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Health Beliefs and Barriers to Healthcare of Rohingya Refugees

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Abstract
In recent years, over 1,000 Rohingya families have been resettled to Milwaukee, Wisconsin from areas where they faced trauma and health disparities. To better understand their health beliefs and barriers to healthcare, we conducted a qualitative study with ten community health workers and stakeholders serving the Milwaukee Rohingya community. Interviews were transcribed, coded, and analyzed. Themes included: 1) health is defined as being able to meet basic needs of the family/community; 2) prior and existing mistrust and fear of systems of authority impact healthcare seeking behavior; 3) past-trauma negatively impacts physical and mental health; 4) religion and spirituality influence beliefs about illness, recovery, and wellbeing; 5) linguistic, cultural, and educational barriers impact access, quality of care, and understanding of disease. These results begin to address the significant gap in our knowledge of the health beliefs and needs of the local Rohingya community and underscore the need for tailored interventions.

Keywords Refugee · Rohingya · Health · Beliefs · Barriers

Background

The Rohingya are a stateless ethnic group that lived in Myanmar for centuries until they were stripped of their citizenship in 1982. At that time, the Myanmar government contested the Rohingya were Bengali immigrants and began a military operation to purge the so-called illegal foreigners. As tensions escalated, violence broke out and the government placed Rohingya into detention camps. In 2015, the government passed a series of laws imposing limits on the number of children, frequency of births, and inter-religion marriages or conversions [1]. The Rohingya fled the nation in increasing numbers to escape persecution and now account for 1 in 7 of the global population of stateless people [2]. Upon arriving in neighboring countries, most Rohingya are not granted refugee status and are therefore vulnerable to abuse by authorities [1]. For example, 90% of Rohingya in Bangladesh live in unofficial refugee camps ineligible for governmental humanitarian assistance [3]. In these overcrowded refugee camps, they often lack access to healthcare, safe drinking water, latrines, and food [4].

The Rohingya also seek asylum in countries such as the United States (U.S.), and since 2017, over 1000 Rohingya families resettled to Milwaukee, Wisconsin. Like many refugees immigrating to a new country, the Rohingya struggle to navigate the complicated US healthcare system [5]. Given the lack of medical care access in Myanmar and poor living conditions in refugee camps, most refugees have limited experience with western medicine and preventive services, impacting their health-seeking behaviors [6, 7]. Further, when Rohingya are resettled to the USA, they are often placed in low socioeconomic status neighborhoods with limited access to health-related resources exacerbating poor health outcomes. Despite these negative outcomes and the increasing number of Rohingya migrating to the USA, limited efforts focus on the health of this vulnerable community. Research is needed to gain a deeper understanding of the multi-level factors that may influence the health and health-seeking behaviors of Rohingya refugees. In this qualitative study, we aimed to gain new knowledge about the Rohingya community's perceptions of health, as well as the barriers and facilitators to healthcare to generate explanatory pathways. Such information will inform future interventions to address unmet needs.

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Methods

Study Design This study used a qualitative design to conduct stakeholder key informant interviews.

Study Participants As we initiated this work, we developed a multi-step plan to learn, engage, build trust and work toward the development of culturally relevant research questions and interventions. We began with community volunteering to establish relationships and observed there was great trust invested in certain stakeholders. These stakeholders maintained deep connections with the Rohingya and offered critical expertise on unmet needs. Leveraging our community engagement efforts, we recruited a convenience sample of trusted stakeholders identified as community leaders or health workers through personal e-mail invitations. Community leaders, some of whom were refugees themselves, were advocates deeply involved with the community and invested in their welfare. Health workers were employed within grassroots health-related service organizations (e.g., community health clinics, Mosque-associated refugee health relief programs) serving the Rohingya community. Inclusion criteria included: English speaking, working with the Rohingya community for at least 5 years, present at multiple Rohingya community events over a year of community engagement, and willing and available to complete the interview. We sought to include 8–10 community leaders and health workers combined, with no requirement for age group or gender, but wanting to include both genders across a broad age range.

Study Procedures We completed Key Informant Interviews (KII) using a semi-structured question guide (see Table 1) that addressed topics including community priorities, health beliefs (e.g., what does health mean, health goals), and barriers (factors that make it harder) to access healthcare, achieve/maintain good health and meet health-related needs. Interviews were 1–2 h and allowed time for further exploration of particular topics of interest. One researcher conducted the interview while a separate note-taker transcribed participants' responses verbatim. We used this approach rather than audio recording based on feedback during our early community engagement work that many would be uncomfortable being recorded. Study activities were approved by the Medical College of Wisconsin Institutional Review Board.

Data Analysis

We used a grounded theory approach for analysis. This approach is appropriate for allowing new knowledge to emerge from the data [8]. The two interviewers reviewed the first two transcripts to identify codes using open coding. They then met to discuss discrepancies and create a codebook. Codes were added and discussed as needed during analysis of remaining interviews. A third reviewer then read all interviews using the existing codebook to identify any new codes. No new codes were discovered. Following this, all authors met to discuss relevant relationships between codes to identify themes and connect these with relevant text.

Results

Participants included four community leaders (2 health advocates, 2 community navigators) and six health workers (1 physician, 2 community health workers, 1 nurse, 1 physician's assistant, and 1 social worker). Three of the four community leaders self-identified as Rohingya refugees. Of the 10 participants, four identified as men and six identified as women. Ages ranged from 25–60. Five themes were identified after in-depth coding and thematic analysis.

1) Health is perceived as being able to meet basic needs (i.e., financial, housing, safety) of the family/community and community is prioritized over individual concerns.

   Stakeholders shared that community members' perception of health is based on their ability to work, not fear persecution, and have basic needs met.

Table 1 Community Leader and Health Worker Interview Questions

Please tell us about your work as a community leader
Please tell us about your work involving the Rohingya community
Tell me about the priorities the Rohingya face, and where health fits in
What does health mean to the Rohingya community?
What are the health goals of your clients/patient and the community overall?
What are some challenges that you see in achieving the vision of a healthy community, as you have described?
What are your and the community's thoughts on seeking help from doctors/nurses?
How do you think Milwaukee can best support your vision of a healthy community? Are there any programs/resources already in place toward supporting these efforts?

> Health right now means having stable housing, having a job, and not being sick. Lifestyle things, simple, basic. The things that cause stress if you don't have them. That's what I've noticed with the population. (KII 6 Health worker 2, female)

Interviewees hypothesized this definition of health stems from the refugee's lack of access to healthcare services in their home country and refugee camps and the reinforced need to focus on basic survival. They emphasized the value of leveraging community health workers to provide information and support to Rohingya community members to integrate physical health into their perception of overall health.

> The system is so different than back home that it takes time to get accustomed. One thing I like from (organization) is that they help us a lot, and they do not treat it simply as a hospital, it is more of a healing system. So we work to ensure that refugees understand that health is important and that we can help them navigate American Culture. (KII 7 Health worker 3, male)

Stakeholders also shared the importance of honoring the value of collectivism wherein health and welfare are family and even community-focused, as opposed to on the individual. This may require non-traditional approaches to providing health-related support.

> It is important for the community to see you as someone who is willing to come over, hang out with the family, and become part of their own community. Some people see that as blurring the boundaries, but I see that as the only way to build trust. You have to connect with the leadership in the communities, and there are some (leaders) that are appointed while others have a lot of influence in the community, and you have to figure out who they are. (KII 6, Health worker 2, female)

2) Prior and existing mistrust for healthcare institutions and fear of systems of authority (i.e., workplace, government) impact healthcare-seeking behavior.

Systems of authority in Myanmar and neighboring Bangladeshi refugee camps have consistently been oppressive, violent, and exploitative. As such, the Rohingya community harbors a justifiable, widespread mistrust for systems of authority, which consequently impacts health-seeking behavior.

> With the Rohingya they have been treated violently by institutions and so they immediately connect institutions with violence, and so the trust is very hard to gain from what I have seen in my experience working with many Rohingya refugees. (K11 5 Health worker 1, female)
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> Trust. The population has been pushed into the sea and they only trust themselves. Everyone else has been abusing or exploiting them in some form. The Rohingya are uncertain as to where they can extend their energies and their trust. Years of betrayal have led to mistrust. When they come to the doctor and don't have trust, and don't think the doctor has the best intentions for them, then they will not come back the second time and third time. (KII 10_Health worker 6_male)
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> Trust is an issue. There are lots of examples of refugees being treated badly by health professionals. Many Rohingya only trust fellow Rohingya. (KII 1 Community leader 1,female)

3) Past trauma is common and negatively impacts physical and mental health.

Stakeholders recounted how refugees often arrived with poor health status including evidence of untreated chronic diseases such as diabetes and high blood pressure, poor nutritional status and absence of preventive healthcare among. They also shared how the physical and psychological trauma they had faced was intertwined with their health. Trauma often manifested as psychosomatic disorders and exacerbated chronic comorbidities including but not limited to diabetes, hypertension, lung disease and cancer, adding complex challenges to achieving health goals.

> Many are dealing with some sort of trauma-related disorder. We cannot get at the trauma and mental health and pain issues in the 15 minutes I have with them. Trauma has manifested itself with physical symptoms and the connection between those doesn't get made due to the limited time. (KII 9 Health worker 5 male)

Stakeholders also highlighted the consequences of mental health conditions that go unaddressed.

> Individuals in the Rohingya community are not 'suicidal' in the traditional sense but they are 'passively suicidal' because they will often neglect their health because they do not want to live long due to the trauma they faced in their past. (KII 5 Health worker 1, female)
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> Also, there's a lot of PTSD, as there are some families that don't even open the door for me. For some, I had to get the neighbor to help get the family to open the door for me. It depends on where the Rohingya are coming from, as it seems the ones from the camps are the most severe. Home visits are very good. I liked what [Com-

munity leader] did, as she went around and did home visits. Some of the Rohingya will not leave their homes, as they have this fear. There is a lot of PTSD and many don't even go to therapy. (KII4 Community Leader 4, female)

4) Culture and religion influence beliefs about illness, recovery, and wellbeing.

Results highlighted how culture is deeply intertwined with health perceptions and practices. For example, patriarchal values stigmatize discussions surrounding reproductive issues, as reflected in Rohingya women's discomfort discussing their health with male providers or translators.

> Male control of the health decision of their partner has been an issue. We might have a woman who comes here independently and asked to be on birth control. And then the husband comes in and becomes irate around the fact that the woman is on birth control. (KII 7 Health worker 3, male)
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> There is the cultural taboo of having a man be a woman's health provider. I see that many translators and most of the staff that the Rohingya women are seeing are men, and that is leading them to be more cautious. (KII 9 Health worker 5, male)

Patriarchy is also evident in the minimization of domestic violence by religious leaders.

> The domestic violence has been a big issue. For me, I've talked about domestic violence with [community leader]. There was a lady from Indonesia who married a Rohingya man, and he was abusive. He beat her up with a bat once. So she went to the mosque to try and get help for it, but they just told her to work together on it and did not encourage a divorce. It seems like a lot of Rohingya are coming from an area of great patriarchy. Ever since we started the [organization], a lot of the women we worked with for domestic violence issues are no longer going to the mosque, as there is no point since mosque leaders do not encourage divorce or leaving the relationship. (KII4 Community leader 4, female)

In addition, religion and spirituality play a complex but influential role in health-seeking behavior. Stakeholders affirmed that health and illness are viewed through the lens of faith, thereby altering the ways that refugees seek treatment for their mental and physical health conditions.

> To deal with questions regarding stress or trauma, they go to the Imam. They believe it is because of an evil spirit attacking them, and that it is best addressed by the Imam. I think it's a stigma of mental illness. The word mental illness may not exist in every language. (KII 6 Health worker 2, female)
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> We make a lot of dua (prayer). Superstition is big, and jealousy from others or when I feel sick my mom will start to pray for me. And if I am sick then my mom will put some of my hair and chili and mix it up to take away the 'jealousy.' If I have some stomach-ache then we eat garlic. (KII 2 Community leader 2, female)

5) Linguistic, educational, and economic barriers impact access and quality of care and understanding of disease, leading to fatalistic attitudes.

Stakeholders delineated distinct hurdles of language barriers and using translator services in caring for Rohingya patients. They specified how no one language represents the whole Rohingya community and many of the lesser-known languages are not available through medical interpretation services. These communication barriers impact refugees' capability to access care, prioritize health, and trust healthcare providers.

> The main issue in everyone's work is interpretation (of medical information from provider to the patient), going from formal to informal or volunteer. Translational services and the language barrier is a huge issue. People do not want to hire refugees as translators, but refugees need to make money to send home. Prejudice exists even between the interpreter and the client. For example, some people say they can speak Rohingya dialect, but they cannot. (KII 1 Community leader 1, female)

Results also reflected how the common lack of formal education and low levels of health literacy among many Rohingya refugees exacerbates the language barrier and influences cultural beliefs related to health and health behaviors. These barriers, compounded with aforementioned cultural differences, challenge navigating clinical encounters and therefore discourage Rohingya members from seeking medical care.

> Because education is less accessible, especially for refugees, and because there is not a lot of financial backing, in addition to the language barrier, there are a lot of things that prevent making health a first. Patients will go to the emergency room if there is any immediate health concern, but they will not seek out preventative care as often, if ever...It was an issue surrounding culture, but also surrounding health literacy and trust. (K11 9 Health worker 5, male)

In addition, stakeholders discussed the economic insecurity faced by this community. Many Rohingya members do not have formal job training, and thus become employed at factories throughout Milwaukee. Many factories have unsafe, physically-taxing work environments with long hours, minimal break time, and exceptionally low hourly wage.

> Some of them think of the cost, and we've had issues where some of them don't have government health insurance by either losing it or for some other reason, and they don't want to go to the doctor because of that. They don't take their kids for check-ups either. Health-wise, they definitely look at the cost, and that is a big issue for them. As long as people can provide (for their families), they are healthy. It doesn't matter if their back hurts or other things, but if they are able to provide, they are healthy. Some of the people work in factories, and a woman was working in the factory until she legitimately couldn't, and then had to go to the doctor because she was killing herself with pain. It sees as if they don't put their health before working, providing for their kids, providing for their family. (KII 4 Community leader 4, female)

Discussion

This study provided essential stakeholder insights into community priorities, health beliefs, and perceived barriers to healthcare among Rohingya refugees living in Milwaukee, Wisconsin. Findings highlighted this community prioritizes financial stability, religion and spirituality, and the well-being of the community over individual health concerns. Preventive health practices are unfamiliar to many community members and seeking healthcare is mired by multiple barriers. These barriers include economic insecurity, linguistic barriers, culture and religion influencing beliefs around healthcare, the burden of unaddressed trauma, and fear and mistrust of authority. Stakeholders described how these barriers prevent the Rohingya from meeting their health goals and visions of a healthy community.

As demonstrated throughout our findings, an essential strength of the Rohingya community is a collectivist value system that prioritizes the well-being of the family and community. Key to familial and community well-being is financial security [10]. Yet, this community has faced many hardships including ongoing financial insecurity. This burden fosters the income-driven motivation to attain stability, which is prioritized over health. At the same time, this community has had minimal exposure to the practice of preventive healthcare and given decades of poor health access face significant physical and mental health challenges. Stakeholders emphasized the importance of providing holistic care that addresses health, education, and economic security. Weida et al. demonstrated that addressing the financial root causes of poor health by integrating financial health into clinical practice improved overall health among underserved communities [10]. This type of coordinated care requires community and social service organizations work together. However, too often organizations work independently and fall short of interprofessional collaborations [11]. Generating efficient communication strategies between organizations would facilitate addressing the complex socioeconomic hurdles that impact access to and use of healthcare.

Health literacy and mistrust of authority influence healthcare-seeking behavior, and these are impacted by language. The Rohingya speak several languages, including Chittagonian Bengali, Arabic, and a unique dialect of Burmese specific to the Rakhine region [12, 13]. The Rakhine dialect of Burmese is a purely spoken language with no written form, creating challenges during healthcare encounters and in the dissemination of health-related information [14]. Stakeholders noted that barriers to communicate with providers foster mistrust, low self-esteem, and learned helplessness. This is further exacerbated by low levels of healthcare literacy and formal education [15, 16]. As a result, Rohingya community members are often passive during clinical encounters and do not receive the benefits of preventive health messaging. Previous studies highlight language as a primary obstacle to healthcare among Somali, Iraqi, Vietnamese, and other refugee populations [17]. Although medical translators can address language and healthcare literacy barriers, our data revealed the challenges of bringing translators into patient rooms. First, translators do not speak the Rakhine dialect of Burmese, which can lead to miscommunication of important health information. Additionally, translators may unwittingly omit important cultural, historical, and reproductive health information raised by Rohingya patients during clinical encounters, preventing providers from delivering holistic, and trauma-informed care. Further, translators speak the governmentally mandated Burmese language which invokes connections with governmental oppression. Stakeholders shared how this leads to concerns about discrimination and/or breeches in confidentiality resulting in greater patient passivity. To address these barriers, stakeholders recommended culturally sensitive training for providers and translator services in the correct dialect to ensure patient-centered care. An important focus of future work will be to explore best practices for addressing linguistic barriers and how this impacts trust and health-seeking behaviors.

Culture, religion, and spirituality are deeply connected to health and wellness in the Rohingya community. Stakeholders discussed that many Rohingya perceive health problems

as stemming from extrinsic forces rather than organic causes. For instance, certain chronic medical illnesses caused by spiritual curses or faults in religious capabilities. Efforts to benefit health and wellness are embedded in religious practices including prayer and recitation of the *Quran*. Further, illnesses are often addressed via herbal and spiritual remedies or consulting with imams and religious leaders as opposed to seeking out trained healthcare providers. Rayes et al. reported similar findings among Syrian refugees who relied on spiritual help to manage their mental health [18]. These authors recommended leveraging these help-seeking behaviors by developing faith-sensitive interventions and bringing religious mediators into clinical settings to facilitate positive relationships between providers and patients [18]. In our study, stakeholders emphasized the value of partnering with mosques and religious community services as healthcare support systems. They also recommended that providers respect faith-based practices by considering how treatment choices may or may not align with religious or cultural beliefs.

Related to cultural and religious beliefs, stakeholders observed how patriarchal values impacted women's health by limiting their autonomy in decision making. Typically, men lead discussions and decisions around reproductive health, with women playing a passive role. Women may be further isolated and intimidated by having male practitioners or translators who maintain the status quo. Stakeholders also observed that unaddressed domestic abuse is strikingly common and contributes further to learned helplessness and lack of autonomy among Rohingya women. Studies note that the patriarchal foundations in many refugee communities including Ethiopian, Sudanese, Serbian, Iraqi, and Croatian lead to domestic violence and lack of female autonomy [19–22]. Stakeholders recommended solutions including providing female representatives during clinical encounters, increasing provider awareness about the cultural stigma surrounding reproductive issues, and tailoring women's health education to be culturally sensitive [23–25].

Finally, trauma was a prominent cross-cutting theme. Stakeholder perspectives revealed how traumatic experiences prior to coming to the USA continued to impact the mental and physical health of Rohingya refugees. Khan et al. observed an association between indirect and direct trauma among Rohingya refugees and PTSD [26]. Prevalence rates vary, but one study of Rohingya refugee adults in Bangladesh found that 61% exhibited PTSD symptomatology [27]. Further, functional impairment, as measured by the World Health Organization Disability Assessment Schedule, was higher among Rohingya refugees who fled to Bangladesh to find shelter [26]. Our findings highlighted how oftentimes this trauma is manifested in physical symptoms such as persistent headaches, gastrointestinal distress, and chronic pain leading to clinical encounters which could present opportunities for psychological support. Unfortunately, these issues are often left unaddressed due to multiple barriers including time, training in trauma informed care, and trust. Notably, only a small subset of resettled refugees suffering from PTSD seek mental health services, emphasizing the need for holistic interventions that address mental and physical health [28]. Such programs would ideally target health literacy, but also encourage and support health-seeking and promotion activities that could impact overall health and quality of life.

Our study represents one of few that explores the needs and interests of the Rohingya refugee community, addressing an important gap in the literature. This work has implications for healthcare, research, and workforce diversity. Our study identified not only barriers but also community resources that can be leveraged to facilitate relationships allowing for the successful delivery of holistic trauma-informed healthcare [29]. Organizations such as community centers, mosques, and houses of community leaders are considered safe and trustworthy spaces where onsite language tutoring services, preventive healthcare training workshops, and community events could be held to disseminate health information and even healthcare. Our work also has implications for future research. We began this initiative through community service and partnership building. A critical next step is to hear from community members themselves. Having a foundation of knowledge about the Rohingya community's priorities, beliefs and barriers will enhance cultural understanding. These findings will also inform recruitment strategies, interview question guides, and relevant ways to disseminate our current and future findings. Finally, our work highlighted the critical need for community representation within healthcare and research. Rohingya youth are quickly becoming fluent in the English language and Western customs, such that they can navigate complex care systems with ease. Concerted efforts to engage youth in structured opportunities to learn about and gain experience in research and healthcare professions will benefit the youth, their community, and our healthcare systems.

Limitations should be noted when considering study results. The sample was small and limited to community health workers and stakeholders who self-selected to participate, introducing bias. However, participants represented a variety of provider and grassroots organizations and had deep knowledge of and meaningful experiences with the Milwaukee Rohingya community. Importantly, we did see thematic overlap across interviews, suggesting saturation. An additional limitation is that we did not directly interview Rohingya community members, and we cannot assume that the stakeholders' perspectives match those of community members at large. Finally, although Milwaukee is home to the largest Rohingya community in the USA, our results cannot be generalized to other Rohingya or refugee communities.

Conclusion

Reports from stakeholders serving the Rohingya community highlighted barriers to health and preventive care including mistrust and low access to linguistically and culturally tailored health resources. Facilitators include collectivism, religious devotion, and spirituality. While these findings are valuable, understanding perspectives from community members themselves is critical. These efforts can inform the co-design and evaluation of sustainable health promotion interventions grounded in community strengths and tailored to community needs.

At the same time, this community has had little exposure to the practice of preventive health and given decades of poor access to mental and physical healthcare, faces a significant health burden. These findings are similar to those reported by investigators analyzing other refugee populations, including Somali, Syrian, and Pakistani communities [9].

Author Contribution Shabi Haider and Aniya Maheen developed the study protocol and conducted the interviews for this qualitative study. Mr. Haider, Ms. Maheen, and Mr. Ansari analyzed the data. All four authors contributed equally to the writing of the manuscript. All work was conducted under the mentorship of Dr. Melinda Stolley.

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Data Availability De-identified transcripts of interviews will be provided upon request.

Code Availability Not applicable.

Declarations

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