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ORIGINAL PAPER

"Can I Ask That?": Perspectives on Perinatal Care After Resettlement Among Karen Refugee Women, Medical Providers, and Community-Based Doulas

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Abstract This study characterized the perspectives of Karen refugee women in Buffalo, NY, their medical providers, and Karen interpreters/doulas on perinatal care for Karen women in resettlement. In-depth qualitative interviews with Karen women (14), Karen doulas/interpreters and key informants (8), and medical providers (6) were informed by the social contextual model and focused on women's questions about and opinions of perinatal care in Buffalo and on providers' experiences caring for Karen patients. Karen women expressed gratitude for and understanding of perinatal care in Buffalo, and providers described Karen patients as agreeable but shy. Karen doulas offered an alternative view that exposed women's many questions and concerns, and described how doula training empowered them as patients' advocates. Low self-efficacy, trauma histories, and cultural expectations may contribute to Karen women's seeming agreeability. Doulas/interpreters possess insider knowledge of women's concerns and facilitate communication between patients and the care team.

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Background

Over 120,000 refugees from Burma have resettled in the US since 2001, including over 30,000 Sgaw Karen speakers [1, 2]. The Karen are the largest of multiple ethnic groups displaced for generations in Thai refugee camps by a protracted civil war rife with human rights atrocities [3–7]. Seventy-five percent of individuals departing Thai camps have come to the US [3]. After arrival, resettlement challenges often motivate Karen refugees' secondary migration to cities with established kinship networks and community-based organizations which facilitate access to economic, educational, and medical resources [3, 5].

Women and children disproportionately bear the health consequences of humanitarian crises. Maternal mortality ratios in conflict zones are among the highest in the world due to poor access to health services, disruption of support networks, poor sanitation, and violence [8, 9]. Nine to fifteen percent of women in Thai refugee camps reported a history of conflict-related or interpersonal violence [9, 10]. At the time of resettlement, many refugee women worldwide have experienced physical and psychological trauma, malnutrition, infectious disease and high parity, and many have unmet reproductive health needs [8, 11–13].

Despite the modern health infrastructure in resettlement countries, upon arrival refugee women face new challenges that may contribute to disparities in maternal health outcomes. Barriers to perinatal care affecting migrant women in general and refugee women in particular are well-documented and include transportation, difficulty

navigating the health care system, unfamiliarity with preventative care, low health literacy, low socioeconomic status, racial/ethnic discrimination, and inadequate language interpretation [5, 12, 14–17].

Even when medical providers use professional interpreters, an intervention proven to improve health outcomes and patient satisfaction, intercultural communication barriers remain salient [18, 19]. Studies of communication between racially/ethnically discordant physician-patient dyads reveal lapses in empathy and information sharing, possibly attributable to physician bias, different explanatory models of health/illness, and conflicts of individualist versus collectivist values [20, 21]. Identified barriers to open communication include physicians' closed questioning style and lack of general knowledge about patients' country of origin and culture [22]. Refugees' deference to authority may also prevent patients from initiating conversations with providers despite available language interpretation [23].

Niner and colleagues situated these barriers to care within a broader discourse on migrant discrimination and identity, suggesting that poor maternal outcomes in resettlement countries reflect a systematic marginalization and devaluation of migrants. Their study exploring Karen refugee women's perinatal experiences in Australia found that Karen women's internalization of this outsider status created a state of "gracious acceptance," in which Karen women suppressed criticisms of their birth experiences and instead expressed appreciation for whatever "undeserved" care they received [24].

Community-based doulas may offer an antidote to refugee perinatal patients' marginalization. Doulas are non-medical personnel who provide continuous emotional and physical labor support while orienting women to the unfamiliar maternity ward [25]. An early study of ethnically congruent labor advocates for minority, non-English speaking women found improvements in maternal outcomes when these support persons were present [26]. Doulas have since been shown to reduce rates of cesarean section, analgesia use, and patient dissatisfaction, possibly by bolstering women's confidence and control [25]. Foreign-born women in Sweden credited community-based doulas with mitigating a sense of isolation during childbirth, and Swedish midwives characterized the doulas as facilitators of culturally-competent care [27, 28]. Bilingual, trained doulas from refugee communities may be ideal advocates for vulnerable refugee patients.

The purpose of this project was to study the perspectives of Karen refugee women in Buffalo, NY, their medical providers, and Karen interpreters/doulas on perinatal care for Karen women in resettlement. We aimed to describe Karen women's perinatal experiences and the role of doulas/interpreters in facilitating patient-provider communication.

Theoretical Framework

The theoretical basis for this study draws on Sorensen et al.'s social contextual model (SCM). This model holds that there are multiple psychosocial, population, and structural/environmental factors that influence health behaviors [29, 30]. The SCM draws on Bandura's theory of self-efficacy and identifies individuals' perceived ability to alter their life circumstances as constituting a key social contextual factor [31]. The social contextual factors of race/ethnicity, gender, age, refugee status, income, and social ties are essential to consider in this study because little is known about how Karen women experience perinatal care or what elements of social context influence their experience of and attitudes about care.

Methods

Setting

We conducted this study in Buffalo, New York, where a community of ~4000 Karen refugees continues to grow through direct resettlement from Thai camps and secondary migration from other US cities. Participants were patients or employees of a community health center where many Karen refugees receive care. The center coordinates many social service programs for refugees, including one that trains female refugee interpreters as doulas.

Participants

We recruited female Karen patients and doulas/interpreters from the Karen community and the health center. Participants included 14 Karen patients, eight Karen doulas and community leaders, and six representatives from the clinic. One researcher and the study interpreter attended a church service to recruit Karen women who were 18 years or older and current patients of the health center who had either given birth in Burma or Thailand at any time or in Buffalo within the past 3 years. Interested women contacted the interpreter directly or via the pastor's wife. A clinic-employed interpreter also called eligible patients to invite them to participate. Researchers recruited Karen interpreters and doulas using snowball sampling [32]. A clinic physician informed clinic staff about the study via email and a researcher then contacted providers to schedule interviews. All Karen participants received $20 for participating. The Memorial Hospital of Rhode Island Institutional Review Board approved all protocols. The researchers obtained written informed consent from participants prior to the interviews. For Karen speakers, the explanation and form were in the Karen language.

Instruments

We developed interview guides for each participant group using open-ended questions informed by our theoretical framework, a review of the literature, and one of the co-author's (KL) year-long work as a medical case manager for Karen patients at the study site. Prior to the interviews, the Karen interpreter reviewed the questions for appropriateness and clarity. Interviews with Karen perinatal patients focused on experiences during pregnancy, labor, and the postpartum period in Burma, Thailand, and/or Buffalo; women's questions about and opinions of perinatal care in Buffalo; challenges faced during the perinatal period; and Karen perinatal traditions (see Table 1). Karen key informants were queried about their roles in perinatal care and their perceptions of Karen patients' questions and concerns (see Table 2). Interviews with medical and social service providers focused on barriers to and strategies for meeting the medical and social needs of Karen perinatal patients (see Table 3).

Data Collection

One researcher conducted 1- to 2-h semi-structured individual interviews with participants in July and August 2011. The same professional Karen interpreter accompanied the researcher for interviews requiring interpretation. Karen patients were interviewed in their homes, alone or in pairs according to their preferences. The researcher interviewed Karen community key informants in their homes or at the clinic, and medical providers at the clinic or by telephone. Data collection continued until thematic saturation was achieved [32]. Interviews were audio recorded and transcribed. For interpreted interviews, only the interviewer's and interpreter's comments in English were transcribed. Because the interview transcripts did not include the conversations in the Karen language, lack of confirmatory re-interpretation could lead to systematic misinterpretation and therefore errant analysis. To reduce this risk we conducted a focus group in 2014 with Karen doulas and patients not involved in the initial study to further validate the data through member checking [33].

Data Analysis

The coathors analyzed the transcripts in three phases, using an iterative group discussion process both during and following completion of data collection. In the first phase we undertook an immersion/crystallization approach in which we individually read and reflected upon the transcripts, taking notes as each of us identified themes [34]. We then met as a group to discuss our individual interpretations of emerging themes, working together this way until we came to consensus. Using these themes and the social-contextual model, we constructed a set of codes for a Template Style approach to data analysis [35]. The Template Style approach allowed for application of a codebook of defined codes, in addition to spontaneous identification of codes as we coded the transcripts line by line using TAMS Analyzer software [36]. The co-authors then met as a group to further analyze the topical code reports thematically for final interpretation of the data. The analytical process generated many categorical and thematic topics. This paper reports our interpretation of the data related to Karen women's challenges during, and questions about, perinatal care.

Results

We conducted 28 interviews. Fourteen participants were Karen patients, ages 18–41. Eight were key informants from Buffalo's Karen community: three trained doulas, three women who had attended births only in Burma and Thailand and required Karen interpretation, and two male Karen interpreters with extensive exposure to perinatal care in Buffalo. Six clinic staff members participated: two family physicians, one nurse practitioner, two service coordinators, and one volunteer.

Table 1 Selected interview questions for Karen perinatal patients

How was your medical care during your pregnancy in Buffalo different from your care in Burma or Thailand? How was it similar?
Was there anything you wanted your doctor in Buffalo to do or to ask that he/she did not do? What would you have wanted? Did you feel that you could tell your doctor? If no, what made you feel that you could not?
During your pregnancy, doctors in Buffalo order tests. What kinds of tests did you have? When the doctor told you to have those tests, what did you think about that? Did you have any questions about the tests, and were you able to ask those questions?
How informed did you feel during your pregnancy about what the doctors were doing and why? Would you have liked more information?
In Buffalo, did you have a language interpreter during your prenatal visits? Did you have one when you had tests done outside of your doctor's office, for example at the hospital or the lab? How did you feel about the interpretation that was provided? How well did you feel you and your provider understood each other?

Table 2 Selected interview questions for Karen key informants, doulas, and interpreters

In what ways have you been involved with Karen women during pregnancy and labor? Where have you been involved, in Thailand, Burma, or Buffalo?
Can you think of any tests or procedures that doctors do in Buffalo that seem to worry or confuse Karen women? What do you think the source of the confusion is? How do you think we could best address the questions women may have?
What do you perceive the specific needs of pregnant Karen women to be?
What services are available to your community to address these needs? What services seem to be most useful and why?
What needs do you see as going unmet by the doctor's office, the hospital, and the community?
How effective to you think the interpretation is for Karen women at their prenatal visits with the doctor? During their stay in hospital? Do you think that the doctors or nurses and the patients understand each other?

Table 3 Selected interview questions for medical and social service providers

What are some challenges you encounter in caring for pregnant Karen women? Karen women in labor? Postpartum Karen women?
What do you perceive the specific needs of pregnant Karen women to be that are different from the other women you care for?
What services are in place at your practice to address these needs?
How well do you think Karen women understand aspects of perinatal care?
What support systems do pregnant or postpartum Karen mothers seem to have?
What interpretation strategies do you most frequently employ when meeting with Karen women?

Agreeability and Gratitude from "Easy-Going" Patients

Agreeability and gratitude pervaded Karen refugee women's perspectives on accessing and understanding perinatal care in Buffalo. While Karen women identified transportation and hospital navigation as particular challenges during the perinatal period, many women derived a sense of security from plentiful medical resources and reported they would not have altered their perinatal experiences. One woman explained that her perinatal care in Buffalo was "very different (from care in Thailand). Here they have Medicaid so everything went well. When [I] was pregnant the doctor took care of [me], everything." Most women trusted their medical providers' judgment and dutiful intentions, and reported that qualified interpreters were used. A few women mentioned receiving support from volunteers and doulas.

Women likewise reported satisfaction with their understanding of perinatal care in Buffalo. Karen patients overwhelmingly stated that they had no questions about their perinatal care: "No, [I] didn't have any," "No questions," "No, nothing." Women generally reported understanding ultrasound. Though they had less specific knowledge about lab tests, most did not want more information. Women often equated the use of an interpreter with understanding care.

Medical providers' accounts of Karen perinatal patients echoed these themes of agreeability and gratitude. Providers described their Karen patients as "trusting" and "easy-going," and, in contrast to some other refugee populations they cared for, "the Karen women just kind of go with the flow, and if you suggest something and explain it easily, they obey." While providers valued their Karen patients' appreciation, they expressed frustration that patients' "shy" and "embarrassed" demeanors prevented Karen women from fully engaging in care. Some were wary about what might underlie their agreeability: "No matter how many ways you ask, 'Do you have any questions?,' they always say, 'No, I'm good.' But are [they] really? Or, are they afraid to question almost because they are afraid of how I'm going to respond?" Providers identified many challenges facing Karen perinatal patients, including language barriers, history of trauma, depression, areca nut use (a seed, also known as betel nut, with stimulant effects and debated association with low birth weight), domestic violence, lack of transportation, gestational diabetes, and poor nutrition [37]. Nevertheless an air of ease prevailed and, according to one provider, "From a doctor's standpoint, the Karen are very easy to take care of. We do not view them as a challenging population."

"Can I Ask That?": Another View of Karen Perinatal Preference and Understanding

Karen doulas and interpreters, along with a few Karen patients, offered an alternative perspective on Karen women's perinatal preferences and questions, challenging

the doctor-patient narrative of unquestioning, easy-going gratitude. The women who did voice complaints were educated Karen community leaders who spoke some English. They stated their concerns after much hesitation and then did so indirectly through questions, asking, for example, why laboring women had been told to wait for a doctor to arrive before pushing. No Karen patients reported discussing this concern with a medical provider. Doulas noted many aspects of routine intrapartum care that Karen women disliked but that neither patients nor medical providers mentioned as problematic. One doula shared that Karen patients "don't want to be touched during contractions … Drawing out blood, IVs, … monitoring baby and mom, they don't want to do it at all." Affronts to Karen women's modesty also surfaced in multiple interviews, as doulas noted that women were often "uncomfortable" with the lack of privacy in the hospital and "feel like test equipment" when trainees perform cervical exams. Only one woman, an English-speaking Karen doula, directly stated a complaint in the interview as well as to her physician, about perceived mismanagement of her own labor: "I am strong woman. I was fighting. I talk with doctor … Here technology is everywhere. In my country, they have no technology so they have to use the brain."

Another contradictory backstory emerged regarding patients' understanding of perinatal care. Some patients acknowledged having had questions they did not ask. One woman stated that "As a patient [I] don't know what they test for … As a weakness, [I] think [I am] supposed to ask what the tests are, but [I] didn't ask." Consuming the providers' time, trusting the providers' intentions, and having painful contractions were explanations women offered for not asking questions. One woman explained: "To ask takes time. Sometimes the doctor will not be available. They are working; they have so many other [patients]. [I] understand." Women were skeptical of the interviewer's suggestion that they discuss their questions regarding pushing, lab tests, or contraception with their providers: one responded, "Can I ask that?"

Karen doulas and interpreters also reported that patients in fact had questions about various aspects of perinatal care, including blood tests, intravenous lines, medications, and paperwork. Women often asked questions only after the provider left the room. A doula explained: "Most of them, they don't know their right. They don't know their options, so that is why they don't say anything until the people are gone and they tell you, *Why [are] they doing that?*" Like the medical providers, community members attributed Karen patients' silence to fear, possibly stemming from their traumatic refugee histories:

> Most Karen or Burmese women grew up like that. We are afraid of something all the time. So even though they are not here, their minds start. They grew up with the fear. So when they go to the hospital, they want to ask something, but they are afraid. They keep it in their heart because of the fear.

Doulas who participated in member checking strongly reiterated that Karen women were hesitant to ask questions, in part because questions met with reprimand in Burma's former dictatorship.

Karen Doulas: Patient Advocates on the Health Care Team

Karen doulas who had previously worked as interpreters revealed insider knowledge of Karen women's perinatal preferences and questions. Doulas credited their training with empowering them to use this knowledge in their work to advocate for Karen patients. One Karen doula offered: "A lot of people are complaining because they want to … walk around a lot and some of [the nurses] say no, but I didn't know we had to ask. After doula training I know that the nurses say yes." With regard to multiple cervical exams, a doula stated, "I didn't know before if the patient [had a] right to say no to them, but after doula training I told them, she doesn't like it." Member checking corroborated doula training's ability to transform interpreters into more self-confident advocates.

Karen doulas also described fielding and legitimizing patients' questions. While they answered questions appropriate to their level of training, doulas counseled patients to ask providers directly: "I teach them.…*Next time, you ask in front of [the] doctor. I will translate it for you. Otherwise you will not get the information.*"

Medical providers highly valued the role Karen doulas and interpreters played in facilitating perinatal care. Providers attributed much of the ease of caring for Karen patients to longstanding partnerships with Karen community leaders: "Having people who can translate the culture …, the doulas and translators … as part of our practice help[s] us. They give us tools." Another provider noted, "We believe that our doulas really help to make for a better birth outcome." Though providers did not share the doulas' familiarity with Karen women's preferences and questions, providers assumed responsibility for identifying and training community-based patient advocates.

Discussion

Although Karen refugee women expressed an overall satisfaction with and understanding of their perinatal care in Buffalo, interviews with Karen interpreters and doulas suggested that Karen women in fact had many concerns

and questions. To some extent our study recapitulated elements of the existing communication structure between Karen perinatal patients, their medical providers, and Karen interpreters or doulas, in that participants' general reluctance to voice negative opinions about their care with the researchers echoed the women's conversations with their providers, who therefore viewed Karen patients as agreeable and easy-going. As in the clinical environment, Karen doulas and interpreters offered a rich insider perspective on Karen women's concerns and questions.

Our study supports Niner's finding of "gracious acceptance" among Karen perinatal patients in Australia [24]. Furthermore, our interviews with medical providers in Buffalo, NY show that providers also characterize Karen perinatal patients in terms of their unquestioning agreeability. In so far as this agreeability may be a marker of Karen refugee women's internalized outsider status and feelings of unworthiness to receive care as Niner et al. suggested, communication between Karen women and their providers may enact a broader division, or otherness, between Karen women and their resettlement country [24]. Such "gracious acceptance" may be the ultimate manifestation of low self-efficacy in health care settings.

As doulas/interpreters suggest, Karen women's seeming agreeability may stem in part from fear in the wake of repeated trauma, displacement, and resettlement. Although we did not collect data on our participants' victimization rates, documented violence and trauma among refugees from Burma coupled with the forced displacement inherent in refugee status indicate that our participants are part of a historically traumatized community. According to community members and providers, fear prevents these women from voicing their questions and concerns, and may enact the helplessness well-described among traumatized patients [38].

Another framing of Karen women's agreeability and reticence to ask questions draws on cultural norms of the physician-patient relationship. Medical paternalism has been well described in traditional Southeast Asian cultures, where an engrained social hierarchy defines the doctor-patient relationship, preventing Karen women from engaging in care as equal partners [39]. Karen women's compliance with medical recommendations despite limited understanding likewise echoes the indifferent and uninformed obedience to perinatal testing described among Southeast Asian immigrants in Australia, where women sought to please their physicians and comply with the norm [40]. This hierarchy represents another social contextual factor, which, along with Karen refugees' protracted sense of displacement, yields an exaggerated deference to physician-authorities in resettlement.

Interviews with Karen doulas and interpreters revealed that although agreeability and gratitude characterized interactions between Karen patients and their providers, it did not define communication between Karen women and their fellow community members. By including the perspectives of medical providers and doulas/interpreters, our study identified the vital role trained Karen doulas play as facilitators between Karen women and the health care system. That doula training transformed experienced interpreters into more capable patient advocates speaks to key differences between the interpreter and doula roles, the latter better described as a community health promoter [41]. As recent work with Afghan and Kurdish refugees suggests, trained Karen doulas may model self-efficacy for, and therefore encourage self-efficacy among, the greater Karen community [42].

When providers perceive Karen women's attitude to be unquestioning agreeability, it may lead providers to underestimate Karen patients' real challenges and questions, preventing Karen women from accessing needed resources. Trained interpreters and doulas from the community may help bridge this communication gap, allowing providers to better partner with/care for their Karen perinatal patients. While this study specifically explored perinatal experience, the communication structure between Karen women, medical providers, and Karen community members certainly extends beyond issues of perinatal health.

Directions for Future Research

Limitations of this study include its relatively small sample size drawn from patients of one Buffalo clinic. Karen patients in cities with smaller Karen communities and from other Buffalo health centers may face different challenges or may perceive the same challenges differently in light of the available support structures, especially with regards to available interpreters. It is possible that our sampling techniques did not capture the most vulnerable women due to their isolation from the clinic or the church. Although we employed one professional Karen interpreter for all interviews, interpretation may have led to subtle miscommunications or to censoring among participants. As described above, member checking using a different interpreter after completion of the data analysis confirmed our interpretations.

While we drew on one co-author's prior observations of Karen patients during medical consultations, future research utilizing direct observation and audio/video recordings of clinical encounters could expose subtle details participants did not notice, value, or recall. Studies of labor and delivery nurses' perspectives on Karen doulas in the delivery room would offer rich insight into intrapartum communication challenges and the doulas' intermediary role. The current study suggests maternity care for Karen refugee women may include community-based doula programs, and focused

future research could inform doula training curricula and health care provider cultural awareness.

New Contributions to the Literature

While there are many studies of immigrant women's perinatal beliefs and experiences, most interview only patients and key informants. By triangulating the views of patients, providers, and doulas/interpreters as only a few other studies have done, our study elucidates a communication structure rather than cataloging preferences [43, 44]. This study adds to a growing body of literature on Karen refugees in general and on Karen perinatal experience in particular [24]. It corroborates prior descriptions of Karen women's apparent agreeability and offers new insight into medical providers' perspectives on caring for Karen patients. Our interviews with Karen doulas further develop the qualitative literature on community-based doulas as advocates for refugee women.

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