develop trustworthy, reliable digital resources to provide information about public
5 benefits for refugees and asylum seekers. Such information should be up-to-date with accurate legal
6 information.
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13 There are several limitations to our study. This study included a modest sample size of 24 refugees and
14 asylum seekers. However, this is on par with Creswell's guidance for 30 participants in qualitative
15 interviews,⁷⁶ and recruitment was completed once data saturation was achieved. Recruitment was through
16 convenience sampling through WCCHR, and may have resulted in the inclusion of participants who were
17 more likely to engage in health programs and research compared to refugees and asylum seekers who
18 were not WCCHR clients and had not sought any medical attention or evaluation from any clinic. While
19 women make up 50% of displaced populations,⁷⁷ the majority of the research participants in this study
20 were females (66%, or 16/24). This observation is consistent with other qualitative research studies with
21 displaced persons.^{36,37,39,40} All participants were provided a gift card to remove any monetary barriers to
22 participation related to missing work obligations and incurring expenses while traveling to the interview
23 site.⁴⁵⁻⁵³ This compensation mechanism could have introduced participation bias. Thus, the characteristics
24 of participants may differ from those who chose not to participate (e.g., age, employment). Having said
25 that, similar compensation mechanisms in health research improved response rates and the
26 representativeness and did not introduce a significant participation bias.⁷⁸
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46 This study complied with the four core components of qualitative research: credibility, dependability,
47 confirmability, and transferability (**Supplementary Table 1**).⁷⁹ The interviewers are highly experienced
48 with the target population through leadership roles with the Weill Cornell Center for Human Rights. They
49 have extensive training in trauma and culturally informed research. The investigators are leaders in the
50 field of refugee research and have a track record of conducting qualitative and clinical studies with this
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3 population, several of which are federally funded. All research personnel have received human subject
4 and ethics trainings and certificates. The interviewers tested the interview protocol through three
5 independent pilot interviews. Interviews were audio-recorded and stored as de-identified files on a secure
6 server before being transcribed. The research team met weekly and bi-weekly to ensure that the research
7 is conducted according to highest ethical standards. Two types of triangulation methods were
8 implemented: method and investigator triangulation.⁸⁰ Two purposive techniques, typical case and
9 heterogeneous sampling, were used to capture the heterogeneity of this population and the variations in
10 the responses. Data saturation was measured per interview and throughout the entire dataset such that no
11 new codes and concepts emerged through an iterative process.
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26 **CONCLUSIONS**

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28 This qualitative study enabled the collection of data-rich interviews from refugees and asylum seekers on
29 the obstacles they experience to accessing healthcare in the United States. These barriers included
30 pragmatic barriers, knowledge gaps, and mistrust in healthcare systems, which persisted even after the
31 2019 Public Charge Rule change was reversed. Our findings point to the benefits of exploring a new path
32 forward using digital technology to improve immigrant healthcare access.
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3 **Data availability statement.** All data relevant to the study are included in the article or uploaded as
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5 supplementary information. All data used and analyzed in this study are available from the corresponding
6
7 author upon reasonable request.
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45
46 responsibility for the integrity of the data and the accuracy of the data analysis. Authors Pilato, Yale-
47
48 Loehr, Powers, Bazarova, and Kaur contributed to the concept and design. All authors (Pilato, Taki,
49
50 Sbrollini, Purington, Maley, Yale-Loehr, Bazarova, Bhandari, Kaur) participated in the acquisition,
51
52 analysis, and interpretation of data. Taki, Pilato, and Kaur drafted the manuscript; all authors participated
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54 in the critical revisions. Authors Purington, Maley, and Powers completed the analysis using qualitative
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56 software. Taki, Yale-Loehr, Powers, Bazarova, and Kaur obtained funding for the work. Pilato and
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3 Sbrollini gave administrative, technical, and material support; Yale-Loehr, Powers, Bazarova, Kaur
4 supervised the entirety of the study.
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9 **Ethics Statement.** This study involved human participants and was conducted in accordance with the
10 ethical standards of the institutional research committee and with the Helsinki declaration. IRB approval
11 was obtained from the Weill Cornell Medicine Institutional Review Board (IRB Protocol #20-07022320).
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Written informed consent was obtained from all individuals who participated in this study.

Competing interests. None.

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Supplementary Table 1: Four Components for Trustworthiness in Qualitative Research

Research component	Research element	Study detail
Credibility	Engagement with the participants	The interviewers hold leadership roles in the Weill Cornell Center for Human Rights & the Human Rights Impact Lab. They have engaged with asylum seekers for numerous hours in the setting of providing pro-bono forensic evaluations. Prof Yale-Loehr is a leader in immigration law and oversees a pro-bono law clinic that assists hundreds of asylum seekers in their immigration applications. Drs. Barazova and Powers have extensive experiences in conducting qualitative research with disadvantaged groups.
	Interviewing process and techniques	The interview guide was developed through extensive research and review of the available literature, a process that took over six months. The interview protocol was tested using a pilot interview, and was intentionally open-ended, and minimally structured to ensure gathering of information-rich data.
	Establishing investigators' authority	The investigators have several IRB-approved, NIH-funded protocols with displaced populations, and have extensive experience with conducting qualitative surveys and collecting sensitive clinical information from this population. All research personnel have taken human subject training and research ethics certificate. The study has a certificate of confidentiality from the NIH. Medical and legal experts on the research protocol participated in development of the interview guide.
	Collection of referential adequacy materials	All interviews were audio-recorded. The recordings were stored on a secure server. All recordings were de-identified before being transcribed.
	Peer debriefing	Weekly and bi-weekly meetings were held with the research personnel and collaborators to ensure that all research was conducted with the utmost ethical standards.
Dependability	Description of the study methods	A detailed description of the development and conceptualization of our interview guide was provided. Inclusion and exclusion criteria were clearly defined.
	Reproducibility	Coding accuracy was measured and reported. Inter-rater reliability coefficient of 90% was achieved.

Confirmability	Reflexivity & triangulation	<p>Two types of triangulation methods were used: method and investigator.</p> <p>Method triangulation: interviews were used in this study. Prior observations and field notes were based on 400+ affidavits from clients who received forensic evaluations from the Weill Cornell Center for Human Rights and 50+ clients of the pro-bono clinic of the Cornell Law schools representing this population.</p> <p>Investigator triangulation: this study was led by four lead investigators: medical lead investigator (Gunisha Kaur), law lead investigator (Stephen Yale-Loehr), and 2 qualitative research investigators (Jane Powers and Natalie Bazarova) who have decades of experience working with this population. The study design and findings were discussed in bi-weekly meetings.</p>
Transferability	Purposive sampling and data saturation	<p>Two purposive sampling methods were used: typical case and heterogenous sampling. Data saturation was measured per interview and throughout the entire dataset such that no new codes and concepts emerged through an iterative process.</p>

SRQR Checklist for Reporting of Qualitative Research:

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Purpose or research question	Introduction, pg 5
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Context	Methods, pg 5-6
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