Centering the Experiences and Perceptions of Health and Well-Being in the Burmese Community: A Community-Academic Partnership

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ABSTRACT

Background: Many Burmese refugees to the United States experience multimorbidity primarily from displacement. Immigrant and refugee community leaders have identified communication with service providers and minimal community support as challenges.

Objectives: To center the experiences and perceptions of Burmese refugees regarding health and well-being.

Methods: In this qualitative descriptive community-based participatory research study, 18 Burmese participants across 9 families engaged with researchers to generate and analyze data through the participatory group level assessment method.

Results: We identified 4 main themes and corresponding community needs: Navigate cultural differences: need to balance Burmese cultural lifeways and U.S. society; complex journey of information access: need for qualified interpreters and cultural brokers; family health care and social support: need for collective relationship-based decision-making; and system and institutional barriers: need to eliminate discontinuity in holistic health care and towards basic health needs.

Conclusions: Providers must recognize the specific health needs and develop culturally protective practices.

KEYWORDS: community-academic partnership, qualitative description, community-based participatory research, Burmese, Kachin, Karen, Zomi, access to healthcare, racial discrimination, strengths and resilience

Introduction

The Burmese diaspora population is rapidly growing in the United States (U.S.).[1-5] Although the Burmese population increased from 17,000[6] to 100,200[7] persons between the years 2000-2010[6-7] to 185,406 by the year 2020,[7] this community continues to be underserved in healthcare. Many Burmese experience multimorbidity, brought on primarily by displacement[1] and moreover, this trajectory often begins early in life.[1-5] There are 2,049 Burmese refugees in Oregon[8] and 5,154 in Washington in the U.S. Pacific Northwest.[9] The non-profit Immigrant & Refugee Community Organization (IRCO), a large refugee resettlement, is assisting this expanding Burmese community. IRCO leaders identified communication with service providers and minimal community support as challenges.[10] A community-based care priority is to support the health and well-being lifespan of the Burmese community. This article describes the impact of our community-academic partnership initiative. This enterprise was carried out through community leadership involvement in the generation of study data and analysis with researchers. We use Burmese as an umbrella term and recognize the sensitive nature.

Burmese Community Context

While over 2/3 of the population speak Burmese,[11] the community encompasses about 135 different ethnic groups speaking over 100 languages.[1,11] Ethnic subgroups include the Kachin, Karen, and Zomi groups; each with their distinct cultures, language, customs, and history.[10] The Burmese were the largest refugee group to resettle in the U.S. between 2000 and 2019,[12] primarily due to extreme political, religious, and economic oppression and violence.[13] Beginning in 1824, the Burmese civil war is the longest civil war in the world.[11] Burma has undergone multiple periods of British colonization, Japanese occupation, political and economic instability, and violent conflict between the various ethnic groups and the military junta.[14] The harmful effects

of the war include psychological and physical trauma and health issues. The Burmese-specific health outcomes following resettlement are poorly understood, as they are obscured in the historical aggregation of all Asians in epidemiological and survey data.[11,15] There is a great need for research on the health-related experiences of Burmese refugees.[5] Providing space for conversations to share cultural strengths and stories of resiliency may allow individuals to understand their own trauma and facilitate pathways to healing.[16]

Community-Academic Partnership

Authenticity, trust, and respect are foundational to community-based participatory research (CBPR). These principles guided the formation of the community-academic partnership. The lead nurse scientist is the multiple principal investigator (MPI [CKYN-T]) at Washington State University (WSU) Nursing and Systems Science Department, a council advisor of IRCO and Pacific Islander & Asian Family Center (PI&AFC), and has a well-regarded presence since 2008.[17] In 2021, the nurse scientist MPI brokered the following partnerships: IRCO Community Health and Public Health Program; WSU Advanced Practice and Community-Based Care Department, PhD in Nursing Program, Human Development Department, and PhD Prevention Science Program; and PeaceHealth. In 2022, IRCO leadership underwent a transition. The nurse scientist MPI subsequently orchestrated partnerships with IRCO PI&AFC Director, Health Services and Behavioral Health Departments Manager, and Burmese Community Health Workers (CHWs). The community-academic partnership previously conducted an anti-racism CBPR program, and we are cognizant of the identified microaggressions, healing from racial trauma, and mistrust and fear surrounding intentions of the body.[18]

This Study

This qualitative descriptive CBPR study aim was to center the experiences and perceptions of Burmese community members regarding health and well-being, such as surrounding healthcare access, racial

discrimination, and strengths and resilience. We adapted the Community Cultural Wealth framework as Acevedo and Soloranzo[19] described from a strength-based lens as a guide for the study. We adapted the concepts as an accumulation of strengths as cultural capital. Refer to Figure 1. For example, Acevedo and Soloranzo[19] asserted that racism (discrimination) is an everyday risk factor, and the different strengths can be utilized by community members as a protective factor or factors against racism.

Methods

Design Overview

We chose to do qualitative descriptive research that collects and analyzes data as given by participants as Sandelowski described it.[20,21] We used a CBPR approach that represented our partnership throughout the research process.[22] We also discussed and established a shared understanding on how we want to learn and work together as agreed statements (Figure 2). We recognized our roles as partners (Table 1), discussed, and clarified viewpoints and uplifted voices for inclusion.[22,23]

Ethics

The WSU Human Research Protection Program approved the study (#19178).

Setting and Participants

A Burmese-Zomi speaking CHW (VLM) and a Burmese-Karen speaking CHW (TDW) recruited 9 Burmese family dyad clients (N=18) as parent and child participants at IRCO PI&AFC in the Pacific Northwest who can speak to the study aim to obtain a purposive sample. Recruitment was done between August through November 2022. Each participant has a trusted connection with CHWs and with IRCO PI&AFC as a trusted source for health and social services. In doing research with Burmese parents and children, researchers discovered the need to build trust, through such activities such as recruiting through a trusted organization or

spending a sufficiently long period of immersion with the community.[24] Sessions were scheduled on a weekend to accommodate participants' work and school schedules and were held in-person at the IRCO Main or PI&AFC. The sample size of 18 was sufficient for code saturation.[25] We compensated participants with a $120 Visa gift card to honor and appreciate their time.

Data Collection and Analysis

Participants chose to have a Burmese CHW for interpretation support. The academic researchers-facilitators (CKYN-T, MR, or SFW) obtained signed consent from adult parent participants, assent from child participants, and the demographics via the WSU Qualtrics.

We adapted the scientific qualitative, modified participatory group level assessment (GLA) method through a social justice lens.[26-28] The modified GLA method centers storytelling and uplifts participants' leadership through generating data and initial analyzing the data with researchers in real time.[27,28] The GLA method included steps: *climate setting*, *generating data*, *appreciating perspective*, *reflecting*, *understanding*, and *selecting main themes* (Table 2). The family dyad interviews lasted 1 hour. We debriefed and completed additional data analysis and reviews (Figure 3).

Results

Background of Burmese Participants

Nine family dyads (N=18) participated in the study (Table 3). Participants were mothers, ranging in age from 28 to 47 years ($Mean_{motherage}$=36.3 years), and children, ranging in age from 7 years old to 18 years old ($Mean_{childage}$=10.4 years). Families identified as refugees with an average of 7.8 years having lived in the U.S.

Main Themes

We identified 4 main themes and corresponding community needs with Burmese participants. We used flower names as pseudonyms in exemplar testimonies.

Theme 1 – Navigate Cultural Differences: Need to Balance Burmese Cultural Lifeways and U.S. Society

The homesickness and longing to return to a familiar cultural environment with connected family persists. Recognizing and understanding where people have come from and where they are now in navigating between Burmese cultural lifeways and U.S. society is important. There are firmly-held beliefs and values that are culturally protective and it can be difficult for Burmese families to navigate the differences and balance their Burmese cultural lifeway of being from that observed in the U.S. society. Trying to have balance in a U.S. society where caring practices are different was apparent. Refer to Table 4 for testimonies that illuminated a cultural divide within the healthcare context, experienced by the Cherry (Karen) and Orchid (Karen) families.

Theme 2 – Complex Journey of Information Access: Need for Qualified Interpreters and Cultural Brokers

Timely information access via language access and quality of language are challenges in the context of healthcare and social services. Most parent-caregiver participants described having learned English through their children. Most Burmese family participants described having received interpreter services from a stranger, but there are issues with a family member asked to serve in that role. The differences between cultural brokering, conversational support connected to culture and eliciting a family history versus interpreting, needs to be clarified for continuity of care. This situation can be complex, as family members may feel obligated to provide interpretation for family members, despite limited professional interpretation capacity. The testimonies of the Lotus (Zomi) and Cherry (Karen) families illuminated efforts in advocating for quality communication interactions, whether with an interpreter or for conversational support with a healthcare provider (Table 4).

Theme 3 – Family Health Care and Social Support: Need for Collective Relationship-Based Decision-Making

Social support within families and extended families is imperative to their health and well-being. Burmese understandings of family go beyond the Western constructs of the nuclear family, such as extended to family, friends, and community members. The roles people have and the support level and attention that families give to each other impact the ways in which health care and services are received and utilized. Parents recognize that their emotional and physical states are noticed by others and impact their familial relationships. Families emphasize that immigrant and refugee community organizations are doing good work to dismantle barriers. Advocacy from CHWs is integral. The Orchid (Karen) and Basil (Kachin) families highlighted their resilience as they counteract hardships through connection with nature, spending time with their loved ones, and spirituality (Table 4).

Theme 4 - System and Institutional Barriers: Need to Eliminate Discontinuity in Holistic Health Care and Towards Basic Health Needs

Systemic and institutional barriers to accessing health and human services are intertwined with a lack of culturally responsive communication strategies that can prevent families from receiving holistic health care. Feelings of helplessness in having to navigate the systems supposedly aimed to support them were described by the Padauk (Karen) and Thazin (Karen) families (Table 4). Barriers such as lack of case management communication, institutional filing systems and records, strenuous applications, and minimal or no translation services contribute to the strain of immigrant and refugee communities. The Paduak parent described that she and her 15-year-old child have pre-diabetes. The request to have blood sugar checked every 3-6 months may not be feasible for families. No teach-back opportunities were provided to describe what a pre-diabetes diagnoses

and management means. The Thazin family shared that their experiences of discrimination were fueled by stereotypes of resource reliance and also experienced barriers that caused further financial stress. This runs parallel in addressing social determinants of health, with the Thazin family in attempting to access needed financial and food assistance.

Key Strengths and Challenges Encountered

Our community-academic partnership's initiative to center the experiences and perceptions of the health and well-being in the Burmese community is a main strength. While there are key strengths, there were a number of challenges encountered (Figure 4).

Discussion

Navigate Cultural Differences

Diaspora or displacement can have lasting impressions. The United Nations High Commissioner for Refugees reported ongoing refugee camp needs for Burmese because of increasing violence from the long civil war.[30-32] We learned from Burmese family participants about homesickness and acknowledged their longing to return to cultural familiarity persists. We also learned from Burmese family participants that there are firmly-held beliefs and values that are culturally protective and can be hard for Burmese families to navigate the difference and balance their Burmese cultural lifeway of being and doing from that in the U.S. society. Trying to have balance in a U.S. society where caring practices are different was apparent. A cultural divide does occur in a healthcare context. These findings are similar to a study describing how Burmese communities are often overlooked in regards to cultural collective practice in survival and protection from physical and mental threats.[2] Interactions in a healthcare system outside of a family system can be challenging to navigate.

Complex Journey of Information Access

Timely information access via language access and quality of language are challenges in the context of healthcare and social service agencies. All Burmese family participants shared about how this has hindered or delayed care or services. The language barrier is often the first barrier when Burmese people interact with healthcare and social service agencies. Even if a qualified interpreter is found to translate the information, that information also needs to be relayed in a way that is culturally responsive, and that means the services of a cultural broker are also necessary. Cultural brokering is one way to give voices to clients and provide care or services that respects history and cultural practices.[2,24] While language concordance can be helpful, Burmese family participants described their efforts in advocating for quality communication interactions whether with an interpreter or for conversational support. Systems collaboration can be powerful within the family system, community-based organizations, and community-based care.

Family Health Care and Social Support

Social support within families and extended families is imperative to their health and well-being. Burmese understandings of family goes beyond the traditional Western nuclear family construct and extends to family, friends, and community members. The types of roles people have and the level of support and attention that families give to each other impact the ways in which health care and services are received and utilized. Parents recognize that their emotional and physical states are noticed by different people and impact their children and household dynamics. Accessing services is a barrier, but adding the challenges of language is another layer. This can be further compounded with distrust of healthcare providers and the system infrastructure not well developed or trained to support immigrant and refugee families. In tandem with our findings, doctor/provider reported barriers in pursuing end-of-life conversations were interpretation issues, spiritual beliefs surrounding death, patients' health literacy, and mistrust of the healthcare system.[33] The role of

CHWs in our CBPR study were imperative. This suggests the future supportive role of CHWs that may advance the systems and institutions to provide needed services to promote wellness and to build trust between community and providers.

System and Institutional Barriers

Systemic and institutional barriers to accessing the health and human services and not engaging in culturally responsive communication strategies can prevent families from receiving holistic health care and towards basic health. The notion that families feel *lazy* when they are unable to access services or have not been given the opportunity to be agents in their care plans with consistent communication with providers, is interpreted as feelings of helplessness in having to navigate the systems supposedly aimed to support them. These experiences speak to the healthcare systems focus on treatment, rather than manageable prevention efforts. Strenuous application processes and follow ups are required to access such services, and barriers such as lack of case management communication, institutional filing systems and records, as well as language contribute to the strain of the lived experience of immigrant and refugee families. The experiences of trauma and social and emotional distress as a refugee are then exacerbated by the barriers encountered in attempting to reach social and financial stability. Zeidan et al.[34] identified several barriers for newly arrived refugees in the U.S., including limited understanding of the complex healthcare system, unique mental health and trauma-informed needs, and challenges identifying clinics that offer comprehensive interpretation, accept Refugee Medical Assistance, and are geographically accessible. These findings are consistent in our study. The need persists for appropriate interpretation/translation of services throughout patient contact with refugee communities.[11,35] Additionally, our findings are echoed in another study exploring Burmese Chin patients'

experiences, such as the importance of non-verbal communication, lack of parental engagement in care, feelings of discrimination, and challenges with using interpreters.[36]

Limitations and Future Research

There are limitations to this study. Findings are not generalizable to broader Asian populations but can be transferable because the thick descriptions illuminate the unique experiences and perceptions of Burmese communities with diverse languages, spiritual and cultural practices where voices are not well represented within the current literature. Our aim was to provide a safe space to listen to the stories of parents and children, and identify previously hidden insights. There were some apparent tensions surrounding spaces to share stories of discrimination and trauma, and this work, although vital, can be difficult to navigate in research. Future research should aim to deepen understanding of culturally protective factors by increasing Burmese CHWs, interpretation and provider capacity, while advancing leadership with those with lived experience and the multi/transdisciplinary/cross-sectoral CBPR approach.

Implications for Practice and Policy

Results from this study have a host of implications for healthcare and service providers and policymakers. The Burmese People continue to face significant challenges, and results indicate that while healthcare providers often perceive their decisions as helpful to their patients, there is the potential for conflicts between healthcare providers' recommendations and clients' cultural values. Our results corroborate the study findings among Burmese population in the Eastern U.S.[37] Healthcare institutions should create an inclusive environment where providers can receive training in cultural context considerations, including sensitive, responsive communication with Burmese clients and families. This can mitigate misunderstandings, mistrust, and advance health equity. Our findings also imply incorporating a culture of safety and humility into policies.

Some of the participants' experiences suggest that satisfaction with healthcare visits was low. The Teach-Back method may be a useful tool for providers serving refugee populations that can help improve patient understanding and management, decrease call backs and cancelled appointments, welcome family members during interactions, and improve patient satisfaction and outcomes.[38] Our findings also inform caring and treating clients of Burmese descent who have faced trauma in their countries, travel, and arrival in the U.S.[1] and adds to the literature.[39-41] Community-based interventions should focus on raising mental health recognition and culturally appropriate support for Burmese adults and provide early screening for pediatric populations, such as online platforms and resources that increase access to care.

Conclusion

The experiences and perceptions brought forth by Burmese refugee families in this CBPR study highlight persistent barriers and gaps in health care and services for this community. Findings support a call to healthcare and service providers to recognize specific health needs and attend to them through culturally protective practices regarding family and mental health care. Advancing health equity requires bridging the divide between Burmese community members and providers, through greater sensitivity, responsiveness, and humility by the providers and uplifting the vital role of Burmese CHWs. Providing Burmese CHWs with sufficient support and increasing the numbers of CHWs and expanding their roles regarding capacity are critical to the health and well-being of the community. Uplifting Burmese community members as leaders in participatory action research can further advance the goals of health equity.

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38. Agency for Healthcare Research and Quality. Use the teach-back method: Tool #5. c2020. [cited 2023 August 25]. Available from https://www.ahrq.gov/health-literacy/improve/precautions/tool5.html

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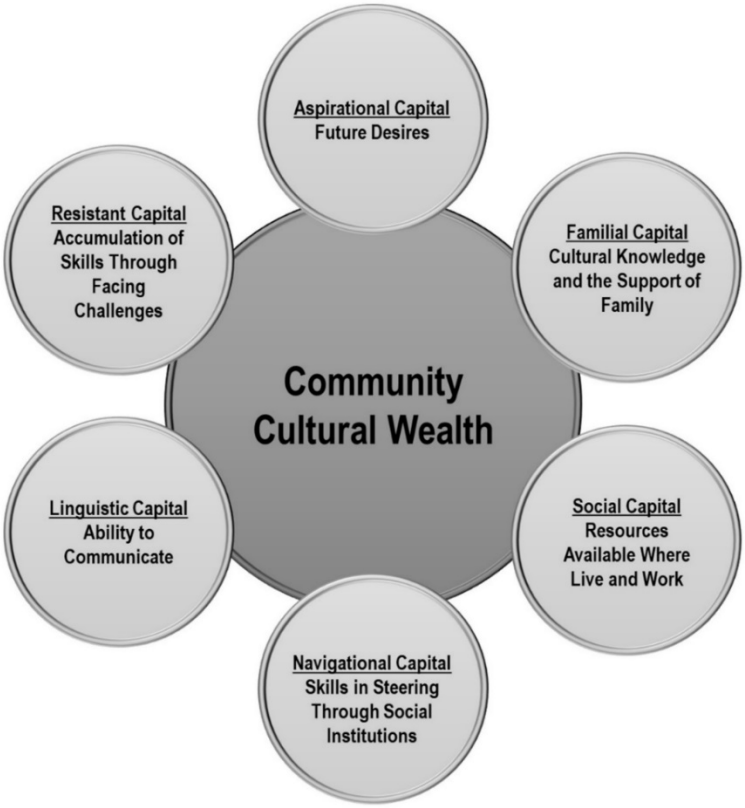
41. Hill E. "I Need to Keep Me and My Mother Safe": the asylum crisis at the US-Mexico border. *Ann Fam Med*. 2021;19(5):463-465.

Figure 1. Adapted Community Cultural Wealth Framework



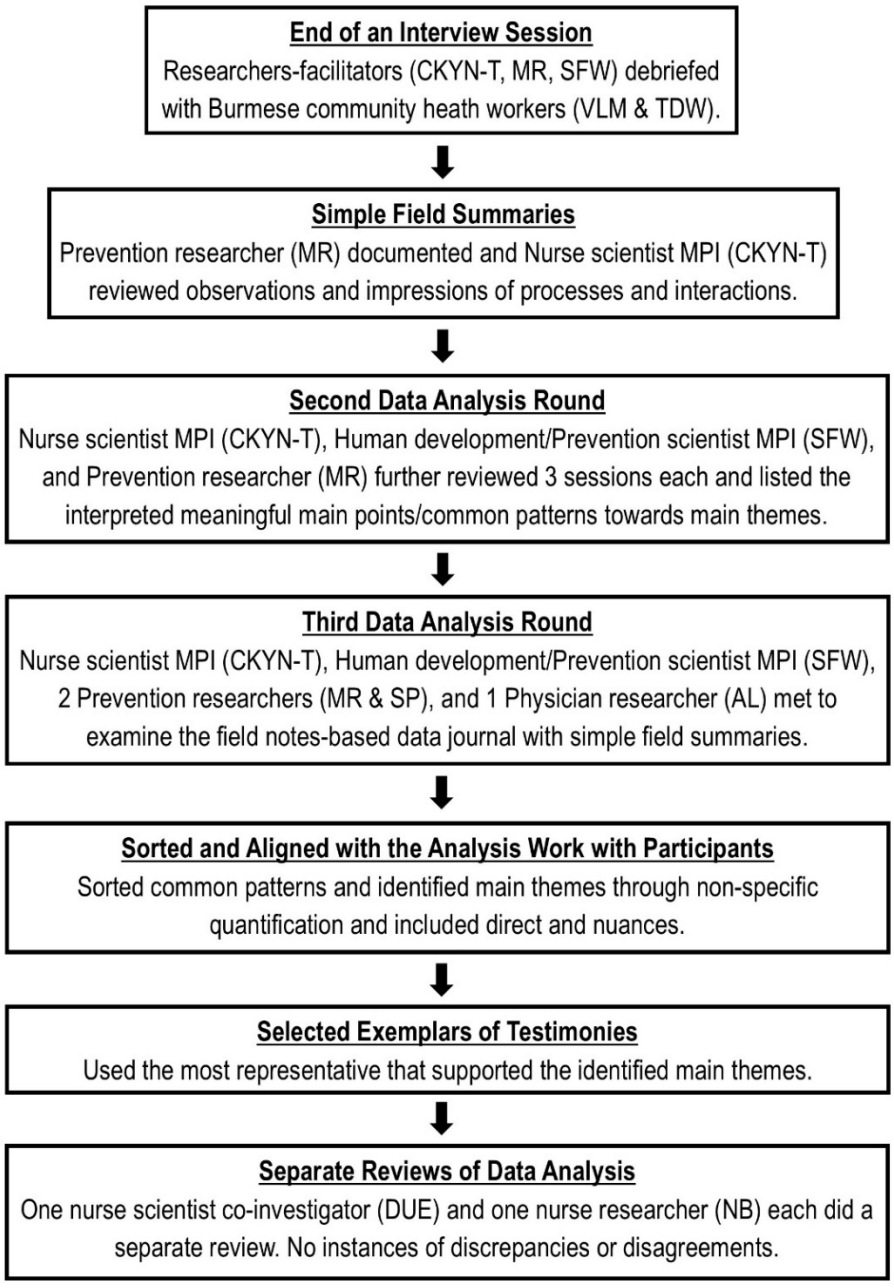
Note. Adapted concepts as cultural capital from the Community Cultural Wealth Framework, including aspirational capital, familial capital, social capital, navigational capital, linguistic capital, and resistant capital. This is not a reused figure.
Acevedo N, Solorzano DG. An overview of community cultural wealth: toward a protective factor against racism. *Urban Educ*. 2021;58(7):1-19.

Figure 2. Established a Shared Understanding on How Want to Learn and Work Together: Community-Academic Partnership Agreed Statements

- Commit as a cross-sectoral, multi-disciplinary, and diverse community-academic partnership to learning from one another and doing own work in reflective learning.
- Recognize individual and collective empowerment through shared power.
- Reflect on what each partner brings into the CBPR partnership space that is unique from their background and how informs strengths in roles in CBPR
- Engage in collaborative decision-making.
- Create opportunities for role contributions for inclusion.
- Check-in regularly by video conference, phone, or email on how doing and ongoing improvements in mindful, responsive communications.
- Recognize and uplift accomplishments during synchronous community-academic CBPR partnership sessions and asynchronous conversations; state authorship and acknowledgement credits in dissemination.

Note. Community and academic partners discussed and established agreed statements.

Figure 3. Debriefs, Additional Data Analysis, and Reviews



Note. Authors' initials are in parentheses. Interpretation variances enhanced credibility. We used reflexivity throughout the process, addressing the influence of biases on results.

Figure 4. Key Strengths and Challenges Encountered

- Community and academic partners remained flexible during the transitions in new IRCO and PI&AFC leadership.
- Academic partner, community directorship, health services and behavioral health departments manager worked with the CHW coordinator and built on strengths with Burmese CHWs.
- Burmese CHWs have deep community connections, trust, and sociocultural language interpretation skills.
- IRCO and PI&AFC offered accommodations, such as interpreter, childcare, and transportation support.
- Academic researchers discussed a need for spaces where can talk with a parent and then a space to bring together a parent and child. While childcare was offered, participants preferred that their children remain with them throughout the data collection and analysis process.
- CHWs bridged trust in the setting between participants and academic researchers through small conversations and art supplies.
- Although the IRCO International Language Bank provided support, due to the specific languages, an interpreter was available alongside the Burmese-Zomi speaking CHW for a family dyad and another interpreter alongside the Karen-speaking CHW for a family dyad.

Note. IRCO, Immigrant & Refugee Community Organization; PI&AFC, Pacific Islander & Asian Family Center; Community Health Worker, CHW.

Table 1. Background and Roles of Community and Academic Partners in the CBPR Partnership[a]

Community and Academic Partner Organizations	Background (Authors' Initials) and Roles[b]
Immigrant &Refugee Community Organization and Pacific Islander & Asian Family Center [non-profit]	
Immigrant & Refugee Community Organization Main: Community Health and Public Health Programs Office	• **Community Health and Public Health Programs Supervisor (KFR): Black; CHW, caregiver in community and public health professional; culturally specific and linguistic wrap around health and services** Role: Engaged in community-academic CBPR partnership sessions; reviewed and contributed to the study proposal; helped to connect with CHW Coordinator's office upon leadership transition; contributed to dissemination
Pacific Islander & Asian Family Center	• **Director: Cambodian; public/population/community health; culturally specific and linguistic wrap around health and services** Role: Engaged in community-academic CBPR partnership sessions; study implementation coordination support to the Health Services and Behavioral Health Departments Manager, CHW Coordinator, and academic partners
Pacific Islander & Asian Family Center: Health Services and Behavioral Health Departments	• **Health Services and Behavioral Health Departments Manager (WMLK): Burmese; background training as a physician and researcher in Burma; culturally specific and linguistic wrap around health and services** Role: Scheduled and engaged in community-academic CBPR partnership sessions; managed study implementation support to CHW Coordinator, Burmese CHWs, and academic partners; assisted in arrangement of an additional interpreter from Immigrant & Refugee Community Organization International Language Bank to support Burmese CHWs and helped with verification checks; and reserved in-person meeting space for sessions; offered childcare and transportation as needed; contributed to dissemination
Pacific Islander & Asian Family Center: CHW Office	• **CHW Coordinator: Burmese-Zomi; culturally specific and linguistic wrap around health and services** Role: Engaged in community-academic CBPR partnership sessions; coordinated implemented and supported Burmese CHWs and academic partners • **Burmese-Zomi speaking CHW (VLM): culturally specific and linguistic wrap around health and services** Role: Engaged in community-academic CBPR partnership sessions; conducted outreach and recruitment; scheduled 4 sessions with Burmese-Kachin and -Zomi family dyads; bridged trust between participants and academic researchers as a cultural broker in climate setting through light conversations and provided art supplies to children; provided sociocultural language interpretation during

	sessions; debriefed after a session with academic researchers; followed-up with participants on requested services; contributed to dissemination • **Burmese-Karen speaking CHW (TDW): culturally specific and linguistic wrap around health and services** Role: Engaged in community-academic CBPR partnership sessions; outreach and recruitment; scheduled 5 sessions with Karen family dyads; bridged trust between participants and academic researchers as a cultural broker in climate setting through light conversations and provided art supplies to children; provided sociocultural language interpretation during sessions; debriefed after a session with academic researchers; followed-up with participants on requested services; contributed to dissemination
Washington State University [public academic]	
Nursing and Systems Science Department in the College of Nursing	• **Lead Nurse Scientist MPI[c] (CKYN-T): Vietnamese and Guamanian Micronesian Islander; health equity, disparities, health promotion across the lifespan, parenting/caregiving leadership in health and early learning, CBPR, immigrants, refugees, and marginalized communities, historical trauma, Indigenous and cultural ways, including Asians, Micronesians, and Native Hawaiians/Pacific Islanders** Role: Brokered and connected all community and academic partners in CBPR partnership; scheduled and facilitated community-academic partnership CBPR sessions; did lifting work alongside in going over informed consent and assent; intake of sociodemographic and background; a facilitator of all 9 sessions; concurrent data collection and analysis in real-time with participants and an additional data analysis round following; held debriefings with Burmese CHWs and co-facilitators Human Development and Prevention Scientist MPI and Native American and Asian Indian prevention researcher; reviewed and co-documentation of field notes-based data journal; led and mentored in dissemination
Advanced Practice and Community-Based Care Department in the College of Nursing	• **Nurse Scientist Co-Investigator[c] (DUE): Black; psychiatric mental health and family nurse practitioner; mental health and family, nursing and community-based care practice** Role: Engaged in community-academic CBPR partnership sessions; engaged in the additional round of data analysis through review of interpretations and meanings; contributed to dissemination
PhD in Nursing Program in the College of Nursing	• **Nurse Researcher[c] (NB): Black; Graduate Research Assistant; research in stress contexts, including immigrants, refugees, and marginalized communities** Role: Engaged in community-academic partnership CBPR sessions; engaged in the additional round of data analysis through review of interpretations and meanings; contributed to dissemination

Human Development Department in Vancouver in the College of Agricultural, Human Development, and Natural Resource Sciences	• **Human Development and Prevention Scientist MPI[c] (SFW): White; developmental and prevention sciences, early relationships, health equity, trauma and resilience, CBPR** Role: Engaged in community-academic CBPR partnership session; did lifting work alongside Nurse Scientist MPI and Native American and Asian Indian prevention researcher in going over informed consent and assent; collected sociodemographic and background via Qualtrics; asked clarifying questions as a co-facilitator of the first 4 sessions; engaged in concurrent data collection and analysis in real-time with participants and an additional data analysis round following; engaged in debriefings with Burmese CHWs, facilitator Nurse Scientist MPI, and co-facilitator Native American and Asian Indian prevention researcher; reviewed and co-documented in the field notes-based data journal; contributed to dissemination
PhD Prevention Science Program	• **Prevention Researcher[c] (MR): Citizen of the Haliwa-Saponi Tribe and Asian Indian; Graduate Research Assistant; public health practitioner, intergenerational trauma transmission, caregiver-child dyad, CBPR, strength-based behavioral health strategies, Indigenous methodologies, equity, social justice** Role: Engaged in community-academic CBPR partnership sessions; did lifting work alongside Nurse Scientist MPI and Human Development and Prevention Scientist MPI in going over informed consent and assent; collected sociodemographic and background via Qualtrics; asked clarifying questions as a co-facilitator of all 9 sessions; primarily documented in the field notes-based data journal; engaged in concurrent data collection and analysis in real-time with participants and an additional data analysis round following; engaged in debriefings with Burmese CHWs, facilitator Nurse Scientist MPI, and co-facilitator Human Development and Prevention Scientist MPI; co-led dissemination • **Prevention Researcher[c] (SP): Korean-American; Graduate Research Assistant; health equity, culturally-grounded prevention programs, CBPR, food sovereignty and justice** Role: Engaged in community-academic CBPR partnership sessions; engaged in the additional round of data analysis, contributed to interpretations and meanings, and documented as memos of team's additional data analysis discussion; contributed to dissemination
Family Medicine in the PeaceHealth Care System [not-for-profit]	
Family Medicine	• **Physician in Family Medicine (AL): Colombian; Physician Researcher; public health, community health, disease control, health informatics, access to quality medical information** Role: Engaged in community-academic CBPR partnership sessions; engaged in the additional round of data analysis and contributed to interpretations and meanings; contributed to dissemination

Note. CBPR, community-based participatory research; CHW, community health worker; MPI, multiple principal investigators; PhD, Doctor of Philosophy.
[a]The community-academic CBPR partnership referred to Wallerstein et al. (2018) and Maurer et al. (2023) resources and recognized roles as partners, discussed, and clarified viewpoints and uplifted voices for inclusion.
Wallerstein N, Duran B, Oetzel J, Minkler M. Community-based participatory research for health: advancing social and health equity. 3rd edition. San Francisco, CA: Jossey-Bass; 2018.
Maurer ME, Hilliard-Boone T, Frazier K, Forsythe L, Mosbacher R, Carman KL. Examining how study teams manage different viewpoints and priorities in patient-centered outcomes research: results of an embedded multiple case study. *Health Expect*. 2023. Epub ahead of print.
[b]Community and academic partners chose to share based on their comfort, for example, about their race-ethnicity and identified experiences in addition to their professional background.
[c]Academic partners committed to doing lifting work in recognition that there were community leadership transitions and expanded to working with Burmese CHWs.

Table 2. Summary of Adapted Scientific Qualitative, Modified Participatory Group Level Assessment (GLA) Method Steps[a] with Researchers-Facilitators,[b] Burmese Community Health Workers, and Burmese Family Participants

GLA Steps	Researchers-Facilitators (Author Initials), Burmese Community Health Workers (Author Initials), and Burmese Family Participants
First Climate Setting Step	Burmese Community Health Workers (VLM & TDW) bridged trust between Burmese family participants and researchers-facilitators (CKYN-T, MR, & SFW) through introductions, small conversations about how a family spends time and what activity like to do, and art supplies.
Second Generating Data Step	The researchers-facilitators used a semi-structured and open-ended participatory discussion guide. The researchers-facilitators provided participants with prompt options, and Burmese family participants chose to talk about what they felt comfortable to share in the context of health and well-being. The following were examples of health and well-being prompts: *health care needs and barriers to access, racial discrimination, and strengths and resilience, and what would you feel comfortable in talking about regarding health and well-being?* Follow-up questions included: *Can you give us an example or examples when you said…, Have you or a family member experience…?* A prevention researcher (MR) documented stories and comments in a field notes-based data journal in all sessions, and these were reviewed by the nurse scientist MPI (CKYN-T) and human development/prevention scientist MPI (SFW).

Third Appreciating Perspective Step	Researchers-facilitators reviewed main points with Burmese family participants.
Fourth Reflecting Step	Researchers-facilitators verified and/or clarified interpretations and meanings with participants to assure trust in the data[c] Burmese Community Health Workers (VLM & TDW) were interpreters and cultural brokers. Interpretations and meanings of experiences and perceptions were bound to the interview sessions as well as culture and history[d] The Immigrant & Refugee Community Organization International Language Bank provided additional interpreter support that helped with selected verification of interpretation checks.
Fifth Understanding Step	Researchers-facilitators discussed with Burmese family participants and understood the generated data through identifying potential themes.
Sixth Selecting Step	Researchers-facilitators discussed with and selected potential themes with Burmese family participants.

Note. [a]Vaughn LM, Lohmueller M. Calling all stakeholders: group-level assessment (GLA)-a qualitative and participatory method for large groups. *Eval Rev*. 2014;38(4):336-355.

[a1]Fritz RL, [1]Nguyen-Truong CKY, Leung J, Lee J, Lau C, Le C, Kim J, Wong K, Nguyen TH, Le TV, Nevers JI, Truong AM. Older Asian immigrants' perceptions of a health-assistive smart home. *Gerontechnology*. 2020;19(4):1-11. [[1]Two First Authors]

[a1]Nguyen-Truong CKY, [1]Leung J, Micky K. Cultural narratives of Micronesian Islander parent leaders: maternal and children's health, the school system, and the role of culture. *Asian Pac Isl Nurs J*. 2020;4(4):173-182. PMID:32055685. [[1]Two First Authors]

[b]The researchers-facilitators were the following. The nurse scientist MPI (CKYN-T) served as the lead facilitator, and a prevention researcher (MR) assisted as a co-facilitator for all 9 sessions. The human development/prevention scientist MPI performed as a co-facilitator (SFW) for the first 4 sessions.

[c]Lincoln YS, Guba EG. Establishing trustworthiness. In: Naturalistic Inquiry. Beverly Hills, CA: Sage; 1985. p. 289-331.

[d]Chatham RE, Mixer SJ. Methods, ethics, and cross-language considerations in research with ethnic minority children. *Nurs Res*. 2021;70(5):383-390.

Table 3. Parent Self-Reported Demographic Information

Variable	Percent of Sample
Race/Ethnicity	66.7% Karen 22.2% Burmese and Kachin 11.1% Zomi
Relationship Status	88.9% married 11.1% widowed
Highest level of education	33.3% graduated from high school 33.3% some elementary school 11.1% some middle school 11.1% some high school 11.1% no school
Employment status	55.6% not employed 22.2% part-time 22.2% full-time
Total household income	44.4% $15,000-30,000 44.4% $30,000-50,000 11.1% $60,000-75,000
Health Insurance	100% Medicaid/Oregon Health Plan
Location of non-emergency health care services	66.6% county health clinic 22.2% private primary care provider 11.1% community health service center
Preferred language when speaking with healthcare provider	44.4% Karen 11.1% Karen and English 11.1% Burmese 11.1% Burmese and English 11.1% Burmese and Kachin 11.1% Zomi

Table 4. Main Themes, Corresponding Community Needs, and Exemplars of Testimonies

Main Themes and Corresponding Community Needs	Exemplars of Testimonies
Theme 1 – Navigate Cultural Differences: Need to Balance Burmese Cultural Lifeways and U.S. Society	***Cherry Family (Karen)*** • The Cherry child shared that they lost pets while growing up in the refugee camp, but recently the family was able to have a cat at home now that brings them much comfort. The Cherry child seemed to have exhibited some homesickness from reminiscing of their time in the refugee camp and noted wanting to return there with their father. The Cherry child shared some experiences with their education such as certain subjects were easy versus difficult. The Cherry parent shared they have only spoken with faculty or staff via a phone interpreter service through school services, but they shared these experiences have been good. • The CHW shared that when her people immigrated to the U.S., they do not know how to identify discrimination within the context of the U.S. They find and share gratitude with those that help them, and the health services that they receive here are profoundly different than what they would receive back home. The CHW noted that, in the refugee camps, you cannot choose when to access utilities, such as lights; people pay money for a service that you cannot control. ***Orchid Family (Karen)*** • *One of the doctors came to a medical center, and I went away for 2 hours, and I came back and the first time I heard, they didn't have my permission, and they told me we had found a place for your dad to live in a nursing home. They set it all up without my permission. I asked the doctor why. And I said they never talked to me….I said no, I am not going to take my dad to the nursing home,…the doctor…said we planned it because you have kids at home. My Karen family, we take care of our family, and we don't take our parents to the nursing home.* • *I got so mad…The doctor and the nurses came around…told me that he was old…dying…When I said no to the doctor, they said you can take your dad home…Didn't give any next steps or share the health conditions...I worked for 6 months in a nursing home, and I knew how it is there. My dad only eats Karen food and traditional food.*
Theme 2 – Complex Journey of Information Access: Need for Qualified Interpreters and Cultural Brokers	***Lotus Family (Zomi)*** • *The first thing related to healthcare, I don't speak English, and I need an interpreter all the time so that is a barrier. When we go to the emergency [room], we feel like it is very serious…we have to wait…2-3 hours before getting seen by the doctor. We feel like we could die while…waiting a long time. It's usually at night so we can't get an interpreter. Another barrier is the translation of other information like emails or notices. It's not in Zomi, it's in Burmese, and we don't read Burmese.* Regarding racial discrimination, the Lotus parent described that some patients pretend they have a more serious situation and that is why they get called first. The Lotus parent explains that although their situation is very serious, *"We don't pretend, but we don't get seen."* The Lotus parent also described crying because of pain.

	• *If we go with someone who can speak English well, we are taken better care of than if we go without one. Primary care referred me to a brain specialist for my headaches, but that specialist is at a downtown clinic where it is hard to find an interpreter. I could only get an interpreter on the phone, and they did not speak Zomi smoothly or clearly. I couldn't understand the interpreter and they were yelling at me, You can't understand me?! I asked for a different interpreter and was told no…They [clinic] have canceled my appointments three times…and right now they won't schedule with me again.* ***Cherry Family (Karen)*** • The Cherry parent shared that once an alternative interpreter was found, there was clarity on what was said in the clinic health appointment, and the language barrier in that instance became less strenuous. The Cherry parent shared that her sister serves as a primary interpreter for the family, and although she does not have professional experience as an interpreter, the Cherry parent noted always choosing and requesting her sister over an interpretive service. The CHW discussed that it is common to have a parent's child(ren) or those family members that speak English to serve as an interpreter, and although they do not know the medical jargon, they can provide conversational support, to relay the important information - coming from a trusted individual. The Cherry child shared that coding between two languages is easy, and talking with healthcare providers was not a concern. The Cherry parent continued to share that it is a huge barrier to not be able to access healthcare services in Karen.
Theme 3 – Family Health Care and Social Support: Need for Collective Relationship-Based Decision-Making	***Orchid Family (Karen)*** • When her father's providers made a care plan for him to be placed in a skilled nursing facility, she was not involved in the plan, although she was his caregiver. She perceived this care plan as being decided behind her back, leading to anger and frustration. She shared that she placed her trust in God…, and her father lived past what was anticipated. *"I can't trust [the hospital healthcare system] and what other services might be available".* The Orchid parent shared that the healthcare providers' focus was on end-of-life care; whereas the Orchid parent focused on responsibilities of taking care of an older aging parent and anticipated that the visit would provide insights into her father's illness. The Orchid parent shared that healthcare providers thought about how she had young children at home as a rationale for why they had arranged a skilled nursing facility to care for her aging parent. However, this was viewed as a decision made without her. The providers had not discussed palliative care services with her prior. ***Basil Family (Kachin)*** • The Basil parent shared how she accessed behavioral healthcare when her husband passed and used prescribed anxiety and sleep medications to aid in processing her grief and anger. The Basil parent expressed affirmation for her friends who continue to provide much encouragement and support since the passing of her husband. She also emphasized community gatherings centered around food, gardening, and nature to strengthen familial and friendship connections during times of grief and throughout daily life. The Basil parent emphasized wishing that she could continue sharing and learning more about her emotions and how to support her children and strengthen their relationships. She mentioned that one of

	her daughters experienced similar emotions and was focused on getting social, emotional, and behavioral support for her and her children, with the advocacy from community organizations. • At several points throughout the conversation, the Basil parent exhibited emotional stress and was crying through her grief and frustration. Her youngest child came by and once seeing their mother cry, too began to cry. In her emotional distress, she was unable to tend to her children during the conversation.
Theme 4 - System and Institutional Barriers: Need to Eliminate Discontinuity in Holistic Health Care and Towards Basic Health Needs	***Padauk Family (Karen)*** • The Padauk parent shared examples of food management for pre-diabetes and how the follow-up health care visits had been before stopping. Padauk parent was told it was best to *"manage the food first, blood sugar tests every visit at the clinic and not at home."* Padauk parent reported being *"lazy"* and stopped going for healthcare visits for the past 6 months and had not taken her 15-year-old child for a check-up for 6 months. • *…my son doesn't listen, and he eats whatever he wants,…he doesn't want to go see the doctor anymore...It's kind of hard for me because I ask my kids to follow the steps from the doctor…,...I don't think he understands, he's a kid...and as a mom you worry...The doctor plans what is good and shares the benefits of following the steps...but doesn't ask the child.* ***Thazin Family (Karen)*** • The Thazin family shared that they have one adult within the household who is working, an elder lives with them, and three children are being raised at home with the Thazin parent. The Thazin parent described their experience when they attempted to access food assistance through a state service department. They described the difficulty in navigating the application, to the point where they were unable to secure food assistance for months. The Thazin parent noted barriers to accessing support and updated information from the state service department. Although they shared that the household had previously accessed services, they had not known that they needed to apply every 6 months. The Thazin parent expressed that with consistent changes in case workers (high turnover), they did not have the appropriate contact information to gain information regarding their status in accessing assistance. They continued to note that food is getting expensive, speaking to inflation and a household with an elder three children, while their husband is the only person working. Barriers to other resources such as utilities also caused further financial stress. Shared feelings of sadness in navigating dynamics and services in the United States and feeling discriminated against because of being a refugee.

Note. Used pseudonyms as flower names for participants. CHW, Community Health Worker.