

BMJ Open Qualitative research on maternal care access among Arabic-speaking refugee women in the USA: study protocol

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ABSTRACT

Background Refugees tend to have greater health needs and pre-existing medical conditions due to poor living conditions, lack of health services, exposure to a variety of risk factors, and a high level of stress and trauma prior to entry to a host country. Notwithstanding distinctive needs and inherent conditions, there is a paucity of literature on refugee maternal health, especially for Arabic-speaking refugee women resettled in the USA.

Methods and analysis The paper delineates a qualitative study protocol to explore the experiences of Arabic-speaking refugee women in the USA when accessing maternal care. Informed by social cognitive theory, the study will employ two qualitative research methods; in-depth interviews and 'go-along' interviews with Arabic-speaking refugee women. Go-along interview will be used to elicit spatial experiences in situ to explore perceptions of environments among study participants and environmental and structural barriers. 20 refugee women who meet the inclusion criteria will be recruited through snowball sampling with support from community partners. Two researchers will code the transcription and fieldnotes using MAXQDA 2020 (VERBI Software, 2019). The analysis will involve deductive content analysis using a structured categorisation matrix based on the theory while also incorporating inductive codes that may emerge through the process.

Ethics and dissemination The study has been reviewed and approved by the Human Subjects Protection Programme at the University of Arizona (IRB 2104716241). The study results will be condensed in a summary report, which will be shared with community partners, including refugee resettlement agencies and relevant staff at the state department. Also, community feedback will be garnered from the dissemination workshops to inform community discussions for actions and an intervention to address the identified needs.

BACKGROUND

Since the Refugee Act was passed in 1980, more than 3 million refugees have been admitted and resettled in the USA (the Immigration and Nationality Act (INA) stipulates the definition of a refugee as follows: an alien 'who has experienced past persecution or has a well-founded fear of persecution on account of race, religion, nationality, membership in a particular social group, or political opinion.')

Strengths and limitations of this study

- This study operationalises the key constructs of social cognitive theory for qualitative research on refugee maternal health.
- It elicits spatial experiences of refugee women using 'go-along' method and explores the potential of the method.
- Although the application of a theory could provide a useful lens through which sociocultural and physical environments could be better understood, the boundaries on the foci of inquiry could be circumscribed.

Refugees tend to have greater health needs and pre-existing medical conditions due to poor living conditions, lack of health services, exposure to various risk factors such as violence, and a high level of stress and trauma prior to entry to the host country.¹ Refugee women in particular are at greater risk for sexually transmitted infections, gender-based violence and harmful practices such as female genital mutilation due to their experiences before resettlement.²⁻⁴

Despite distinctive needs and conditions inherent in refugee populations, the programmes designed for refugee health promotion in the USA tend to be short term, mostly targeting refugees who have stayed in the country for less than 2 years.^{5 6} One study, in which the majority of participants were refugees residing in the country for more than 5 years, found that the refugees still had limited access to healthcare due to language barriers and lack of insurance.⁷ Other studies also resonate with these findings and provide further evidence of the challenges faced by refugees in accessing health services, including communication barriers, limited knowledge of complicated healthcare systems, inadequate health insurance and difficulty in cultural adjustment.^{1 8-11}

Pregnant women with refugee status in a host country also face challenges in accessing

healthcare, especially maternal healthcare.¹² Several studies found that migrant women, including refugee women, have an increased level of maternity-related risks such as gestational diabetes, stillbirth, infants with low birth weight, early neonatal mortality, prenatal mortality and preterm birth compared with women in the host countries.^{13–15} Although maternal care especially prenatal care provides a unique opportunity to mitigate the risks through screening, diagnosis and treatment,¹⁶ utilisation of prenatal care of refugee women was lowest among migrant women.^{14 17}

Notwithstanding peculiar needs and challenges with regard to experiences of refugee women, there is a paucity of literature on refugee maternal health, especially in the USA.¹⁷ Even when maternal health for the refugee population residing in the USA is investigated, they are aggregated with other migrants even though refugees tend to have worse health outcomes and experiences compared with other migrant populations.¹⁴ Aggregation of heterogeneous migrant groups makes it difficult to identify challenges and health outcomes that are unique to the refugee population and to develop more targeted and nuanced interventions for the refugee population.¹⁴

Arizona has been among the states that have long welcomed refugees, with more than 87 000 refugees resettled in the state since 1981.¹⁸ In the fiscal year 2018, it ranked sixth among all states in terms of the number of resettled refugees. Arab countries, including Iraq, Syria and Somalia, have been among the top ten origin countries for refugees admitted to the USA over the decades. In Arizona, around 40% of refugees resettled over the past decade were from Arab countries such as Iraq (19%), Somalia (12%), Syria (5%), Sudan (2%). Little has been known, however, about access to maternal care of Arabic-speaking refugee women in the state.¹⁹ The study seeks to explore the experiences of Arabic-speaking refugee women resettled in Arizona in order to identify needs, barriers and facilitators related to access to maternal care.

Theoretical framework

In this study, the key constructs of social cognitive theory will be used as a lens to better understand individual and social level facilitators and barriers faced by refugee women as they navigate through the maternal healthcare system in the USA. Key constructs of social cognitive theory include perceived self-efficacy, knowledge, outcome expectation, goals, perceived facilitators and impediments. Based on these individual and social level constructs, the theory provides a theoretical framework to ‘inform, enable, guide and motivate people to adopt habits that promote health.’²⁰

As one of the most widely applied health behaviour theories, the theory has provided a framework for various contexts, including managing chronic diseases, psychological disorders and community health promotion programmes.²¹ The theory has also been used to inform a behavioural intervention for reducing incidence of preterm birth among a minority population²²

and determine the relationships between self-efficacy, one of the key constructs of the theory and psychological distress and subjective well-being among refugee populations.^{23–25} In this study, the key constructs of the theory inform the study design and data analysis.

METHODS AND ANALYSIS

Research procedure

The study will employ two qualitative research methods: in-depth interviews and ‘go-along’ interviews. In-depth interviews will be done with Arabic-speaking refugee women residing in Arizona based on a semistructured interview guide. The first author initially developed the semistructured interview guide based on the key constructs of social cognitive theory²⁰ and operational definitions of the constructs used in other existing literature (table 1).^{26–29} The semistructured questions were then shared with the other authors, were revised, and refined based on the feedback. To ensure that the questions are culturally relevant, they will also be reviewed and tested with community partners, trained Arabic native interpreters and refugee women.

Before interviewing, participants will read the informed consent form, which is translated into Arabic. For those who have difficulty reading, an interpreter would read it to them. Once they agree to participate, the interview will begin. Demographic information such as age, education, years of residency, country of origin and marital status will be collected before the interview. Then, an author will conduct the interview with the assistance of an interpreter following the interview guide. To accommodate the different dialects of Arabic, multiple Arabic speakers will be recruited including a Levantine Arabic speaker, a Somalian Arabic speaker and Iraqi Arabic speaker. The interpreters will go through training on research aims, ethics and interpretation guidelines prior to conducting interviews.³⁰ The interview will be recorded and transcribed verbatim. The interview would last up to one and a half-hour, and participants would be given a small amount of compensation for their participation.

‘Go-along’ interviews, in which informants are accompanied on an outing, would be used to elicit spatial experiences in situ while integrating participant observation and interviewing.³¹ ‘Go-along’ provides a unique opportunity for researchers to explore perceptions of environments among study participants and how they interpret and navigate the physical landscape.³² In the study, the researcher will accompany refugee women to their medical appointment when they get maternal health services. Following the journey from their house to the clinic and observing how they experience and navigate transportation and health systems, the study would be able to glean information that is too implicit and subtle to be captured through ‘sit-down’ interviews.³² It would also help reveal environmental and structural barriers when they navigate the systems in the host country. The ‘go-along’ will use a set of prepared questions with regard

Table 1 Operational definitions and example questions informed by social cognitive theory

Key constructs for social cognitive theory	Operational definition	Example questions
Knowledge	Knowledge about the health risks of pregnancy and benefits concerning maternal care	<ul style="list-style-type: none"> ▶ Do you know how many times you are recommended to visit a health provider during pregnancy? ▶ What would be the benefits of getting maternal care from health care providers? ▶ What would be the risks if you do not get maternal care?
Perceived self-efficacy	Confidence and control in the ability to get maternal care that are formed by previous mastery experiences, vicarious experiences through observational learning, social persuasion and emotional arousal ⁴⁰	<ul style="list-style-type: none"> ▶ When you visited the health facilities for maternal care, what were your overall experiences? ▶ After visiting the clinic, how did you feel about yourself? ▶ Have you seen women from your community (either from your country of origin or other Arab communities) receiving maternal care?
Outcome expectations	Physical, social and self-evaluative outcome expectations of getting maternal care	<ul style="list-style-type: none"> ▶ What would be the outcomes of getting maternal care from health care providers? ▶ What are the perceptions of family and friends or any other people that are close to you concerning maternal care? ▶ How is maternal care different in your country of origin and the United States? Also, are there any differences in perceptions concerning maternal care and its needs between your country of origin and the United States?
Goals	Health goals people set for themselves and the concrete plans and strategies for realising them	<ul style="list-style-type: none"> ▶ What would be health goals for you during your pregnancy? ▶ (If pregnant now and a pre-natal visit is one of her health goals, follow-up questions might include) When is your next appointment with a health provider? How are you going to get there? After the appointment, how are you going to make a follow-up appointment? If you have difficulty communicating, how are you going to address the issue? If you cannot make it to the appointment for some reason, what should you do? Who is going to take care of your children? ▶ (if pregnant in the past) If you were to be pregnant again, when do you think you would make an appointment to visit a health provider? How do you think you will make an appointment? How are you going to get there?
Perceived facilitators	Social or environmental factors that influence access to maternal care positively	<ul style="list-style-type: none"> ▶ What has been helpful for you to get maternal care? <ul style="list-style-type: none"> – Informational support: where do you get information concerning prenatal care, pregnancy, delivery? – Functional support: When you go to a clinic, who takes care of your children? How do you get to the clinic? Who helps you? ▶ If there are pregnant women who do not get maternal care, what would be the reasons, and what could support them?
Impediments	Social or environmental factors that influence access to maternal care negatively	<ul style="list-style-type: none"> ▶ What would be the biggest barriers to getting maternal care? (perceived discrimination, transportation, language barriers, etc.) ▶ What could be done to mitigate the challenges?

to experiences of public transportation, maternal health-care access and utilisation along with impromptu questions using spatial cues. The researcher will accompany refugee women with an interpreter, and the interview will be recorded with consent. Locations, landmarks, names of streets or any other particular things worth noting will be recorded in the fieldnote as recommended by Carpiano.³² During the medical appointment, the

interpreter will interpret for the refugee women. There will be a follow-up interview right after the appointment to glean her experiences based on the interactions with the healthcare provider.

Research team

The research team consists of individuals with multi-cultural and diverse backgrounds. All the authors are

immigrants from Asia, Europe and Africa, having lived experiences of navigating the unfamiliar US health system. SY, the first author, had worked at an international development organisation as an evaluation and research specialist for more than 6 years, and later in her career, she worked as a senior programme officer for Syrian refugee projects. Also, she worked as a caseworker associate at one of the refugee resettlement agencies in the USA. The interactions and experiences working with the population led to the formulation of this research question. PM is specialised in medical anthropology, and PM, HA and AO all have extensive knowledge in global health with experiences working with multiple international development organisations and marginalised communities.

Sample selection, recruitment and size

As there is no sampling frame readily available for Arabic-speaking refugee women and the population is somehow 'hidden and socially connected' with subgroups representing different nationalities, the study will employ snowball sampling and quota sampling with support from community partners including refugee resettlement agencies in the state.³³ Quota would be based on the nationalities of refugees. Study participants will be recruited from the top countries with the highest number of Arabic-speaking populations, such as Somalia, Iraq, Syria, Sudan. Once a participant is interviewed, she would refer another person till the numbers allocated per quota are met.

Inclusion criteria

The study will recruit study participants that meet the following criteria. As the study is focused on the experiences of refugee women, other immigrant populations, including asylum-seekers, will not be eligible for this study given distinctive conditions and characteristics.¹⁴

- ▶ Refugee women who have resettled in Arizona, the USA.
- ▶ Whose mother tongue is Arabic.
- ▶ Who are pregnant or have been pregnant or given birth in the USA at the time of recruitment.

Recruitment

The recruitment process will be twofold. First, one of the refugee resettlement agencies based in Arizona (Phoenix and Tucson), would provide contact information for potentially eligible individuals. They will be contacted first and given information concerning the study via text messages and phone calls. After that, snowball sampling, a recruitment technique in which study participants recommend potential participants, would be used. An electronic version of the recruitment flyer will also be posted on social media venues widely used by refugee populations in Arizona. For those who participate in the in-depth interviews, the researchers will ask whether they are interested in participating in 'go-along' interviews as well. The researchers will reach out to those who agree to

participate and proceed with 'go-along' interviews after making an appointment.

Sample size

A growing body of literature has explored the concept of saturation in qualitative research. The characteristics of samples and the scope of domain often determine the level of saturation.³⁴ One empirical study in relation to saturation found that twelve would suffice when involving a relatively homogeneous population with similar questions on a narrow domain.³⁵ Another study concluded that 16 or fewer would be sufficient when interviewing relatively homogeneous groups.³⁶ As the study involves knowledge, belief, and behaviours concerning maternal health that could be shared by Arabic-speaking refugee women, the study aims to recruit 20 individuals based on the existing literature. However, if new information and themes still emerge after interviewing participants, more participants would be recruited.

Data analysis

Two researchers will qualitatively code the transcribed texts so as to ensure the reliability and consistency of the coded data. Deductive content analysis using a structured categorisation matrix based on social cognitive theory will guide the initial process.³⁷ Then, the researchers will also create inductive codes based on emerging themes that may not be part of research questions or the constructs of the theory. Patterns and themes that may differ depending on ethnicities and countries of origin of the study participants will also be recorded and reported. The codebook structure will follow the recommendation by MacQueen, which entails 'the code, a brief definition, a full definition, guidelines for when to use the code, guidelines for when not to use the code, and examples.'³⁸ The researchers will code full responses and discussions between the researcher and participants that fall under one elicitation as one segment to provide nuanced meaning and preserve the flow and context of the discussion.³⁸ The reviewers will review data and reach a consensus on determining the segments for coding after an initial review of the data. Also, they will see whether the matrix of codes and categorisation based on the theory and research questions is relevant and make revisions as deemed necessary. Once a list of code names is proposed, a more detailed codebook will be devised, including definitions, guidelines and examples. Then, the researchers will code the same two transcribed interviews independently and compare and assess the consistency of application of codes as well as segmentation. If any discrepancy is observed, they would reach a consensus through discussions and code the entire interviews with periodic checks. MAXQDA 2020 (VERBI Software, 2019), a qualitative data analysis software, will be used for data analysis. The results will be reported based on the Consolidated criteria for Reporting Qualitative research.³⁹

Patient and public involvement

The study will engage community partners and study participants in the study process. First of all, community partners will provide insights for culturally relevant interview questions and recruitment strategies. Also, the preliminary findings from in-depth interviews and go-along interviews will be summarised and shared with study participants and community partners, including refugee resettlement agencies and relevant staff at the state department, through dissemination workshops and materials. The study participants will provide input for a preferred method of dissemination, such as a format of materials, a venue for dissemination and a list of invitees for dissemination workshops. The findings will elucidate the health needs among the population and inform community discussions for actions and an intervention to address the needs. The community feedback garnered from the dissemination workshops will be incorporated into the research findings. The findings and lessons learnt will be published and presented at conferences to contribute to the body of knowledge on refugee maternal health in the USA. Also, the results will be epitomised into an executive summary and shared with the refugee resettlement agencies and relevant staff at the state department along with presentations.

ETHICS

The institutional review board has approved the study through the Human Subjects Protection Programme at the University of Arizona, and informed consent would be obtained prior to each interview. Deidentified transcription will be used for analysis. The participants' names will not be recorded anywhere other than the consent form, which would be stored separately. The study participants will be provided some compensation for their time. Although the risks associated with this study are deemed minimal, some women may be subjected to emotional stress as a result of sharing their experiences. Each participant will be assured from the outset that they can stop at any moment if they are uncomfortable, and that they are not obligated to share their experiences if they are distressed. They would also be notified that if they decide to leave the interview in the midst, they will still be rewarded for their time, reducing the possibility that they will feel forced to stay despite their feelings for the sake of compensation.

Contributors The first author SY designed the study, devised the study procedure and drafted the manuscript. PM and HA provided substantial feedback on the overall study procedure. AO provided feedback on the initial concept of the study. All the authors reviewed, provided valuable feedback and approved the manuscript.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

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