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BUILDING COMMUNITY-ENGAGED RESEARCH PARTNERSHIPS WITH BHUTANESE-NEPALI REFUGEES: LESSONS LEARNED FROM A COMMUNITY HEALTH NEEDS ASSESSMENT PROJECT

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Introduction

More than 10.4 million people each year are displaced from their homes due to persecution, war, violence, and human rights violations (UNHCR 2014). Of those, more than 70,000 refugees are resettled in the United States annually, with a majority currently from Bhutan, Burma, Iraq, and Somalia (ORR 2014). Not only do refugees fleeing political conflicts experience significant physical and mental health symptoms, they also face a myriad of post-migration difficulties, such as language barriers, separation from family, worry for relatives left back in the home country, and difficulty maintaining cultural and religious traditions (CDC 2012; Costa 2007; ORR 2014). Furthermore, accessing health and social services can be extremely difficult for refugees and is often exacerbated by cultural and linguistic barriers.

To date, more than 75,000 Bhutanese-Nepali refugees live in the United States (Steel et al. 2009). Bhutanese-Nepali refugees are people of Nepali origin. The initial migration of Nepalese into Bhutan began in the 1620s; however, the majority of Nepali-speaking people migrated to Bhutan in the 19th century (Aris 1979; Cultural Orientation Resource Center 2007a, 2007b). In the mid-1980s, Bhutan implemented the "One Nation, One People" policy to unify the country under the Drukpa regime (CDC 2014). The so called, "Bhutanization" process undermined the cultural, linguistic, and religious traditions of the Lhotshampas (Southern Bhutanese who are of Nepalese ancestry) in Bhutan, which sparked political protests and civil unrest (BBC 2010). The Drukpa regime began to expel the Lhotshampas by stripping away their citizenship rights, seizing land and property, and shutting down businesses (Cultural Orientation Resource Center 2007a, 2007b). Within two years, Bhutan expelled one-sixth of its citizens. People fled into neighboring India and Nepal, forcing thousands of ethnic Nepalese to live in refugee camps in Eastern Nepal, some as long as twenty years, prior to being resettled in the United States and other developed countries.

There is limited research concerning the post-migration experiences and challenges faced by Bhutanese-Nepali refugees in the United States. National research has focused on the high

suicide rate among Bhutanese-Nepali refugees (CDC 2012). A study conducted by the Centers for Disease Control and Prevention (CDC 2012) showed that the suicide rate among Bhutanese-Nepali refugees is twice that of the United States population (24.4 vs 12.4 per 100,000). Socio-psychological factors including not being able to provide for the family, lack of social support, and having been diagnosed with anxiety, depression, and distress were contributing factors for the high suicide rate (CDC 2012). Research is particularly lacking in addressing the difficulties faced by the community concerning health, social, and cultural needs. We posit that interdisciplinary collaborations among anthropologists, public health practitioners, and community organizations are critical in this research, especially in ensuring the results can be translated to action.

The purpose of this article is to describe a community-engaged approach to developing and implementing a community health needs assessment with a Bhutanese-Nepali refugee community in a Midwestern United States city. Community-engaged research is a collaborative approach between communities and researchers to address community health concerns (Pasick et al. 2010). Our interdisciplinary research team is trained in anthropology and public health and includes members of the Bhutanese-Nepali refugee community. We describe our research process and lessons learned developing a community-academic partnership and identifying health priorities of the Bhutanese-Nepali community. This study was approved by the Ohio State University Institutional Review Board (IRB).

Building Community Partnerships

Refugee Women in Action (RWIA) is a non-profit organization which provides resources for newly resettled refugees in greater Columbus, Ohio. RWIA's mission is to connect refugee women to resources such as English language classes and employment and social services. Since its inception, the organization has grown to serve diverse refugee populations, including the Bhutanese-Nepali community. To better understand the needs of the community it serves, the RWIA board, of which the Jennifer Kue (first author) is a member, requested a needs assessment with the Bhutanese-Nepali community. We initiated multiple discussions with members of the Bhutanese Community of Columbus (BNCC), a non-profit created by Bhutanese-Nepali serving the local Bhutanese-Nepali community. BNCC agreed that the community health needs assessment was overdue and would benefit both organizations by providing information to assist them in developing culturally appropriate programs that addresses the health and social needs of Bhutanese-Nepali refugees.

A nine-member Cultural Community Advisory Board (CCAB) was formalized to help guide the project, identify community priorities, recruit bilingual and bicultural interviewers, and ensure that the project follows culturally appropriate methods. Members of the CCAB included four individuals from the Bhutanese-Nepali community, specifically members of the BNCC, and five individuals from the RWIA group. Given the leadership serving on the CCAB, the support we received gave our project credibility and greater acceptability in the community, which is an important key aspect of community-engaged research (Minkler 2005).

One of our most formidable challenges in conducting a community-engaged study is the time commitment by CCAB members. Ideally, the CCAB should meet together; however, due to factors such as members' conflicting schedules, over-extended staff at the Community Based Organization (CBO) level, and change in leadership with one of our partners, the Principal Investigator (Jennifer Kue) met with each CBO separately.

Hiring and Training Bilingual and Bicultural Interviewers

With assistance from the CCAB, we initially identified two bilingual and bicultural individuals from the Bhutanese-Nepali community to administer the community health needs questionnaire. Two male interviewers (Nepali speaking) and one female interviewer (non Nepali-speaking) were initially hired. The female interviewer was not of Bhutanese-Nepali descent, but worked with Bhutanese-Nepali refugees and had substantive experience conducting survey research and interviews and working with refugee communities. We initially hired her to conduct interviews with only English-speaking women, while we continued to search for bilingual/bicultural female interviewers. Additional interviewers were identified, and training was conducted for all; however, only one of the Nepali-speaking women completed the mandatory human subjects protection training in order to be approved to collect data.

Challenges and Lessons Learned

Hiring staff with research experience is ideal; however, finding community members with research experience from recently resettled refugee communities can be a tremendous challenge. One of our main challenges was hiring a female Bhutanese-Nepali interviewer. We were able to quickly identify potential female interviewers in the community, but finding someone who could commit a substantial amount of time to successfully complete the human subjects training was difficult. To be in compliance with the university IRB, all research key personnel must complete training in the basics of human subjects research, ethical conduct, and research ethics. We had interviewers complete the Collaborative Institutional Training Initiative (CITI) (https://www.citiprogram.org/). Although some of our potential interviewers could read, speak, and understand English, the CITI training is extensive and all on-line, making it difficult for those who do not have access to the Internet nor the time to complete the modules. Furthermore, the content and language (e.g., academic jargon) is difficult to comprehend for those who are not familiar with research. Other reasons for not being able to participate as an interviewer for the research project included other commitments (i.e., job, family).

Researchers may also want to be prepared for staff turnover and re-training. Members of the community who are gatekeepers or key "go-to" people are often in high demand because of their unique skill set and/or position to navigate within mainstream society and their cultural community. These individuals have the understanding of both worlds to be able to liaise between the two. In turn, they may not be able to give the research project the dedicated amount of time necessary or may have to step back from the study before its completion.

Participant Recruitment, Informed Consent, and Questionnaire Administration

Recruitment was conducted, primarily through word-of-mouth with a convenience sample using a standard recruitment script by trained bilingual/bicultural interviewers at various locations (e.g., community center, social service agencies). Individuals were eligible to participate in the study if they: (1) self-identified as Bhutanese-Nepali, (2) were eighteen years or older, and (3) lived in Columbus, OH.

A waiver of documentation of informed consent was obtained from the university's IRB as we expected that many participants would not read English, nor would they read Nepali; therefore, translating the informed consent form into Nepali might not have been a good use of our limited resources. In addition, finding a bilingual witness for non-English speaking participants might have compromised the confidentiality of the participant. This is a small, tight-knit refugee community, and the need for a witness, whether that witness is provided by the participant or by researchers, creates a situation in which an additional person knows that the person is a study participant (Kue, Thor-burn, and Keon 2015). We expected that the interviewers would be able to seamlessly move between languages without adding any stigma to situations in which participants do not speak English and need anywhere from a few words, or the whole interview, provided in Nepali.

Face-to-face administered questionnaires were conducted after obtaining participants' informed consent. Questionnaires were conducted in Nepali, English, or both, depending on participants' preference, and took place in participants' homes or in private rooms at community locations. The questionnaire took approximately fifteen minutes for English proficient individuals and forty minutes for participants with lower English proficiency.

Challenges and Lessons Learned

We decided not to translate the questionnaire due to limited funding, as well as the confidentiality reasons stated above. Although we trained interviewers to mitigate potential issues, we could not anticipate how to respond to every single question from participants. For some participants, particularly among those with low English proficiency, a translation of the questions was not sufficient, and rather required more detailed explanations.

Furthermore, navigating family dynamics was sometimes a challenge for interviewers as multiple generations tend to live in one household. For example, male household members were willing to participate; however, female household members did not necessarily always have the autonomy to participate and tended to wait for approval from their spouse, especially if they were to be interviewed in a private room. We tried to reduce this problem by gender matching interviewers and participants as much as possible, but we could not always meet this criterion.

Lastly, due to our budget limitations, and in order to ensure a large sample with limited resources and time, we limited our research to a quantitative questionnaire. However, all three of the authors of this paper, and two of the interviewers, recognized quickly the need to follow-up with a qualitative component to obtain more information on some of our initial

findings, which are currently in preparation for publication. Our plan is to conduct a mixed-methods study to further examine, specifically, barriers and facilitators to cancer screening, role of primary groups (e.g., husbands, male head of household) on cancer screening behavior, and the underlying factors of refugee trauma on health seeking behavior.

Conclusions

Initial analyses indicate that there are some questions (e.g., mental health stigma) that still need to be addressed using a qualitative research framework. As more Bhutanese-Nepali refugees resettle in the United States, there will be greater challenges in addressing the health and social needs of these new arrivals. Taking a community-engaged approach is a critical step in addressing the health and social needs of this refugee community in a culturally sensitive and appropriate manner. The primary lessons learned in this process of establishing a collaborative community-academic partnership and implementing a survey study will not only enhance awareness of the health care needs of Bhutanese-Nepali refugees, but can also be applied to research with other refugee communities in the United States.

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Biography

Jennifer Kue (mailto:kue.2@osu.edu), Ph.D., is an Assistant Professor in the College of Nursing at The Ohio State University. Kue is Hmong American and a former refugee from Laos. She has over fifteen years of professional experience working with refugees and immigrants and medically underserved minority populations. Kue's research applies the principles of community-engaged research to understanding and addressing cancer health disparities, including cervical cancer prevention, cancer screening, and survivorship in underserved ethnic minorities. She has an M.A. in Anthropology from San Diego State University and a Ph.D. in Public Health from Oregon State University.

Sudarshan Pyakurel (pyakurel.1@osu.edu) is a member of the Bhutanese-Nepali community in Columbus, OH. He has a Master's degree in English Literature (India) and B.A. in Anthropology from The Ohio State University. He volunteers for the Bhutanese-Nepali Community of Columbus helping families with various needs, and serves as an interpreter and translator for local agencies. He worked in the education field for eight years

in India prior to moving to the United States. He is pursuing further education in public health.

Kelly Yotebieng, MPH, is a Ph.D. student with The Ohio State University's Department of Anthropology (see introduction for full bio).

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