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Regular Article

"I promised them I would be there": A qualitative study of the changing roles of cultural health navigators who serve refugees during the COVID-19 pandemic

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ABSTRACT

Cultural health navigators (CHNs) are one type of community health worker (CHW), a front-line cadre critical to mitigating the COVID-19 pandemic among marginalized communities. Yet little is documented about the roles of CHNs serving resettled refugees both before and during the pandemic. The objective of this study was to examine shifts in how CHNs carried out their work with refugee patients at a particular time point in the COVID-19 pandemic. In August 2020, we conducted virtual and serial semi-structured interviews with ten CHNs at a U.S. healthcare system serving ethnically and linguistically diverse refugee communities. We used a thematic analysis approach to code and interpret data. The analysis indicated that CHNs' descriptions of their work with refugee clients and communities largely mapped onto established CHW roles: cultural mediation, care coordination, system navigation, education, and outreach and social support; however, how CHNs fulfilled their roles shifted dramatically during the pandemic. CHNs were unable to physically navigate patients through the system due to safety measures and telemedicine and deeply felt the loss of providing in-person outreach and social support. To offset constraints, CHNs increased the number and scope of virtual contacts with patients and launched novel education, outreach, and social support strategies. Through their adapted strategies, CHNs nurtured a strong foundation of trust to provide continuous care under challenging circumstances, although they were concerned that the lack of in-person interactions decreased patients' sensitive disclosures. The analysis illuminates the important and often unrecognized work of CHWs and informs ongoing efforts to prioritize community health work in U.S. healthcare policy and practice.

1. Introduction

By August 2020, Community Health Workers (CHWs) received recognition for playing a critical role in mitigating the effects of the COVID-19 pandemic among disproportionately impacted ethnically minoritized, rural, and hard-to-reach populations (Calo, Murray, Francis, Bermudez, & Kraschnewski, 2020). Largely overlooked, however, were the contributions of CHWs working with resettled refugees who are among those disproportionately affected by the pandemic. Resettlement is the process by which individuals forced to flee their home country reestablish their lives in a new country. Equipped with cross-cultural, language, and navigational skills, CHWs are uniquely positioned to

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assist refugees who resettled to the United States (U.S.) in the aftermath of war and forced migration to access a healthcare system largely set up to serve English-speaking patients familiar with U.S. social service systems. Indeed, CHWs were identified as the health system actors best poised to access communities declared hard to reach by mainstream public health efforts during the COVID-19 pandemic (Goldfield et al., 2020). Yet, the work of CHWs during the pandemic, to date, has been largely overlooked to the detriment of community-based health work.

Localized CHW-based programs in the U.S. have grown over the past decades in response to needs identified by refugee communities, practitioners, and health agencies. These programs have shown promising results with regard to maternal health (Banke-Thomas, Gieszl, Nizigiyimana, & Johnson-Agbakwu, 2017; Mosley et al., 2021; Sabo et al., 2021), diabetes (Sous et al., 2021), and cancer screening (Kamaraju et al., 2022; Percac-Lima, Ashburner, Bond, Oo, & Atlas, 2013), among other areas. When the COVID-19 pandemic overwhelmed health systems and disrupted the standard of care, leveraging existing CHW programs was an important strategy for COVID-19 education, screening, and contact tracing to vulnerable communities (Calo et al., 2020) including the resettled refugee population (Harris et al., 2020). However, it is unclear how the urgent pressure and expansion of services to include COVID-19 affected the roles and work of CHWs.

A CHW is a "frontline public health worker who is a trusted member of and/or has an unusually close understanding of the community served" so that they link "health/social services and the community to facilitate access to services and improve the quality and cultural competence of service delivery" (Community Health Worker Special Primary Interest Group, 2009). As community insiders, CHWs bridge gaps in language, culture, and trust in a way that mainstream health systems do not (Olaniran, Smith, Unkels, Bar-Zeev, & van denBroek, 2017). CHWs have delivered education, case management, patient navigation, and social services across the U.S. population (Kim et al., 2016). Rigorous randomized controlled trials and systematic reviews have shown that CHW services improve continuity of care (Kangovi et al., 2014) and condition-specific outcomes (e.g., BMI, hemoglobin, blood pressure, mental health symptoms, see Barnett, Gonzalez, Miranda, Chavira, & Lau, 2018; Kangovi et al., 2017), while generating a return on investment to Medicaid payers (Kangovi, Mitra, Grande, Long, & Asch, 2020) and decreasing emergency visit costs (Heisler et al., 2022). CHW services to uninsured, underinsured, and publicly insured immigrant communities have similarly demonstrated positive outcomes across chronic diseases (e.g., Islam et al., 2018) and maternal health (e.g., McCue et al., 2022). Yet, very little research has reported on the work of CHWs who serve the diverse population of refugees who resettle to the U.S. and face significant linguistic, cultural, and economic barriers in navigating complex social service systems (Clarke et al., 2021).

CHWs have a flexible scope of practice and adaptable skills that enabled them to engage patients in the prevention, detection, and diagnosis of COVID-19 in the course of their routine encounters (Wells, Dwyer, Calhoun, & Valverde, 2021). Critically, CHWs provided services during the multiple intensive, stressful, and confusing phases of COVID-19 exposure and infection, including quarantine, hospitalization, recovery, and re-exposure (Wells et al., 2021). In Pennsylvania, CHWs launched live virtual COVID-19 *telementoring* sessions for Spanish and later Nepali language speakers and shared recordings on YouTube to increase access to reliable information (Calo et al., 2020). In Arizona, an ongoing community-based, participatory, and CHW-led program focused on chronic disease reduction among Mexican-origin communities adapted its goals to simultaneously address the social determinants of health, social support needs, and COVID-related concerns (Coulter et al., 2022). The Maricopa County Department of Public Health in Arizona formed the COVID-19 Refugee Outreach Unit to conduct culturally and linguistically appropriate contract tracing, education, outreach, and linkages to health and social services (Cardenas, 2022). In a clinical-resettlement agency partnership in upstate New York, health navigators conducted outreach to refugee and immigrant communities and provided COVID-19 screening, linkages to care, and education (Harris et al., 2020). Yet, it remains unclear how the COVID-19 pandemic affected the work of the CHWs themselves who served resettled refugee communities in the U.S.

Despite growing evidence that CHWs play a critical role in bridging vulnerable communities and healthcare, CHWs remain an overlooked subpopulation of health workers within broader health systems. Several factors contribute to the marginalization of CHWs within the healthcare infrastructure. As the work of CHWs is often community-specific, their positions vary in name (Pérez and Martinez, 2008), such as *community health representatives (CHRs)* serving tribal communities, *promotoras* serving Latinx communities, and *cultural health navigators* (CHNs) serving refugee and immigrant communities (Johnson-Agbakwu et al., 2014). Less than half of U.S. states have formally defined the roles of CHWs, which would promote cohesion across CHW programs and formalize their role within the health system (Cacal, Spock, Quensell, Sentell, & Stupplebeen, 2019). Furthermore, certification pathways vary widely by state, ranging from no clear pathway to university-centered, state-sponsored, and/or multiple pathways, which are often voluntary (National Academy for State Health Policy, 2021). CHW selection criteria and training programs have varied as well (O'Brien, Squires, Bixby, & Larson, 2009), although alignment has become more common with formalized programs. Although states can reimburse for preventative services provided by CHWs through Medicaid, this has not been widely and systematically adopted (Sabo, Wexler, et al., 2021), for many of the reasons outlined above. Too often, CHW programs and services must thus rely on grant funding, risking discontinuity of services.

To respond to these gaps, the CHW Core Consensus (C3) Project led an effort to codify CHW roles and competencies in an effort to "expand cohesion in the field and to contribute to the visibility and greater understanding of the full potential of CHWs" (Rosenthal, Menking, & St. John, 2018, p. 6). Leveraging the National Community Health Advisor Study (Rosenthal, Wiggins, Brownstein, Johnson, & Rael, 1998) and involving 23 of 45 CHW networks at the time, the CHW C3 Project identified 10 roles central to CHWs (Rosenthal et al., 2018). Since then, CHW roles and competencies have been included in federal agencies' standards of care, integrated into training curricula, and endorsed by professional health associations (Rosenthal et al., 2018). But how these core roles are impacted by emergency situations, such as the COVID-19 pandemic, and how CHWs themselves experience these shifts, has yet to be explored.

Therefore, the overarching objective of this qualitative study was to center the voices of CHWs serving resettled refugee communities in an in-depth examination of their work at the height of the COVID-19 pandemic (July–August 2020), before the development and dissemination of vaccines. This paper describes how this specialized group of CHWs, *cultural health navigators* (CHNs), experienced and responded to dramatic shifts in their work during the pandemic.

2. Materials & methods (743 words)

2.1. Context

This study was conducted at Valleywise Health, a public safety-net teaching hospital in Arizona, U.S. Valleywise Health has used a community-based care model to engage resettled refugees since 2008; and in fact, was the first to employ CHNs as a cadre to serve refugee patients in the state. Valleywise Health has been testing and scaling CHN services, demonstrating cultural appropriateness and improved obstetrics (Banke-Thomas et al., 2017; Johnson-Agbakwu, Allen, Nizigiyimana, Ramirez, & Hollifield, 2014) in service to refugee patients from a cumulative total of 71 countries speaking 68 languages. At the time of data collection, 10 CHNs - all respected members of the refugee communities they serve - were employed by the health system.

2.2. Recruitment

The study employed a purposive sampling approach to recruit CHNs. With the support of clinic leaders, the first author engaged coordinators at two established refugee-focused health clinics within the healthcare system. Each coordinator convened a virtual information session to share study objectives and answer questions. Participant confidentiality, anonymity, and how the study was not related to one's employment were emphasized. Interested CHNs subsequently provided their contact information and were invited to participate in two interviews. Participants received an incentive of $40 per interview.

2.3. Data collection

The Institutional Review Boards at Arizona State University (STUDY00012987) and Valleywise Health (2020-061) provided ethical review and approval. All participants provided written informed consent through an online form (Qualtrics XM, Settle, WA). Nine people completed two interviews and one person completed one. Two members of the research team (first and third author) conducted interviews using the telecommunications platform Zoom with the video function enabled with the consent of participants and when supported by adequate bandwidth and preference of participant. Participants chose pseudonyms as their personal identifiers for use in analysis and dissemination. Interviews lasted, on average, 67 min (range 48–113 min). Interviews were recorded in Zoom. The audio recordings were auto-transcribed using Otter.ai software (Los Altos, California) and then reviewed twice with corresponding transcripts by a member of the research team who de-identified and corrected transcripts for accuracy.

2.4. Instruments

The first interview focused on the impact of COVID-19 on participants' work and how they communicate information about COVID-19 to their patients. The second interview focused on community perceptions of public health recommendations for COVID-19.

2.5. Analysis

For this analysis, we used a thematic analysis approach (Bernard, Wutich, & Ryan, 2016) focusing on the deductively derived codes "CHN role", "CHN role changed by COVID-19," and "COVID-19 challenges to providing care," and the inductively derived code "trust." The first author in concert with the team identified themes within these codes following the principles of frequency, universality, differentiation, and emotional response (Baxter & Eyles, 1997). The first, third, and fourth authors independently reviewed the coded segments to identify themes, and these were discussed and reorganized to reach a consensus (e.g., "making sure women understand" and "creating videos and flyers" were grouped under the theme of "education and empowerment"). To further the analytical process, the first and second author then thematically organized dimensions of CHN roles described in the data as per roles delineated in the CHW Core Consensus Project (Rosenthal et al., 2018).

We created a codebook where each code was described in terms of a definition, criteria for inclusion and exclusion, and typical, atypical, and "close-but-no" examples (MacQueen, McLellan, Kay, & Milstein, 1998). The codebook was created in September 2020 and was updated during weekly team meetings through March 2021. Transcripts were re-evaluated any time a significant change to the codebook was introduced. Codes were applied to text by tagging, or adding that code to the entire relevant segment (Bernard et al., 2016), using the software MAXQDA v12 (VERBI GmbH, Berlin, Germany). All excerpts were coded by at least one team member and reviewed by the first author. Participating CHNs were invited to provide input on preliminary results to make sure the findings accurately represented CHW experiences. During a meeting in March 2021, held remotely via Zoom, preliminary results were shared and CHNs were invited to correct, validate, or provide contextualizing information; no significant changes were made to the analysis.

3. Results

The ten CHN participants were a diverse group, reflective of the refugee communities they served. They originated from seven different countries (Burundi, Burma/Myanmar, Democratic Republic of Congo, Iraq, Israel, Rwanda, and Somalia) and had been living in the U.S. for 15.6 years on average (Table 1). CHNs spoke an average of 4.7 languages each and 16 distinct languages among them. Participants had worked in their respective roles for a median of 7.5 years: four CHNs worked in the women's clinic providing care and services to pregnant and postpartum women, four worked in the pediatric clinic, one worked in both the women's and pediatric clinics, and one worked throughout the hospital as a domestic violence advocate. Nearly all CHNs had completed degree programs in higher education (i.e., nursing, healthcare, social work), and three were enrolled in formal degree programs at the time of data collection.

The analysis illuminated CHN roles and shifts during the COVID-19 pandemic, captured thematically in five inter-related domains: (1) cultural mediation of healthcare, (2) care coordination and system navigation, (3) education and empowerment, (4) outreach and social support, and (5) building trust, with quotes attributed to CHNs by their chosen pseudonym.

3.1. Cultural mediation of healthcare

3.1.1. CHNs' key functions within the role

Study participants described cultural mediation as a critically important component of their role, before and during the pandemic. They described providing simultaneous language interpretation to facilitate culturally relevant exchange of information between patients and providers. As Linka noted, "The main issue is not [language] interpretation but culture." Another way that CHNs engaged in cultural mediation, especially those serving women, was by acculturating patients to preventative healthcare. CHNs used their ability to communicate and connect with patients to explain US healthcare in a manner that individuals could readily understand. For example, Moe described the common reaction newly arrived refugee women have when they first hear about annual well-women exams: "'What are you talking about? I'm healthy. Why do I have to have a check-up every year? … The doctor wants my money.'" Amina explained that many women who were displaced in refugee camps did not receive prenatal care and only went to the hospital to give birth, and that her goal was to help them understand why prenatal care is important. CHNs described exploring how best to bridge gaps in understanding, which differed by the patient and necessitated a personalized approach, tailored outreach, and trust.

Table 1
Demographic characteristics of CHW participants serving refugees (n = 10).

Characteristic	Number or Mean ± SD (Range)
Years in U.S.	15.6 ± 9.9 (6, 41)
Number of languages spoken[a]	4.7 ± 2.3 (2,9)
Age	42.9 ± 9.4 (30, 56)
Years of experience as a CHW	6.3 ± 3.1 (2,10)
Highest Level of Education Completed	
High School	1
Associate's	2
Bachelor's	6
Master's	1

[a] Languages spoken included: Arabic (several dialects), Burmese, Chin, Dutch, Kiruba, Kihangaza, Kihaya, Kikongo, Kirundi, Kinyarwanda, Lingala, Lugana, Swahili, Somali.

3.1.2. Challenges introduced by the COVID-19 pandemic

The core mission of providing cultural mediation remained intact. However, fulfilling this role was challenging: COVID-19 safety measures limited and otherwise erected barriers to in-person visits. Katisa described how safety measures, such as masking and social distancing, impeded CHNs' ability to communicate and connect with patients, and to put them at ease.

> The way we provided the services has changed; we have to be wearing those masks so you don't communicate [as before]. Even if we try by voice to be friendly to our patients, not seeing each other creates a barrier, especially with new patients who are new in the clinic … [and] already nervous to go for the first time … It's not too comfortable.

The switch to telemedicine introduced a physical and technological barrier that hampered the personal contact so valued in the CHW model of cultural mediation, fundamentally challenging cultural norms for receiving care. For example, Amina noted: The majority of [patients] don't believe in telemedicine. They say, 'if the doctor cannot see me and touch me, how do I know I got the care I needed?' … Even though via video they can still see the doctor, it's not the same for them."

3.1.3. Adaptations CHNs made in response

While rising telemedicine use during the pandemic was not limited to CHNs, they faced unique challenges to providing cultural mediation and high-quality care over digital platforms. CHNs spent time explaining how the providers were present and actively listening and delivering the same quality of care through telemedicine. This barrier wore down over time, number of telemedicine visits, and sheer necessity, but the preference for in-person care to provide cultural mediation largely remained.

3.2. Care coordination and system navigation

3.2.1. CHNs' key functions within the role

Prior to the pandemic, CHNs devoted significant time to coordinating patient care and helping patients navigate complex systems and departments. Participants described accompanying patients from one area of the hospital to another (e.g., to the lab or pharmacy), escorting patients to the emergency room alongside nurses, and coordinating with front desk triage nurses, pediatrics, and inpatient services. CHNs played an integral role in the referral process by completing and faxing paperwork for patients to see specialists (i.e., mental health and domestic violence providers), and coordinating with government departments for social services (i.e., obtaining health insurance and birth certificates for newborns). CHNs coordinated transportation for patients to get to their appointments, mitigating a significant barrier to care. CHNs also helped patients navigate the deluge of forms and seemingly disparate services, which are particularly overwhelming for refugees who do not speak and/or read English.

3.2.2. Challenges introduced by the COVID-19 pandemic

The COVID-19 pandemic disrupted CHNs' standard approach to care coordination and added new facets. CHNs were unable to physically accompany patients to the same suite of internal services as before the pandemic. In an attempt to replicate the continuity of care, now remotely, CHNs would reach out to patients before appointments to remind them that they would not be physically there and that they were available by telephone. New safety guidelines particularly complicated the role of helping refugee patients physically navigate the health system. For example, simply arranging a hospital visit for a newborn who was exposed to COVID-19 was challenging, especially if the exposure was due to maternal infection and another caregiver uncomfortable with caring for a newborn had to accompany the infant. New guidelines and modes of enforcement could also inadvertently trigger memories of stressful and traumatic events for refugee patients who had experienced war and political oppression. For example, the COVID-19 screening stations located at hospital entrances brought up memories of military or paramilitary checkpoints. Refugee patients described to CHNs that when they got to the hospital, they were stopped and asked questions, and did not understand why. Katisa explained,

> So, I have to tell them, 'don't worry too much, it is not security.' One person actually referred to it as the security barrier or as a security station. And when you think of the security barriers, back from where they come from, or the country they fled … those barriers bring flashbacks. I have to reassure them 'No, no, no, it is just to make sure you're safe and the child you are bringing is not sick.'

3.2.3. Adaptations CHNs made in response

The pandemic added new dimensions to coordination specific to COVID-19 prevention and mitigation. This started with CHNs screening patients for COVID-19 during appointment reminder calls. Katisa noted that this was "a new thing, asking that person if they are sick before even they arrived at the doctor." CHNs coordinated care for individuals who contracted COVID-19; including strategizing with patients on how they could isolate from family, how to care for children while infected, and how to monitor their symptoms to decide if the best course of action was to seek care or to stay at home and isolate. COVID-19 restricted CHNs' ability to physically accompany their patients through many new obstacles created by the pandemic. Still, they played a critical role in culturally mediating new guidelines while remotely navigating vulnerable patients through the health system and through their lives.

3.3. Education and empowerment

3.3.1. CHNs' key functions within the role

CHNs described the important role they played in educating and empowering patients to take the lead in their own healthcare. They spent extensive time making sure patients understood the importance and reason behind each appointment and referral. They taught patients when to call the emergency line (911) and how to coordinate transportation. Before the pandemic, CHNs had conducted targeted educational sessions. Individual sessions, conducted during home visits and follow-up calls, focused on reinforcing messages conveyed by clinical providers during appointments, and providing detailed explanations and guidance on taking medications. CHNs had also facilitated wellness classes for pregnant women on exercise and nutrition, what to expect during birth, postpartum care, and practical guidance (i.e., using car seats). Patients sought CHN guidance on a wide variety of concerns, beyond those strictly about healthcare (e.g., interpreting bills).

3.3.2. Challenges introduced by the COVID-19 pandemic

Since the scientific knowledge of prevention and transmission of SARS-CoV-2 was being developed in real-time, CHNs were put in a very difficult spot of trying to provide up-to-date scientific information in ways that their patients and families could understand. The pandemic dramatically impacted both the content and modes of education; with a pivot from in-person, group classes to primarily telemedicine (video, phone, chat) individual education on COVID-19. CHNs were also tasked with relaying ever-evolving hospital guidelines for in-person appointments. This involved counseling parents who were concerned about putting their child (or themselves) at risk of contracting COVID-19 by attending clinic appointments for vaccinations or other in-person visits. For example, child well visits were in-person for vaccinations but otherwise virtual, and parents were encouraged to bring children in if they were ill, but only with non-COVID-19 symptoms. CHNs were concerned about this leading to patient drop-off. Grace shared, "There are so many people who don't understand the new system … I lose so many patients because of that."

3.3.3. Adaptations CHNs made in response

As trusted resources, CHNs regularly provided COVID-19 education to refugee communities as new information and science emerged. Some of this required cultural mediation; for example, emphasizing that COVID-19 was not analogous to symptoms of diseases that patients were familiar with (e.g., fatigue associated with malaria). CHNs spent considerable time keeping up with the rapidly evolving information, both within and outside of work hours. As Katisa described,

> I try to learn as much as I can from the providers in our clinic, but also listening to the media, the local TV channels, or what the state shares or by participating in webinars. All of those resources I try to use but obviously there are many unanswered questions. And the problem with COVID is that the information has changed.

CHNs reported spending significantly more time engaging with patients on telephone, video, and via social media. CHNs credit this regular effort and connection to retaining patients in care as they worked through the changing clinic guidelines. As Mona said, "I keep talking to them, calling them. Now they understand, they are coming. But at the beginning, it was very hard to get kids in for vaccines." CHNs found themselves combatting misinformation on COVID-19 that circulated globally on social media and contributed to developing and narrating linguistically and culturally specific videos about the COVID-19 pandemic in 11 languages (Gilger, 2021). CHNs reported that patients appreciated seeing familiar faces from the hospital relaying information and that these videos were widely shared on social media.

3.4. Outreach and social support

3.4.1. CHNs' key functions within the role

A core role CHNs had played before and during the pandemic was providing a wide range of social support (i.e., informational, practical, and emotional support) to refugee patients. Heba described, "We do our best to help them in everything. We give them an idea about the country, and whatever they ask … They start calling us about everything they need and we try to direct them in a good way." Going beyond the direct scope of health services, CHNs regularly connected patients to community groups and resources, attended celebrations of life events, and observed holidays with their broader community. Particularly for CHNs working with pregnant and postpartum women and their infants, social support was intertwined with home visits, during which CHNs reviewed instructions from clinical appointments, strengthened health provider and patient relationships, assessed additional needs, and reconnected with patients who had dropped out of care.

3.4.2. Challenges introduced by the COVID-19 pandemic

CHNs continued but struggled to provide these forms of support in the complex health and social landscapes created by the pandemic. The onset of the pandemic abruptly ended all in-person outreach and in-home activities. CHNs lamented no longer being able to conduct home visits and socialize with the broader community, which was how they had typically carried out multiple aspects of their work, including the provision of social support and connecting with new patients needing care. Grace explained,

> It's been horrible because … I'm not able to do outreach or home visit with my patients … Many of them want me to do the outreach but I'm unable to do it, because my work doesn't allow me to be in physical contact with other people. According to our culture, we used to meet as family … and right now, it's just videos or audio calls.

Home visits and providing social support were an integral mechanism for building and maintaining close relationships with their patients. Heba shared,

> When a patient disappears, we go and visit her. When we know some patient is sick, we go and visit her. When somebody has passed away, or we hear they have an accident or something, we go and do a home visit. We make sure that they are good. We give them some donations we give them some gifts and all that help them to make them feel happy, but now all that - we can't.

The new reality dramatically hampered opportunities to identify at-risk patients, who were less likely to share sensitive information over the telephone or by video. CHNs noted that it takes time and repeated interactions across the continuum of care to build a relationship in which a woman would feel comfortable disclosing their experience of domestic violence, for example. Without being able to interact in person, Grace reported that it was more difficult and less likely for women to disclose domestic violence over the phone. Helen explained, "It's not that it's not happening. I mean, we've seen the news, that there is an increase of domestic violence, of child abuse with everybody being in close proximity, but I haven't seen it [among our patients] and that worries me a little bit."

The loss of social interaction and support and physical accompaniment led to CHW perceptions that refugee patients felt abandoned. As Linka recounted, "Sometimes when we put them in the sick room … they think 'you rejected us' … if I am not there in the room, they think that something is wrong." CHNs expressed being particularly frustrated that they were unable to be there in person to support women after birth, including helping patients complete paperwork for birth certificates and social security numbers. They felt as if they had broken their promises to patients, made before the pandemic struck, to accompany them through their pregnancies and to support them during and after they gave birth. These broken commitments impacted patients, as well as CHNs. Helen described, "I've had patients complain actually, because whenever they deliver, we try to make sure that we see them. But we can't do that. I've had patients ask me, 'you don't care anymore?'" Similarly, Moe shared her experience,

> I just feel so bad for the patients … especially the people who are new in this country. We promised them, 'you don't need to worry, even when you deliver, I will be with you, I will be taking care.' They are scared that this is going to be their first experience delivering in this country … I promised them I would be there but [then] I couldn't go. That was really hard for me.

3.4.3. Adaptations CHNs made in response

As described under adaptions to education and empowerment, CHNs increased alternative forms of communication, engaging with patients via telemedicine, telephone, text, and social media. While CHNs found this to be meaningful and important in the other functions (e.g., navigation, education); it did not satisfy the gaps created by ending the in-person forms of social support and outreach that were culturally normative and strengthened connections in a way that was valuable and nourishing for patients as well as for CHNs.

3.5. Building trust

3.5.1. CHNs' key functions within the role

CHNs described the importance of earning, building, and maintaining trust with refugee patients. They described, prior to the pandemic, the ways in which they would systematically build trust by listening to and responding to patient concerns, providing social support, and conducting home visits. In building trusting relationships, CHNs would come to understand their patients' needs in the context of their individual life experiences and refugee journeys.

3.5.2. Challenges introduced by the COVID-19 pandemic

The sheer scale and unknowns that the pandemic presented tested the trust refugee patients had in CHNs and by extension, the healthcare

system, in multiple ways. As Heba shared, "They trust me, they trust the doctors, but this is out of control. Nobody can control it – [not] even the doctors. It is a virus, it is a pandemic." CHNs were put in a position to enforce policies that could be perceived by patients as blocking access to in-person medical care. As CHNs screened patients for COVID-19 symptoms before an in-person visit, CHNs felt they did not always get honest answers from patients, and sometimes later learned someone was, in fact, symptomatic. Furthermore, the rapid and global spread of misinformation about the virus made it difficult for patients to know whom to trust. Given the global nature of refugee networks, misinformation from around the world spreads quickly on social media, often with a mark of medical authority. Katisa recounted,

> The white coats [on social media], who say, 'this is not true, this is true'. … Patients say, 'Oh, this is a doctor who said it, that must be true,' even if it contradicts what the doctor in the office is telling them. Or if it is said by the president or prime minister of their country, 'The prayer will help protect us, don't worry.' Those contradictory messages are the biggest challenge. They don't know who to trust …

3.5.3. Adaptations CHNs made in response

CHNs took additional measures to maintain trust during this vulnerable time. They made concerted efforts to exemplify adherence to masking, personal protective equipment, and distancing guidelines, to demonstrate their care for patients, and to encourage patients to follow suit. As Grace noted, "I think it makes them feel like, 'oh yeah, these people really care about us and they're trying to protect us.'" CHNs made accommodations, such as scheduling early morning appointments and immediately moving patients to exam rooms, in response to patient concerns about potential COVID-19 exposure. The language-specific COVID-19 materials and videos, which featured both CHNs and providers were well-received by the community and gave credibility to the information. These efforts increased CHW responsibilities and workloads. Mona shared,

> I think they trust us that we're doing the right job, reaching out to them with videos and flyers, and telling them, 'sorry I can't bring you in for your own safety' … You try to accommodate their needs and answer questions … even though it might be more work for us. You just have to keep that trust, and they have to trust you that you're doing the right job to protect them so they can bring their kids. They're trusting us with their kids.

The CHNs helped patients navigate the sea of competing claims as best as possible, debunking harmful misinformation through their remote outreach and appointments. In return, CHNs felt that patients demonstrated their trust when they followed CHNs' advice and hospital guidelines, which were oftentimes confusing (i.e. limiting hospital visits to reduce COVID-19 exposure but not refraining from seeking care when it was necessary). CHNs indicated that after initial confusion and not taking the pandemic seriously at first, they felt that patient trust in them increased and described that patients contacted them more frequently to share symptoms, provide updates on situations, and obtain guidance on the next steps.

4. Discussion

Our analysis provides evidence for how the work of CHNs serving resettled refugees before and during the COVID-19 pandemic aligns with the key roles identified by the CHW Core Consensus Project (Rosenthal et al., 2018) and illustrates the adaptations CHNs made to address challenges introduced by the COVID-19 pandemic. During the early stage of the pandemic (through September 2020), CHNs continued to provide cultural mediation of healthcare, care coordination and system navigation, education, outreach and social support, and built and maintained trust with increased effort spent towards activities focused on mitigation of the COVID-19 pandemic and virtual modalities. The COVID-19 pandemic introduced multiple levels of barriers and CHNs responded by increasing their engagements in phone and text interactions and persisted in helping patients acclimatize to the ideas and use of new technologies and safety measures. They increased their efforts dedicated to coordination and systems navigation; and CHNs spent more time strategizing with patients on what to do in cases of COVID-19 exposure and how to minimize the risk of exposure during in-person clinical visits. CHNs played a significant role in culturally mediating understanding of COVID-19 transmission and prevention, intervening when patients used other common (non-infectious) illnesses to relate to COVID-19 and addressing misconceptions about treatments. CHNs spent considerable time educating themselves outside of work hours to understand rapidly changing guidelines and they created linguistically and culturally tailored videos that were widely shared among patients in their geographic area and beyond. Although outreach and social support still occurred, CHNs felt the loss of being able to do these activities in person and were unable to adapt this key aspect of their relationship in ways that felt nourishing to them and (according to the CHNs) their patients. CHNs were concerned about how the barriers to how they typically conducted their roles affected trust with the community and sensitive disclosures, such as COVID-19 symptoms and intimate partner violence. However, CHNs felt largely successful in their increased efforts to sustain the trust that was so valuable to their work, although they noted that the uncertain nature and scale of the pandemic introduced truly unprecedented dimensions.

Our findings that refugee-serving CHNs were able to adapt in many – but not all – of their primary CHW role domains during the COVID-19 pandemic largely aligns with recent literature on CHWs and health workers serving ethnic minority populations across the U.S. CHWs serving refugee communities noted how their patients interpreted the scale of the pandemic through their previous experience. In one case the pandemic was perceived as less serious than living with widespread disease outbreaks in refugee camps (Bearss et al., 2024); and in another case, the quarantine and stay-at-home mandates resurfaced previous trauma of their refugee experience (Stevenson et al., 2022). Hmong CHWs described navigating pandemic restrictions and grief in the community as a result of not being able to honor loved ones through timely and culturally normative burial rituals that prevented their loved ones from reaching the afterlife (Stevenson et al., 2022). In these and other cases, CHWs serving refugees and immigrants have to consider aspects of their patients' life course that are unique to the resettlement and immigration journey, in addition to what Maciel et al. (2020) poignantly described as CHWs' already *"arduous task of … collecting, knowing, systematizing, and translating the anguish and doubts of the population"* in the context of COVID-19.

Similar to our findings, CHWs in other studies reported culturally mediating information on COVID-19 and combatting misinformation as an increased facet of their work as they served Asian, Black, and Hispanic diaspora communities and Indigenous and Pacific Islander communities in Hawai'i, the Midwest, and the Southwest (Jiménez et al., 2023; Moir et al., 2021; Stevenson et al., 2022). In our study, CHNs partnered on the creation of unique video content as did CHWs and CHW networks elsewhere (Jiménez et al., 2023; Stevenson et al., 2022). In other contexts with specific linguistic needs, the creation of culturally and linguistically adapted education materials was led by combinations of community advisory boards turned COVID-19 Task Forces, community leaders, and other health workers (Feinberg, O'Connor, Khader, Nyman, & Eriksen, 2023; Sharma, Devaraj, Miller, & Cuffee, 2022). CHWs serving refugee communities in Upstate New York described how in the absence of COVID-19 information accessible in their languages, social media facilitated the spread of misinformation among transnational refugee communities, which CHWs combatted through door-to-door outreach (Kuroda, Shaw, & Campagna, 2024). Across many CHW settings, CHWs took on the new role of educating, training, and facilitating their patient's expanded use of technology to engage in

healthcare (Bearss et al., 2024; Golden, Jorgenson, & Williams, 2023; Nawaz et al., 2023)

Our findings that CHNs struggled to adapt to the loss of in-person engagement due to the transformation in how they were allowed to do their work resonates with similar studies. The reorganization of the CHW work process to have to physical distance from colleagues and patients while increasing reliance on technology to execute their roles has been described as nothing short of a "radical disruption" (Golden et al., 2023; Mayfield-Johnson et al., 2020). CHWs in South Texas reported that this dramatic change in how they engaged with their patients negatively affected the interpersonal relationships that are central to their work (Zapata, Lesser, Recto, Moreno-Vasquez, & Idar, 2022), which facilitates trust. This switch among CHWs from in-person work to technologically mediated has led to feeling the "expansiveness of work," social isolation, gender inequities, and stress around using/facilitating the use of technology for others (Golden et al., 2023). This has exacerbated the existing pre-pandemic role expansion of CHWs being go-to resources for many areas areas outside of health (Carter, Hassan, & Walton, 2022).

Our findings differ from emerging literature on CHN adaptations during the pandemic in key ways, which may be partially explained by the hospital-based and regular funding status of CHNs in our study. First, CHWs in other studies did conduct outreach in their communities in person (Nawaz et al., 2023; Stevenson et al., 2022). The later timing of some of these events (e.g., following vaccine availability) compared to our August–September 2020 data collection may have contributed. But for hospital-based CHNs, care coordination and systems navigation of healthcare may take priority compared to community outreach roles, particularly when clinically-based health workers sought to minimize the risk they brought to communities. Among the primarily community-based CHW literature, we found limited mention of CHWs adapting their system navigation and care coordination roles during the pandemic; this was present in examples such as screening patients (Moir et al., 2021) and specific interventions launched to connect patients to care for non-COVID-19-related concerns (Carter et al., 2022).

Second, CHWs' requests and demands for resources on supporting patients during the COVID-19 pandemic, including COVID-19-specific information on prevention and treatment, how to counsel patients experiencing distress as a result of personal and collective loss during the pandemic, and how to support their self-care was well-documented (Byrd-Williams et al., 2021; Moir et al., 2021; Nawaz et al., 2023). CHNs in this study did not request additional information on combatting COVID-19 or supporting patients; however, they received very regular (at the time of data collection, daily) health updates from the hospital that community-based CHNs may not have had. This close linkage and transparency with the rapidly changing guidelines may have affected CHNs' own trust in COVID-19 information, which varied among other CHW groups. For example, the majority of Latinx CHWs and Native American CHRs in Arizona reported trusting COVID-19 information from their own healthcare provider "a great deal" but from governmental sources only "a little" (Jiménez et al., 2023). Black CHWs in Ohio, along with their patients, traced the repeated medical and scientific abuses of the Black community to exploitation via COVID-19 (Donley, 2023). Mistrust of Western medicine among refugee communities (althrough not by CHWs) has been similarly reported in the context of COVID-19, with vaccines perceived as "an attempt to exterminate the Hmong community" following the history of persecution in their home country and violence against Asian Americans in the U.S. (Stevenson et al., 2022), and in other complex health conditions that resulted in patient death (Schuster et al., 2019). Finally, while CHNs in this study did express increased workload and role shifts, they did not express feeling undervalued by the health system (Zapata et al., 2022) or resentful towards their role changes (Sims et al., 2022) as was reported elsewhere at a similar time in the pandemic.

There is a robust literature on CHWs, how they facilitate the health and wellbeing of their communities, and increasingly on how resilient they are; but gaps remain as to how to support CHNs as they are now expected to be adaptable and resilient under pandemic conditions. While our study described some pandemic-related costs of conducting their work, a deeper exploration of how role shifts affect CHWs' workload, wellbeing, and relationships with their patients is needed. CHWs were lauded for their adaptability and resilience during the COVID-19 pandemic (Deussom et al., 2022); however, our study identified that CHWs were challenged to adapt when the in-person dynamic was comprised; a dynamic critical in enriching patient-CHW relationships, CHW work, and CHWs' wellbeing (Schuster et al., 2024). It is imperative that health systems plan for continuing the care and services CHWs provide in future crises.

Our findings underscore that deeper integration of CHWs in the formal health system is warranted for the well-being of communities. CHWs have been found to provide a return on investment in terms of patient outcomes (Heisler et al., 2022; Kangovi et al., 2020), be critical in adapting to care needs during the COVID-19 pandemic, and be a leading strategy to return to quality care standards following the pandemic (Belita et al., 2022). Despite this, CHWs remain an under-resourced and under-valued health worker cadre in terms of sustainable funding (Knowles, Rabinowich, Ettinger de Cuba, Cutts, & Chilton, 2016). Coalitions of CHWs, activists, practitioners, and policymakers have brought about Medicaid reimbursement of CHWs for patient education and preventive services in Arizona (Ingram et al., 2020; Sabo, Wexler, et al., 2021), joining other states with CHW funding mechanism laws via Medicaid or other forms of public assistance (Schmit et al., 2022). Calls for more states to create these enabling laws and expand their use in practice have risen, particularly given the essential contributions CHWs made during the COVID-19 pandemic (Anabui, Carter, Phillippi, Ruggieri, & Kangovi, 2021; Bearss et al., 2024; Nawaz et al., 2023) amidst a fragmented public health system. Integration under supportive reimbursement laws (e.g., Medicaid) for health services still comes with challenges that require clear guidelines on how to finance and functionally integrate CHWs into care organizations (George et al., 2020; Rogers et al., 2018); much has to be worked out even with these successes, which do not typically cover CHW work related to outreach, advocacy, and community capacity building (George et al., 2020; Nawaz et al., 2023). These calls for integration raise questions about how CHWs will maintain the same trusting relationship with communities once they are formalized as part of the health system and become "insiders"; particularly if they are primarily focused on health services and less on the non-funded aspects such as outreach, advocacy, and community building under these financial models.

5. Limitations

Although our sample size may appear relatively small, it represented 100% of the CHNs working with refugee patients in a very large public health system at the time of data collection. Conducting two interviews with nine of the 10 participants, furthermore, produced a rich dataset, which allowed us to achieve thematic saturation. As is typical in qualitative research of this nature, our findings are not generalizable to a broader population of CHWs. However, insights gleaned from our in-depth analysis have the potential to inform subsequent research, practice, and advocacy.

6. Conclusions

This study illuminates the important and underrecognized work of CHNs in bridging marginalized refugee communities and the American healthcare system and informs ongoing efforts to prioritize community health work in U.S. healthcare practice, research, and policy.

Our findings contribute a robust and novel examination of the work of refugee-serving CHNs during the COVID-19 pandemic. The analysis serves as a reminder of the unique role CHNs play in transforming access and delivery of healthcare to marginalized communities who may not

otherwise have reason to trust the health system due to systemic discrimination, racism, xenophobia, and anti-Muslim sentiments. Working collaboratively, CHNs ensure patients who came to the U.S. from all over the world following harrowing experiences of war, persecution, and forced displacement receive personalized, culturally responsive, and dignified quality care.

Our findings remain relevant as the consequences of the COVID-19 pandemic endure. CHWs have entered a *new normal* of service delivery that combines pre-pandemic elements with the height of pandemic precautions. They still engage in telehealth communication and have to navigate COVID-19 screening, infection, recovery, re-infection, and downstream impacts. These shifts mark potentially significant changes to community health work, with potential benefits and costs. The long-term effects of this pandemic, and its effects on CHW roles and well-being, are still unfolding. With legislation supporting CHWs' systematization into the healthcare setting in Arizona and elsewhere, we have the unique opportunity to ensure the integration of and support for this critical health workforce moving forward. Mapping which touchpoints of patient care interactions are the key drivers of improved health outcomes can aid in tailoring CHW interventions to best match the needs of the target communities. A system that values CHWs takes steps towards addressing structural injustices and towards one that centers community, trust engagement (lack of institutional trustworthiness in medical institutions), culture centeredness, and a recognition that culture matters especially in a public health crisis.

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CRediT authorship contribution statement

Roseanne C. Schuster: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Resources, Supervision, Writing – original draft, Writing – review & editing. **Karin Wachter:** Conceptualization, Formal analysis, Funding acquisition, Methodology, Writing – original draft, Writing – review & editing. **Kenna McRae:** Conceptualization, Formal analysis, Investigation, Writing – review & editing. **Anne McDaniel:** Conceptualization, Formal analysis, Investigation, Writing – review & editing. **Olga I. Davis:** Methodology, Writing – review & editing, Conceptualization. **Jeanne Nizigiyimana:** Resources, Conceptualization, Methodology, Project administration, Writing – review & editing. **Crista E. Johnson-Agbakwu:** Conceptualization, Methodology, Resources, Writing – review & editing.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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