

Refugee Barriers to Healthcare and Reproductive Healthcare in America: A Formal Literature Review and Interview Process to Identify Barriers and Potential Technological Solutions

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Executive Summary

Refugees, and refugee women in particular, encounter many barriers to healthcare as they adjust to life in America. However, there remains a dearth of studies specifically surveying barriers to reproductive healthcare for refugee women. We know that refugees suffer from worse health outcomes across high-income countries, and that “migrant and refugee women have a higher chance of maternal death and maternal near-miss events, which gives an indication of the risks faced by refugees in less privileged settings¹.” Additionally, we know that “Refugees are at particular risk for infectious diseases, for physical and psychological trauma, sexual violence, and for insufficient access to healthcare and prevention programs, as well as contraception.²” Looking specifically again at reproductive health, we know that “Multiple studies have confirmed increased rates of adverse pregnancy outcomes in migrants, including reduced fetal growth, caesarean section, stillbirth, maternal depression, and other maternal and perinatal morbidities.³” In order to engage with this information, I worked to conduct a literature review, hold interviews with relevant community members, and used this information to identify barriers to refugee health, refugee reproductive healthcare, and finally, make recommendations to help alleviate some of these barriers. I strove to make recommendations only when a course of action was clear, and thus omitted recommendations for some sections, specifically the section of Barriers to Reproductive Health. I also briefly identified two reproductive healthcare issues that are common and relevant amongst female refugees in America, as well as opportunities for further study.

Barriers:

Through my investigation I determined there to be four major barriers to healthcare for refugees in the United States.

- Language Barriers,
- Logistical Barriers,
- The American Healthcare System, and
- Internal Barriers

Narrowing my search further, I determined the following specific barriers to reproductive healthcare for refugee women.

- Stigma
- Ignorance
- Sacrifice

Recommendations:

I identified the following recommendations to alleviate Language Barriers:

- Ensure information surrounding obtaining a translator is accessible and available for represented languages before, during, and after appointment process.
- Schedule longer appointment times for refugee patients or those with language barriers.
- Ensure that translators are trained in medical vocabulary.

¹ Endler

² Dopfer

³ Ibid.

- Through the use of translation services, ensure true understanding of informed consent; perhaps by asking patient to describe medical situation back to the health professional.
- Ensure labels and paperwork are translated into the appropriate languages with paper pamphlets providing explanations and more information.
- **Medical Terminology Training for Translators and Phone Translators**

I identified the following recommendations to alleviate Logistical Barriers:

- While making appointments, refugee patients should be asked about transportation options to ensure they have a way to get to their appointments as well as potential conflicts with appointments.
- While making appointments, refugee patients should be asked about childcare needs in order to ensure medical providers have a clear understanding of refugee needs and potential conflicts with attending appointments.
- Schedule follow up appointments directly after an appointment, utilizing available translation services.
- **Training for Receptionists**
- **Gather More Information for Intake Records**

I identified the following recommendations to alleviate barriers stemming from the American healthcare system:

- Collect more information about sexual and reproductive healthcare from refugees during the in-take examination
- **Educational Videos**
- **Technology Literacy Classes**

I identified the following recommendations to alleviate internal barriers:

- Longer appointment times for refugee patients
- **Continuing Medical Education for Healthcare Providers**
- **Collection of Patient Trauma History**

I identified the following recommendations to alleviate barriers to reproductive healthcare:

- Ensure female practitioners when possible.
- Continuing Medical Education for providers centered on culturally competent care delivery
- Sexual and reproductive health educational videos created by trusted community members in partnership with medical professionals should be produced in a variety of different languages and with an eye towards cultural sensitivity

Introduction

The United States welcomes around 70,000 refugees from around the world each year through the US Refugee Admissions Program⁴. Immigrants make up 22% of King County's population, and 51% of King County's newest residents are from another country. These immigrants are more likely to have a higher number of workers in their households, less likely to own a home, more likely to earn a lower median income than native King County residents, less likely to have a car, and are more likely to be in poverty (11.1% vs. 6.4%). Between 2003 and 2017, Washington welcomed 32,898 refugees to settle in the state, with the majority (around one third) settling in and around Seattle. King County, since 1984, has been the fifth largest recipient of refugees in the United States⁵. Washington has received the most refugees from Ukraine (5,810), Burma (4,720), and Somalia (4,143), followed by Iraq (3,720), Bhutan (2,736), and Russia (2,434)⁶.

During this literature review I found many actions by refugees were framed as disrespect or a refusal to work within the American system but should actually be interpreted as methods of self-advocacy and declarations of autonomy. My own personal biases, the biases of American views on refugees, and the biases of our healthcare system constantly whisper that refugees (often with no common language, and few shared experiences) are confusing, difficult, and other. They are far away from our understanding of how individuals interact within American systems. This results in a systematic stripping of personhood and power from refugees. To truly work for others, we must be working for freedom of movement, freedom of health, and true autonomy. In short, the idea that any of the struggles that refugees encounter in accessing healthcare should be blamed on a refugee is a harmful and simply wrong mindset. I looked for places where there seemed to be breakdowns in the service delivery of healthcare, and as such have omitted financial barriers to accessing healthcare as financial interventions are mostly outside of the responsibility or ability of most healthcare or medical providers.

Methods & Scope

I conducted a literature review using the University of Washington library's database. I utilized the following search terms to investigate this topic.

- Refugee
- Immigrant
- Asylum Seeker
- Healthcare
- Barriers
- United States
- Reproductive Healthcare
- Women
- Tech
- Technology
- Healthcare Utilization
- mHealth

⁴ Wachter

⁵ REWA

⁶ Balk

Disregarding articles earlier than 1990 and mainly focusing on studies in American, although the lack of formal studies on reproductive health for refugees in America made this difficult. I gathered information and worked to create a holistic picture encompassing a range of studies exploring different aspects of refugee experiences with health and healthcare utilization. I then conducted five separate, in-depth, interviews with relevant community members. Those included Mr. Floribert Mubalama, the Executive Director of the Congolese Integration Network, Dr. Mary Kooehke, a pediatrician at Healthpoint, Dr. Sara Baird, a family medicine specialist at Healthpoint, Tara Lawal, the Executive Director at Rainier Valley Community Clinic, and Yodit Wongelemengist, a translator at Harborview Medical Center and a case manager for refugees.

In my review I surveyed 26 research papers and articles that directly related to refugee experiences with reproductive healthcare and 31 additional sources to achieve a holistic understanding of the issue. The barrier of stigma was identified explicitly in 69% of articles. The barrier of language was identified by 65% of articles. Systems or processes were identified in 53.8% of literature. Lack of resources (which may be explained by the fact that only 42% of articles surveyed were American specific) was identified as a barrier in 65% of papers. Discordant health beliefs and expectations were identified in 42% of the literature, and finally, trauma was identified in 54% of the literature. Only 2% of articles made recommendations targeting refugee behavior, while the other 98% focused on implementations and recommendations for medical professionals. A clear majority, at 69% of literature reviewed, identified education, either for medical professionals or for refugees, as a recommendation.

BARRIERS TO HEALTHCARE

1. Language Barriers

This is at its most basic, purely a problem with not having access to translation services, and at its most elevated, a true breakdown of personal advocacy and voice. This ties in with agency and emancipation at both a social and personal level. Enabling refugee success in many realms begins with ensuring language education for the refugee populations as well as provider commitment to patience and full dignity for the refugee patient. Although many refugees attend English as a Second Language (ESL) classes, as they begin to find employment, refugees often find it too difficult to juggle everything and drop out of these classes. According to Wachter, “Women cited a lack of evening ESL classes and difficulties with transportation, as well as not having enough energy or time, as their primary reasons for dropping out of ESL classes.⁷” In many resources examined for this project, refugees and service providers identified the following issues held within the barrier of language and delivery of service:

- Lack of Translators
- Linguistic Differences between Patient and Translator
- Problems with Informed Consent
- Paperwork and Labels
- Misinformation or Miscommunication

1.1 Lack of Translators

⁷ Wachter

This barrier is a problem that comes logically from a high multi-cultural and multi-lingual demand with no corresponding supply. In small clinics, hospitals, and offices, it is beyond the scope of most service providers' ability to ensure a trained, empathetic, and competent translator for every language that needs to be served. When in person translators cannot be found, many providers turn to phone translation services. The translators available by phone often do not have language equivalencies for many medical terms or the conceptual understanding needed to correctly impart and truly translate between service provider and client. Additionally, although translators may be available at many health facilities, refugees often are not aware of the option to ask for a translator. This points to a breakdown of awareness, perhaps with medical staff, but definitely between the overarching organization and the client. It also serves to point out that available resources do not always equal utilized resources. The responsibility to make options like translators known to clients, as well as easily accessible, rests on the organization's shoulders. In every interview I conducted, my interviewees brought up the issue of language.

Small Recommendation: Ensure information surrounding obtaining a translator is accessible and available for represented languages before, during, and after appointment process.

Additionally, it is recommended to schedule longer appointment times for refugee patients or those with language barriers. This allows for full delivery of care without worry for time lost translating from medical professional to patient.

1.2 Linguistic Differences between Patient and Translator

There are around 170 different languages spoken in King County and this number may be conservative as it may not account for the lingual nuances within ethnic and cultural groups. Even if a translator is present, there may be regional or cultural differences between their language and the language of their client. This further exacerbates the difficulty in communication and true understanding. Many articles reviewed emphasized the need for recruiting translators for local refugee communities in order to both provide appropriate translation services as well as create bridges with the community⁸. In the realm of medicine, sometimes slight linguistic differences can lead to worse health outcomes or further existing feelings of isolation. For example, an academic paper identified an instance of a woman being referred for abortion services when she wanted to continue her pregnancy due to her interpreter being Burmese, while she spoke a linguistic variation due to her being Karen.⁹ Additionally, translators often are not trained on medical vocabulary as well as how to effectively communicate that medical vocabulary to their client.

Small Recommendation: Ensure that translators are trained in medical vocabulary.

1.3 Problems with Informed Consent

Even with translators, or refugees with a working understanding of English, there remains a barrier of comprehension if only because refugees may not fully understand the workings of American Healthcare. A dangerous way this presents itself is with the issue of informed consent. Linguistic understandings as well as cultural understandings can play into this. If you are a

⁸ Aishah

⁹ Kumar

refugee woman about to give birth in a foreign hospital with no shared language, how are you supposed to understand your rights or advocate for yourself? When the American doctor hands you something to sign, you might just sign it without fully understanding what you are agreeing to. Even if it is translated to you, there may not be complete understanding. While American healthcare providers may be sure in the idea that they are doing what is best for their patient, the patient may be tense with ignorance, watching things happen to their body, feeling powerless. At the least harmful, the patient is treated well, with their wishes being honored, but perhaps with less personal interaction than would happen in their home country. At the most harmful, the patient may be ignored, pressured to agree to procedures they do not understand, and may experience great emotional or physical trauma as a result of their autonomy not being honored.

Small Recommendation: Through the use of translation services, ensure true understanding of informed consent; perhaps by asking patient to describe medical situation back to the health professional.

1.4 Paperwork and Labels

Language barriers do not only affect verbal communication or direct communication with healthcare providers. Paperwork and labels on medication can prove to be an extraordinary barrier to refugees accessing healthcare. Language on paperwork and medication can often not have direct or even indirect translations into many languages. Oftentimes, the result is that refugees will not take their medication correctly or at all, because they have not been communicated with adequately. Again, what we are really seeing is an inability to address the autonomy of the refugee. Mostly because of logistical problems, and through no direct action of the healthcare provider, there is a breakdown of communication and understanding between the provider and the client.

Small Recommendation: Ensure labels and paperwork are translated into the appropriate languages with paper pamphlets providing explanations and more information.

Recommendation: Medical Terminology Training for Translators and Phone Translators

In order to effectively communicate medical concepts and terminology to the patient, it is vital that phone translation services work to train their employees on appropriate language and delivery. Many specific Western medical terminologies are exclusive to the English language. This makes it extraordinarily difficult for the translator as well as the medical provider to preserve the original message while translating to the client. It is a real life, sometimes literal, game of telephone, in which the client is always the last in the line. Clients then receive less of the original meaning than the provider may realize. Additionally, the confusion and isolation experienced by the client increases as they work to understand their own health. In order to mitigate this, it is important that in-house translators receive medical terminology training, as well as phone service translators. This will alleviate some of the barriers experienced with informed consent as well as basic patient-doctor communication.

2. Logistical Barriers

These issues are a reflection of a constant tension between individuals and institutional structures. According to a 2016 article released by EthnoMed, the authors establish that “competing demands of distinct services such as: social welfare, education, housing, transportation, public health, mental health, primary care, and specialty care encountered by refugees overwhelm them and tax limited resources¹⁰.” We see these logistical barriers compound as refugees work to situate themselves in their new communities. Even for established refugees, these barriers continue to impede access to healthcare. In the examination of literature, as well as interviews, several logistical barriers were identified including:

- Transportation
- Childcare
- Scheduling

2.1 Transportation

Often limited by availability of case workers or family members with drivers’ licenses and access to a vehicle, transportation goes beyond just getting a ride to healthcare appointments. It also speaks to the relative inaccessibility of public transportation for refugees either because of a lack of information about accessibility, accessibility itself, or financial difficulty, among other reasons. This highlights a critical point about how Americans deal with refugees. The pressure to be self-reliant and independent from an early time is a callous and harsh change for many refugees. To move from a host country with a community or from a refugee camp where often people have been living in community for many years to a strange country alone and to be expected to be self-reliant is a distinctly American challenge and one that native Americans do not necessarily notice. We expect refugees to act as islands when they are used to relying on their family and community members. This is an almost horrific challenge on its own, but when you add in cultural differences and language barriers, something as simple as showing up to a doctor’s appointment can become almost insurmountable.

Small Recommendation: While making appointments, refugee patients should be asked about transportation options to ensure they have a way to get to their appointments as well as potential conflicts with appointments.

2.2 Child Care

While affecting all refugees with children, the burden of this barrier falls heavily on the shoulders of female refugees. Additionally, western ideas of childcare can be extremely different than ideas of childcare in the countries these women are coming from. In many other countries, children are taken care of by the adults in the community. Children are more of a collective responsibility, while in America we often delegate the care of children to individuals¹¹. Furthermore, displaced peoples often have understandable difficulty with the inability to entrust care of their children to a close family member or friend, as they have been moved from their community. Americans are often much more comfortable outsourcing the care of children to complete strangers in the form of daycare, etc. As described in a report, “[Women] reported that, unlike the ease with which they left their children with neighbors in their countries of origin,

¹⁰ Jackson

¹¹ Kumar

leaving a child with a nonfamily member was troublesome, unpredictable, and anxiety producing.¹²”

Small Recommendation: While making appointments, refugee patients should be asked about childcare needs in order to ensure medical providers have a clear understanding of refugee needs and potential conflicts with attending appointments.

2.3 Difficulty with Scheduling

In a new country where you maybe don't speak the language and have few cultural or community supports, the concept of preventative care or follow-up appointments can seem useless and a waste of time. Even if that isn't the case, this kind of care is something that can take the backseat to seemingly more pressing responsibilities like finding full time work, getting a driver's license, enrolling children in school, even just household pressures. Through a conversation with Floribert Mubalama of the Congolese Integration Network, it became apparent that difficulty with communication with receptionists can be a significant barrier for refugees. Although many medical professionals get cultural competency training and training on effectively serving refugees or those with fewer English skills, receptionists do not often receive the same training. After unsuccessful attempts to communicate the need for an appointment and subsequent scheduling of said appointment, refugees often give up on follow-up appointments or referrals to healthcare specialists. A refugee surveyed by Kumar explained that “The most difficult issue is getting an appointment, calling to get an appointment... And when I completed the appointment for my child, for the follow up appointment, I ask to arrange right away. I tell the clinic staff that I don't speak English, so I cannot call to request an appointment.”¹³ This refugee was able to circumvent their difficulty speaking English with the receptionist by scheduling an appointment while still accompanied by their translator. However, with differing health backgrounds, many refugees may not make this same effort, and thus will experience difficulty with scheduling an appointment by phone with no translator, perhaps never managing to make a follow up appointment.

Small Recommendation: Receptionists should receive cultural competency trainings as well as best practices for working with refugees or those who have English as a second language. Receptionists should also strive to schedule follow up appointments directly after an appointment, utilizing available translation services.

Recommendation: Training for Receptionists and Intake Records

While many of the logistical barriers have some sort of local solution, such as communities providing transportation to those without in order to get to appointments, one of the most repeated need, both by refugee organizations as well as medical providers, was the need for receptionist training. Receptionists often are not appropriately trained to handle ESL speakers calls, creating an environment of confusion, frustration, and sometimes even hostility felt by clients. Mr. Mubalama, from the Congolese Integration Network in King County, explained that sometimes members of his organization feel so isolated and experience so much difficulty with making appointments online, that eventually they give up. This has huge implications for the

¹² Wachter

¹³ Kumar

healthcare of refugees. This population struggles with specialized medicine and there is a breakdown between getting a referral to a specialized healthcare provider and making or attending an appointment at a new office. How many of this vulnerable population feel overburdened by making an appointment with a receptionist who cannot understand them? At some point, maybe after the second or third attempt, many refugees give up. It is too much, on top of everything else we ask of them, to ask them to try to communicate in a language they do not speak and make an appointment for something they may not see as a priority.

Besides this training, clinical staff should take a complete history of refugee patients that includes housing security, transportation and childcare needs, food security, and scheduling difficulties. This will enable medical professionals to understand the difficulties patients may have accessing care and stressors that may be influencing patient behavior. It also will assist receptionists understand the complexities of scheduling with this population and assist them in working together with refugees to ensure they are able to attend appointments.

3. The American Healthcare System

The American healthcare system, in many ways, is the structure that all of these barriers stem from. Not only are the systems and processes vastly different from what many refugees are used to, America's healthcare system focuses on the "biomedical practice of preventive medicine and primary health care."¹⁴ This difference of our understanding of health and healthcare creates a conceptual barrier for refugee uptake of healthcare. Additionally, it is well researched that refugees struggle with the lack of long-term targeted and proactive support offered by the American healthcare system¹⁵. It has also been documented that integration of refugee healthcare into mainstream healthcare would ensure greater quality of care for refugees¹⁶. This recommendation is important; however, the scale is outside my research. In lieu of speaking broadly about this system, I have identified a few barriers that were mentioned across the literature and in interviews, specifically:

- Insurance
- Cultural Understandings of Healthcare and Medicine
- In-Take Examination

3.1 Insurance

This is also an example of individuals working within structures. It also highlights the sacrifices and binary choices refugees are often forced to make. Because refugees must obtain full time work with benefits by the time their eight months are up, there is just not enough time or resources allocated to accomplish everything. They often need to make really intense declarations of priorities and make difficult choices because of the limits of our healthcare system. According to a study conducted in Ohio, "[Female refugees] cited not having insurance as the most frequent reason for having to postpone care (81%)...[and] for those with insurance needing to see a specialist (24%) did not have their specialist care approved."¹⁷ According to the same study, "those with public or private insurance were at least two times more likely to seek

¹⁴ Jackson

¹⁵ Thiel de Bocanegra

¹⁶ Ibid.

¹⁷ Banke-Thomas

care, three times more likely to gain entry into the health system, and three times less likely to have difficulty in seeing a primary provider, or experience difficulty in seeing a specialist, compared to those without insurance.¹⁸ Mr. Mubalama spoke to the fact that ensuring economic income and stability, as well as housing security, is often the most essential aspect of entering America. Without a job, refugees lose insurance after their initial eight months in America. Finding a full-time job with benefits after only eight months is often extraordinarily difficult for refugees, and once they have secured this employment, utilizing healthcare opportunities is often last on their list. Additionally, full understanding of what insurance provides is often a barrier. Language as well as a lack of resources and information about the American healthcare system prevents refugees from fully utilizing healthcare opportunities. Dr. Sara Baird at Healthpoint spoke to the fact that insurance coverage and access to specialty care specifically is very difficult for refugees. She indicated that this was due to a lack of knowledge as well as financial barriers preventing specialty evaluations and that she sees a potential for those within her organization to become access points between refugees and specialty care.

3.2 Cultural Understandings of Healthcare and Medicine

In essence, this issue relates to the disconnect between pre-settlement life and post-settlement life for many refugees as well as encountering a new form of healthcare. For many, a reactive healthcare system has been the only one they know, with refugees only receiving care in home countries or camps if they have a serious illness or disease. Then, as refugees come to America they are overwhelmed with new responsibilities and structures. As an article points out, “Based on numerous conversations with patients who express the immediacy of their lives and concerns, and the very uncertain sense that the future is preventable or controllable, it seems that the concept of ‘the future’ and ‘the self’ may appear an unaffordable luxury and somewhat ludicrous¹⁹.” As the article goes on to say, there is a very real disconnect between well-meaning provider concerns and plans for the patient’s health, and the patient’s understandings of their own lives, which is often focused on day-to-day survival. Additionally, many refugees assume that because of the limited healthcare options in refugee camps, that they have built up some immunity to health issues²⁰. Many other pieces of literature identified discordant health beliefs and expectations between patient and provider as a significant barrier to full utilization of reproductive healthcare. This extends to underutilization of healthcare outside of a pregnancy. In a study surveying African immigrant and refugee women in Boston, it was identified that “Somali and Congolese women described seeking reproductive and gynecological care in the context of pregnancy, rather than as part of routine care. Participants expressed that they did not feel that seeking care was warranted without pregnancy as pretext²¹.” This conceptual disconnect results in such health outcomes as refugee populations receiving fewer cancer screenings and other healthcare utilization problems that have very real impacts on health outcomes for this population.

3.3 In-take Examination

The CDC is charged with a medical examination before refugees are allowed to enter communities that focuses mostly on communicable diseases. While this does protect

¹⁸ Ibid.

¹⁹ Jackson

²⁰ Mubalama

²¹ Mehta

communities from the spread of preventable diseases, it also neglects this opportunity to provide care beyond communicable diseases. A refugee who has spent the last ten years of their life in a refugee camp with poor access to healthcare is not necessarily going to value on-going healthcare or value their own health. Additionally, the phenomenon of the healthy immigrant effect, is well-documented and was confirmed in conversation with Floribert Mubalama²². The CDC may see a seemingly healthy refugee who then may experience quickly deteriorating health as their bodies readjust to their new way of living. At this point the American healthcare system could be able to find a way to reach out and effectively provide health care to refugees when they need it the most. I would add that limiting the in-take examination to communicable diseases does an extreme disservice to refugees as it completely ignores the health of the person unless they are a danger to existing American communities. Choosing to focus on the health of the American community, while ignoring the health of the refugee reflects a disturbing prioritization of “American health” over the health of the individual. A case study surveying refugee healthcare intervention suggests that “basic questions on pregnancy or pregnancy intention and contraceptive needs and chronic diseases should be a part of a standard assessment.”²³ By expanding the definition of care given during in-take examinations, integration into local primary care may be more effective and meaningful and the health issues of refugees will be known and thus treatable. This simple change could improve healthcare utilization for refugees in a significant way.

Small Recommendation: Collect more sexual and reproductive healthcare information from refugees during the in-take examination.

Recommendation: Educational Videos and Tech Literacy Classes

The American healthcare system can be daunting and challenging to navigate even for native-born populations. Creating educational videos targeted at refugee populations, in their language, explaining the ins and outs of the healthcare system, could be immensely helpful. Medical providers could even create educational videos for specific health issues like cancer or diabetes, with information about signs of illness and the necessity of preventative care as well as processes for each issue. For example, a culturally sensitive video explaining the risks and dangers of breast cancer could include instructions on conducting self-administered breast examinations and explain the purpose and importance of mammograms and annual exams. There is evidence supporting the efficacy of creative methods of disseminating information, specifically through the combination of storytelling with numbers and factual information.²⁴ There is a lot of space here for creativity and for mindful communication that will foster greater knowledge for refugees, and thus greater utilization of healthcare.

Additionally, funding tech literacy classes for refugee populations would be extremely useful to refugees. According to a study surveying Syrian refugee mothers’ attitudes and behaviors towards STD prevention, they found that “less than half of the mothers (41.5%) identified physicians as the main source of information about STIs²⁵.” The barriers preventing

²² Mubalama

²³ Thiel de Bocanegra

²⁴ Plamadon

²⁵ Al-Maharma

female refugees from accessing information on STDs and STIs can be circumvented in part by access to and use of the internet. Being able to google information about healthcare providers, health issues, or insurance information, would alleviate much of the pressure and stress of healthcare utilization. Instead of having to rely on social workers, relatives, or strangers to obtain information, refugees would be empowered to seek out and process answers on their own. Not only would this help with healthcare utilization, but it would also be a huge boon in terms of employment, housing, education, and even just adjusting to American life. It could facilitate community-building in online spaces and become a real tool to tackling life in America. A study analyzing equitable access to maternal health services in Rwanda identified that when initiatives for promoting maternal health were implemented in union with the strengthening of community relationships there was higher program efficacy as well as community building²⁶. In this way we can see that technology literacy classes are not only useful for learning about computers, but they may also be community building opportunities as refugees come together. The classes alone may work dually to educate and foster relationships, and in teaching computer and internet skills, may introduce women to online communities that may provide many resources. Utilizing technology in any way is an issue of equity. The price of technology (computers, cell phones, internet services) can be extremely prohibitive to this vulnerable population, and the barrier to entry is being technologically literate. There have been positive studies showing the benefits of computer technology in reporting intimate partner violence, as well as computer technology facilitating the dissemination of health information in culturally sensitive ways as well as in many languages²⁷.

4. Internal Barriers

What I am choosing to call Internal Barriers reflect the emotional and psychological barriers that can stem from life as a refugee, or even just in moving to a foreign country. Internal barriers, by their nature, are connected to, or even stem from structural and logistical barriers previously identified. The most important lesson from these barriers is that every refugee is one complete, full, and valuable person with a complex and unique life story and mental and emotional processes. Honoring that fully could potentially be a revolutionary act by a healthcare professional or by a healthcare system. Tara Lawal, the Executive Director of the Rainier Valley Community Clinic, spoke passionately about the necessity of community and connection in working to provide vulnerable groups healthcare. She identified a clinic commitment to working through insurance issues for their patients as one of the ways they are able to holistically serve their community. She also identified their commitment to fully knowing and understanding their patients' histories, values, and goals as a productive and valuable method of ensuring beneficial healthcare interventions. She emphasized that it is the providers' responsibility to ensure the patient understands that they are committed to creating a new way of life together. She spoke of how her organization works to treat every patient with honor, autonomy, and dignity. Infusing these values into the structures of our healthcare system at every level is imperative to accomplish real change in this area²⁸. Additionally, it is crucial that we pay attention to these barriers as they can reveal real structural breakdowns in the system and process of healthcare in America. In no way is this a comprehensive list, only broad trends captured within the literature review and interviews. They are as follows:

²⁶ Tuyisenge

²⁷ El Morr

²⁸ Lawal

- Frustration with Process
- Hesitancy to Receive Care as a Result of Mistreatment or Dismissal by Healthcare Professionals
- Trauma from Relocation, Refugee Camps, or Home Country Inform Attitudes Towards Care

4.1 Frustration with Process

As refugees enter America, often after years in refugee camps, they are greeted with new custom, new languages, and a new healthcare system. Understanding America's healthcare system is often a difficult task, as refugees not only begin to grapple with forms, examinations, appointments, and other practical differences, but also a difference in concept of care. America's healthcare system is focused on profit, and the lack of universal healthcare and the idea that we tie healthcare benefits to employment, is often a difficult and frustrating learning curve.

Additionally, Americans often focus on preventative care, a method of healthcare that is often very different from the refugee's home country or experience in the camp. Mr. Mubalama spoke clearly about this issue, and how navigation through this new healthcare system often results in refugees ceasing treatment or feeling too much frustration to continue utilizing any form of healthcare, including reproductive healthcare²⁹. Additionally, in an interview with Yodit Wongelemengist, an interpreter at Harborview and a case manager for refugees, she spoke of the need for health providers and refugees to meet halfway with each other. She spoke of bridging the gap between patient and provider and the necessity of time as a tool to facilitate this bridge. Time for providers to fully understand patient perspectives, and time for refugees to understand the American healthcare system. She emphasized the importance of time to help with this frustration and to build trust between patient and provider³⁰. Fostering connections between patient and provider have benefits such as "improving sustainability, enhancing collective appreciation for the contributions of different domains of research, enabling context-responsiveness, and enhancing capacity to navigate complexity.³¹" Building inclusion, connectedness, and relationship-centric care into healthcare is "inextricable from practices of mitigating power imbalances.³²" Not only would we see better health outcomes as a result of these connections but this kind of treatment actually enables more autonomy for the patient and greater understanding, while also creating a more equitable and dignified healthcare experience.

Small recommendation: Longer appointment times for refugee patients to allow for translation difficulties as well as relationship building between patient and provider.

4.2 Hesitancy to Receive Care as Result of Mistreatment or Dismissal by Healthcare Professionals

Unfortunately, a great many of the reviewed literature pointed to mistreatment by healthcare professionals as a major barrier for refugees to utilize healthcare. Many refugees reported being dismissed by professionals and thus being dissuaded from returning for care. This is an internal barrier for refugees, but it absolutely stems from bias from healthcare professionals

²⁹ Mubalama

³⁰ Wongelemengist

³¹ Plamadon

³² Ibid.

and our healthcare system overall. This problem is often compounded for refugees seeking reproductive healthcare as they encounter both biases based on their status and on their gender. According to a literature review analyzing the factors that influence the sexual and reproductive health of Muslim women indicates that “the attitudes and skills of healthcare providers sometimes affected Muslim women’s access and use of SRH education and services. Barriers included healthcare provider’s misinformation, lack of skills, judgmental and disrespectful treatment³³.” We see frustration with this mistreatment or dismissal result in refugee behavior such as buying over the counter medication in preference to making doctor’s appointments and getting prescriptions. Even if they go to the doctor and get a prescription, they might not have the understanding for going to a pharmacy or the time, and so it becomes easier in many ways to simply use over the counter medication, sometimes in conjunction with cultural remedies.

4.3 Trauma from Relocation, Refugee Camps, or Home Country Inform Attitudes Toward Care

Refugees often have complex histories involving trauma experienced in their home countries, the refugee camps, or during relocation. For female refugees this often involves sexual trauma related to abuse, rape, exploitation, or trauma related to previous reproductive medical experiences, as well as other trauma, including torture³⁴. This trauma often becomes unspoken in American healthcare situations because of a complex tangle of issues; language barriers, cultural expectations around sharing, or the purpose of healthcare professionals, as well as more commonly associated issues with trauma, like repression of difficult memories, and a desire to move forward in life. According to a three-year study conducted by Refugee and Asylum-Seeking Women (RASW) in London, “the vast majority of women interviewed reported suffering from poor mental health...Overwhelmingly, the women attributed their poor mental health to trauma experienced in their country of origin or during the migration journey, exacerbate by anxiety over their asylum claims, dispersal, and living conditions.³⁵” Although this study was conducted in England, we can see clear similarities in refugees located in America. The hesitancy to share trauma should be understood and compensated for by healthcare professionals. Instead, there are many accounts pointing to a lack of that care and understanding for refugees and how day-to-day life can exacerbate that trauma. Mr. Mubalama spoke of the idea of a “double life” that refugees live once they reach America. The violence they experienced in their home countries or in refugee camps continues to affect them once they have left. He spoke also of the idea that although we can uplift and help refugees once they are here, the continuing violence and disruption in their home countries can continue to re-traumatize refugees³⁶. Healthcare professionals are tasked with understanding the complicated histories for refugees and accommodating those potential traumas in a culturally sensitive way.

Recommendation: Continuing Medical Education for Healthcare Providers, and Collection of Patient History with Trauma

Much of the struggle to utilize healthcare for refugee populations comes from the perceived or real stigma they experience throughout the process of obtaining healthcare. The

³³ Alomair

³⁴ Jackson

³⁵ Craig

³⁶ Mubalama

myths and stereotypes perpetrated by American culture about refugees reach all American people, whether we want to accept that or not. Changing attitudes is just as important as changing structures, and in many cases can happen first. Mandating continuing medical education for healthcare providers who work with refugee populations will do much to change these attitudes. Reminding good hearted people of the challenges and specific trauma or health issues that refugees likely experience will do much to assist healthcare providers in providing the best care that they can. It is simplistic to assume that refugees will be the same kind of patients as those who are not refugees. They have different needs, histories, and cultures. Both cultural education, as well as refugee specific education, is much needed in the healthcare community. A study in Michigan on cultural competency training for 2nd-year medical students found that online, interactive patient simulations mimicking care for an Arab American Muslim patient had potential to improve both knowledge and skills for the student³⁷. Prioritizing continuing medical education is an important step to improving care for refugees and implementing this education into medical school may also increase quality of healthcare for refugees. The frequency and type of this education is variable for every healthcare location, but if an office receives refugee patients, they need to be educated appropriately for the visit in order to provide holistic and responsible care.

Collection of patient history including patient trauma can be a sensitive and difficult task, but in the case of refugees it becomes very important to integrate this information with care provided. If gathering this information proves too strenuous on the patient, medical professionals should proceed with sensitivity to their potential traumatic pasts. A study surveying provider-patient discussions of intimate partner violence during prenatal visits found that prompting from the provider during these visits resulted in 90% of prompted women having a risk discussion with their providers. This is a vast difference from women who were not prompted by their provider, who reported have a risk discussion about 23.6% of the time. From this study we can see that provider prompts and interventions during normal appointments helps providers get more information from their patient, and thus provide more information and sensitive care.³⁸

BARRIERS TO REPRODUCTIVE HEALTHCARE

When we begin to look specifically at barriers to reproductive healthcare, we find much of the same barriers outlined above. Additionally, as was articulated in conversation with Mr. Mubalama, in terms of refugees utilizing reproductive health, women have to make choices. The reality of life as a refugee in America, particularly a new refugee, is that in order to secure employment, housing, education, and healthcare, refugees are often forced into false dichotomies. Forced to choose between going to a doctor's appointment or not miss work, which would endanger their health insurance and source of income altogether. Forced to decide between working a low-skill position, though overqualified, and staying home to care for the children. Mr. Mubalama questioned at one point in the interview "What choice to make when it comes to personal empowerment³⁹?" We must examine fully the barriers that are preventing female refugees to utilize reproductive healthcare, but we also must understand that these

³⁷ Smith

³⁸ Humphreys

³⁹ Mubalama

barriers are systemic. Throughout all this, it is essential to hold foremost the fact that although these women are experiencing difficulties within a system, they are individuals with hopes and dreams, and we must work to ensure their empowerment either through the system or in spite of it. When narrowed in scope to reproductive healthcare, the aforementioned barriers become compounded by stigma, ignorance, and sacrifice. We see the issue of Power dominate this area.

1. Stigma

Stigma amongst refugees seeking reproductive care is complicated and multifaceted. There is often stigma coming from three distinct areas:

- Stigma from family and community,
- Self-stigma, and
- Stigma from healthcare providers.

Starting with stigma from family and community, there are often disparate cultural understandings about obstetric and gynecological care, resulting in female refugees being discouraged, judged, or even restricted from taking advantage of reproductive healthcare, especially in cases of unmarried or young women. “Sexual health services may be seen as culturally inappropriate, thus avoided, particularly within cultures that emphasize the importance of pre-marital virginity. Further, patriarchal values and culturally prescribed gender roles may impact on women’s access to family planning services and sexual health screening[s].⁴⁰” Dr. Mary Koehke, a Healthpoint Pediatrician, explained that there is a misperception amongst some of these communities that any healthcare for reproduction, or in the pelvic area, is explicitly sexual. She identified this misperception as having a great impact on the cultural understandings of reproductive healthcare and thus, utilization⁴¹. Additionally, refugee and immigrant women are at a higher risk for issues such as intimate partner violence, often experiencing it within the context of “language difficulties, confusion over their legal rights, and the overall tress of adaptation to new cultural and social structures.⁴²” Additionally, these women are “especially vulnerable because of poverty, social isolation, disparities in economic and social resources (between the woman and her partner), and immigration status.⁴³” Accessing reproductive healthcare services may cause an escalation in intimate partner violence as a result of this cultural stigma. Intimate partner violence can also result in negative sexual and reproductive health outcomes including “discolored vaginal discharge, burning during urination, unwanted pregnancies, menstrual irregularity, as well as sexual risk taking, and consequentially higher likelihood of HIV infection.⁴⁴” We can see plainly that the cultural stigma and familial reactions and attitudes towards accessing reproductive healthcare can have drastically negative health consequences. Women experiencing pregnancy have higher risks of intimate partner violence, and migrant women who experienced this violence were also “less likely to have up-to-date vaccinations, take folic acid before pregnancy, more likely to commence prenatal care after 3 months gestations and to not use contraceptives after birth. They were also more likely to have a history of miscarriage and report more postpartum pain and increased bleeding. They were also more likely to have inadequate social support and report more depression, anxiety, somatization,

⁴⁰ Ussher

⁴¹ Koehke

⁴² Stockman

⁴³ Ibid

⁴⁴ Ibid

and PTSD on standardized tests.”⁴⁵ The cascading effects of cultural stigma of accessing reproductive healthcare has widespread and negative effects on many areas of the refugee’s well-being.

This stigma can become internalized and this is where we see the issue of self-stigma coming through. Cultural attitudes from home countries can often result in female refugees whose understandings of reproductive healthcare vary drastically from American understandings. This is seen frequently in reproductive healthcare that does not involve pregnancy or childbirth. For many refugee women, contraception, vaginal issues, uterine issues, or problems with menstruation can be seen as not a medical problem, or not worth going to the doctor for. Additionally, many women experience feelings of shame, unworthiness, and disgust stemming from these reproductive health issues. One study indicated that “unmarried women in particular described pressure to not seek gynecologic care and cervical cancer screening specifically for fear it would indicate pre-marital sexual activity.”⁴⁶ Additionally, seeking obstetric or gynecological care proved to be more difficult amongst the groups surveyed (Somali and Congolese women in the Boston area), described as “privacy and the pressure to avoid exposure of female anatomy due to culturally valued sexual modesty.”⁴⁷ In conversation with Mr. Mubalama, it became clear that this internalized stigma is made all the worse by a confusing, different healthcare system. One in which they soon find, they are not represented⁴⁸.

Dr. Mary Koehke, identified that misinformation about reproductive healthcare can sometimes intersect with this stigma, resulting in young women adopting fatalistic attitudes about birth control. She explained that many of the young female refugees and immigrants she saw believed that using birth control meant that they must then act in sexually risky ways. She also identified that many young female refugees saw a single failure, for example a missed oral contraceptive, as reason enough to quit taking the pills altogether. This again speaks to a sense of fatalism. She spoke also about how these young women deal with pressure from social perceptions from their communities, as well as familial cultural attitudes. Dr. Koehke imparted that the behaviors resulting from the misconceptions related quite deeply to mental health. She explained that through the utilization of reproductive healthcare, many of these young female refugees experienced a loss of a sense of self as a result of this stigma. This is just one example of stigma and bias surrounding reproductive care directly impacting patient behavior, patients’ self-understanding, and utilization of medication⁴⁹.

Small Recommendation: Ensure female practitioners when possible.

The stigma that comes from healthcare providers is often centered around cultural misunderstandings on the part of the American healthcare provider. This includes both interpersonal problems with the provider, being dismissed or misdiagnosed, and problems with receptionists and making appointments. Female refugees have reported “feeling ostracized and marginalized by the medical community, in regards to their culture, religion, language barriers,

⁴⁵ Stewart

⁴⁶ Mehta

⁴⁷ Ibid

⁴⁸ Mubalama

⁴⁹ Koehke

and other social factors.⁵⁰” This results in an understandable hesitation to receive reproductive care as well as general utilization of available healthcare. Perhaps sensing the lack of comfort many refugee women have with the discussion of sexual health, healthcare providers may hesitate to provide or explain the full range of reproductive options. A Dutch study found that “GPs...discussed contraceptives significantly less often with refugees (51%) and other migrants (66%) than with native Dutch women (84%).⁵¹” We can see from these results that even competent and well-meaning healthcare professionals may allow internalized assumptions about patient culture to inform their delivery of care.

Small Recommendation: Continuing Medical Education for providers centered on culturally competent care delivery.

2. Ignorance

Ignorance of reproductive health is a large reason why refugee women do not utilize reproductive healthcare as widely as American understandings of health would dictate. According to a study, “Across all cultural groups, participants described themselves as having a lack of knowledge about SRH (Sexual and Reproductive Health).⁵²” For many refugee women, the intake exam is the first experience they have with American healthcare, and in this exam, women are only examined for signs of pregnancy or sexually transmitted diseases or infections. This ignores many important reproductive issues and highlights the CDC’s prerogative of protection of the health of the American public. However, this event works to send a message to refugee women that other issues of female health either should not be discussed or are not important enough to bring up. The lack of understanding stemming from their journeys as refugees as well as a lack of sexual education in their home countries does not disappear as a barrier to reproductive healthcare when they finally reach America. Indeed, this ignorance around their own bodies or around reproductive healthcare in general, is then compounded by the barriers affecting all refugees utilizing healthcare, those outlined above. A study described that “Many participants...showed an interest in receiving information on a range of topics including cervical screening, HPV vaccination, sexually transmissible infections, contraception, painful sex, negotiating sex within their marital relationships, preparing daughters for menarche, menopause and sexuality education.⁵³” Developing a variety of educational materials, as well as creating space for dialogue in medical settings, is very important for this group to allow for a range of literacy, understanding, and cultural ideals. Videos in refugees’ first languages providing sexual and reproductive education allows for any level of literacy and allows for continued access and viewing which may result in better information retention as well as a low-pressure learning environment.

Small Recommendation: Sexual and reproductive health educational videos created by trusted community members in partnership with medical professionals should be produced in a variety of different languages and with an eye towards cultural sensitivity.

3. Sacrifice

⁵⁰ Agbemenu

⁵¹ Raben

⁵² Ussher

⁵³ Ussher

Finally, we reach the barrier of sacrifice. In much of the literature and in interviews, it became clear that many female refugees were sacrificing their personal health for the perceived good of the community or family. Many women undervalue their own personal needs when they are confronted with the often transactional way of American life, preferring to bring their child to school, work their job, or provide care for their family or community, instead of attending an appointment for issues not always obvious. According to a 2017 study, “low prioritization is often placed on sexual health needs due to resettlement challenges.”⁵⁴ Because of this prioritization on employment particularly, refugee women are often taken advantage of by employers who recognize the helplessness and desperation of their employees. As Kumar states, “The push for self-sufficiency within a short time period, and the lack of opportunities for higher paying jobs, often culminates in a situation of desperation for the refugees. The lack of orientation and the dearth of jobs is a combination for exploitation by the employers.”⁵⁵ She goes on to identify that refugees are often underemployed, overworked, and misled about how overtime and benefits work, saying “local employees often take advantage of the refugees’ lack of awareness of labor laws, and their forced linguistic isolation. The employers can engage in practices such as forcing overtime, requiring formal and lengthy procedures for sick leaves, and hiring temporarily without offering health benefits required upon permanent hire.”⁵⁶ In order to retain employment, income, and health benefits, refugees often find themselves in an impossible situation, forced to remain in jobs that are harmful to their health in order to support their family. This leads to a continued necessity for sacrifice for refugees and refugee women. Prioritization of personal health is an issue of privilege, and female refugees often are not privileged enough to access reproductive healthcare services in any significant way.

REPRODUCTIVE HEALTH ISSUES

Female Genital Mutilation: The practice of female genital mutilation is pervasive among the Somali population as well as others. The practice of FGM is entangled with cultural ideals, particularly around virginity⁵⁷. Even though FGM is illegal in the United States, complications and health issues resulting from FGM continue to affect women who have arrived here from other countries. Additionally, the cultural importance of FGM can result in dangerous procedures being done to female children of refugees or immigrants. Refugee women in a study done in Australia indicated that implications of FGM resulted in “infection and pain following the initial procedure, which sometimes led to death. Severe pain or difficulties could be experienced during childbirth, especially for women who were continually being de-infibulated and re-infibulated. Painful menstrual periods were also a major problem for women who had undergone [FGM], as were repeat infections.”⁵⁸ On-going medical attention as well as a continually developing and deepening personal relationship between healthcare provider and client is integral to monitoring complications from FGM as well as preventing future instances of FGM. Medical education for providers is essential to mitigate negative health outcomes related to FGM and prevent continuing practice in the US.

⁵⁴ Ibid

⁵⁵ Kumar

⁵⁶ Kumar

⁵⁷ Ibid

⁵⁸ Ibid

Family Planning: Most refugee women want to space children out between births, however, cultural ideas about the worth of women are often tied to the production of children. An inability, either perceived or real, to conceive and birth children can stigmatize and ostracize refugee women. Finding a middle ground where refugee women are able to make the choices they want to make for their bodies and families and get the medical attention they want is imperative to supplying adequate reproductive healthcare. Additionally, it is essential to understand that family planning for refugee families may look very different than family planning for traditional American families, with an emphasis on having more children. Family planning should not exclusively imply restricting pregnancy. Many refugee women would prefer to space the births of children out, but hesitate, for cultural or religious reasons, to utilize common forms of contraception.⁵⁹ Methods of family planning are clearly desired by refugee women, and it is the responsibility of American providers to work to find a method that is culturally acceptable and personally desirable for each individual woman. For many refugee women, family planning is a complex and dynamic issue, one involving cultural attitudes, personal desires, and many other factors. According to responses gathered in a 2017 study, “Across all cultural groups, there were cultural and relational pressures on women to reproduce and a preference for a male child...For most participants, contraception use was negotiated with husbands and in some cases with parents and in-laws, with family planning taken into consideration only after the first child was born.⁶⁰” As we can see, family planning for refugee populations is often much more complex than American healthcare providers may believe without cultural education. Indeed, this study goes on to identify a “need for service providers working with non-English-speaking migrants and refugees to encourage and support families to use culturally safe approaches to sexual health, including provision of information on sexual health screening and contraception, and to provide SRH education in ways that help address intergenerational conflict.⁶¹” Understanding the complicated factors that go into reproductive decision making for refugee women will aid in the development of more culturally sensitive healthcare practices. For example, an article surveyed recommended that this “critical understanding would frame birth control as temporary assistance in spacing to improve the other children’s development, enhanced health for the next child and improved maternal health, all aspects the women [surveyed] endorsed as important.⁶²”

Limitations

There is a real lack of research on the reproductive health of refugees in America. In my research, I was disappointed by how few studies had been conducted in America, with most studies I surveyed being Australian or European. This points to a broader lack of interest and perhaps accepted ignorance amongst American scholars on this topic. The health outcomes of this population will never improve on an institutional level without direct and comprehensive study.

Opportunities for Further Study

I believe that there is much opportunity for further study on this topic. I believe reproductive health outcomes for this population should be surveyed, as well as more research on the barriers to healthcare utilization, specifically research into the institutional and systemic

⁵⁹ Agbemenu

⁶⁰ Ussher

⁶¹ Ibid

⁶² Ibid

barriers to healthcare. I believe it also would be useful for researchers to compare reproductive health outcomes and barriers to reproductive healthcare amongst similar populations, perhaps Native American populations.

Conclusion

Unfortunately, it feels like our healthcare system often strips marginalized individuals of their agency. It does this by making the system difficult, complex, expensive, and exacting. It does this by lacking a solution to the language barriers – creating unnecessary miscommunication and misunderstanding. This only leads to frustration and conflict for both the patient and the provider. The healthcare system provides few supports for logistical barriers and can be harsh to those who do not do things perfectly. You may be met with anger, frustration, or removal of responsibility to the individual. We do not teach refugees about the system itself. We do not explain to them our understandings of healthcare and medicine. And we do not allow them to substitute or inject their own knowledge. We give refugees 8 months to find full time employment with benefits. That is a daunting request even for native-born, English-speaking individuals. We ignore agency and real healthcare emancipation for refugees because it's easier, because we can get more done in less time, because we do not understand them, because it's less expensive. Because healthcare providers rarely have the resources, external support, or even precedence to provide refugees with equitable and empathetic healthcare services. Anything I suggest will only be a band-aid and not a true solution to the national issue of healthcare, and in a broader sense, to the on-going conflict and trauma due to a forced diaspora from one's home. It is imperative that we continue working for personal empowerment in regards to healthcare and a for a system that truly serves those it is meant to.

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