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Perceptions and behaviors of cervical cancer screening in refugee women

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SCHOOL OF MEDICINE

Thesis

PERCEPTIONS AND BEHAVIORS OF CERVICAL CANCER SCREENING IN REFUGEE WOMEN

by

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B.S., Tufts University, 2015

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PERCEPTIONS AND BEHAVIORS OF CERVICAL CANCER SCREENING IN REFUGEE WOMEN

NEHA SANDEEP

ABSTRACT

Background

Cervical cancer is one of the most common forms of gynecologic cancers both in the United States and worldwide. The morbidity and mortality associated with cervical cancer has decreased significantly with the development of effective screening for cervical cancer.[1] However, refugee women in the United States are often impacted by the disparities in health care and experience increased risk of adverse health outcomes.

Literature Review

Current research finds that refugee women in the United States often receive inadequate sexual and reproductive health services, including Pap smears for cervical cancer screening. This disparity leads to a higher burden of preventable morbidity and mortality. For refugee populations, numerous barriers to access have been identified including language, financial, and cultural barriers. Previous studies have identified that refugee women may have limited experience with preventative health care or confront cultural barriers in accessing sexual and reproductive health services. Further research must be done to study barriers to accessing cervical cancer screening among specific populations of refugee women.

Methods and Intervention

This study proposes to interview Iraqi, Bhutanese, and Somali refugee women in the greater-Boston area in order to better characterize experiences and understanding of cervical cancer screening. Investigators will conduct semi-structured interviews to collect narrative data, which will then be analyzed using qualitative analysis software to identify major themes.

Conclusion

This study will seek to characterize perceptions and experiences of cervical cancer screening services among female refugees in the greater-Boston area. Limitations of this study include lack of generalizability and question-order bias.

Significance

The goal of characterizing barriers to access affecting refugee women in the greater-Boston community is to inform development of more effective public health interventions that will be targeted to the specific needs of local refugee populations. Efforts to increase uptake of cervical cancer screening services could result in decreased morbidity and mortality from cervical cancer for a vulnerable sector of the population.

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LIST OF ABBREVIATIONS

ACOG .... American College of Obstetricians and Gynecologists

ASCCP.................................... American Society for Colposcopy and Cervical Pathology

CDC ....Centers for Disease Control and Prevention

CRIAW ....Canadian Research Institute for the Advancement of Women

DPH... Department of Public Health

FDA..Food and Drug Administration

HPV...Human Papillomavirus

HSIL.. High-Grade Squamous Intraepithelial Lesion

LEEP ....Loop Electrosurgical Excision Procedure

LSIL ....Low-Grade Squamous Intraepithelial Lesion

PCR..Polymerase Chain Reaction

SRH..Sexual and Reproductive Health

STI...Sexually Transmitted Infection

UNHCR.. United Nations High Commissioner for Refugees

USPSTF ....United States Preventive Services Task Force

INTRODUCTION

Background

Cervical cancer is the third most common gynecologic cancer in the United States, and the most common gynecologic cancer in developing nations.[2] In the past, cervical cancer was a common cause of death for women in the United States, but the mortality associated with this disease has decreased significantly with the development and widespread implementation of an effective screening method.[1] Cervical cancer is largely preventable with adequate screening, so many new or fatal cases of cervical cancer are a result of absent or insufficient screening.[2] Cervical cancer screening is performed with the Papanicolaou test (Pap smear), the gold standard in the United States and worldwide.[2] Although overall mortality rates from cervical cancer have declined, women of color and women of low socioeconomic status have a disproportionately high incidence and mortality from cervical cancer in the United States.[3]

Immigrant and refugee populations are one of the most rapidly growing sectors in the United States population, with the foreign-born population increasing from around 10 million individuals in 1980 to about 38 million individuals in 2007.[4] Immigrants and refugees face higher rates of inadequate health insurance, poverty, and low socioeconomic status, and therefore represent a sector of the population at increased risk for adverse health outcomes.[4] Refugee women in the United States often exist at the crossroads of racial and socioeconomic disparities in health care, thus experiencing increased risk for adverse health outcomes. In regards to sexual and reproductive health

(SRH) services, refugee women are a particularly vulnerable population who are at risk for health disparities due to various barriers to accessing health care services.[5]

Statement of the Problem

Cervical cancer is a largely preventable disease for which there are clear, evidence-based screening guidelines.[6] However, refugee women are a sector of the population who receive inadequate sexual and reproductive health services in general, including cervical cancer screening. This disparity in screening leads to a disproportionate burden of preventable cervical cancer morbidity and mortality.

Refugees are defined as individuals who resettle in the United States in order to seek physical safety from harm and persecution, with federal and state laws granting refugees access to health care services and other basic services needed for survival.[7] Despite the services available to newly resettled refugees, primary care and preventive services are underutilized, indicating that there are barriers to access for refugees.[8] These barriers to access have been investigated, however much of the focus of SRH for immigrant and refugee women focuses on prenatal, antenatal, and postnatal care. SRH encompasses much more than just care relating to pregnancy. More knowledge is needed regarding other aspects of SRH among refugee women, including preventive care such as cancer screening. Many of the studies involving refugee health are qualitative which is appropriate when trying to understand the personal beliefs, behaviors, and experiences of a population. Although the existing literature is informative and provides a useful framework for thinking about the health needs of refugee women, it is important to

directly evaluate specific populations as different subgroups of refugee women may have unique health care experiences, perceptions, and needs.

Hypothesis

Barriers to access to cervical cancer screening services for refugee women in the greater Boston area are likely multifactorial, including lack of familiarity with cervical cancer and screening guidelines, language barriers, sociocultural differences, financial barriers, and difficulties navigating the U.S. health care system.

Objectives and specific aims

As the population of the United States grows to encompass more immigrants and refugees, it is imperative for the medical community to tailor their approach to care and develop understanding of the specific health care needs of minority populations. This paper will focus on understanding the health care needs of refugee women, specifically Iraqi, Bhutanese, and Somali refugee women in Massachusetts. The goal of fostering understanding of these populations is to eventually develop targeted interventions that will increase utilization of preventive cervical cancer screening and will decrease morbidity and mortality caused by cervical cancer nationwide. This study will utilize one-on-one, open-ended interviews with Iraqi, Bhutanese, and Somali women, three major ethnic groups of refugees in Massachusetts, in order to identify and categorize perceptions and behaviors regarding cervical cancer screening. Specifically, this study aims to:

1. Identify barriers to accessing cervical cancer screening among Iraqi refugees in Massachusetts.
2. Identify barriers to accessing cervical cancer screening among Bhutanese refugees in Massachusetts.
3. Identify barriers to accessing cervical cancer screening among Somali refugees in Massachusetts.
4. Analyze narratives from refugee women to find common themes regarding perceptions/experiences of cervical cancer screening.

REVIEW OF THE LITERATURE

Overview

Cervical cancer is the second most common cancer affecting women,[9] and the most common gynecologic cancer worldwide.[6] Most early cervical cancers are asymptomatic and can therefore go undiagnosed in the absence of regular screening.[6] The majority of cervical cancer mortality is among women in developing countries, where there may be limited knowledge of or access to adequate cervical cancer screening services.[10] The average age of women diagnosed with cervical cancer is 49 years, which is generally younger than the age of presentation for other gynecologic malignancies such as endometrial or ovarian cancers. Thus, screening must begin earlier in life compared to screening for other malignancies such as breast or colon cancer.[6] The greatest risk factor for developing cervical cancer is the absence of regular screening, which underscores the importance of regular screening. Other risk factors include infection with herpes simplex virus, sexual activity, increased parity, lower educational levels, obesity, and smoking.[6]

Epidemiology of cervical cancer

In the United States, cervical cancer incidence has greatly decreased since the implementation of widespread cancer screening in the 1960s.[11] Within the first decade after implementation of routine screening, there was a significant drop in the incidence of cervical cancer in the United States. (Figure 1)[12] Overall, there has been a 75% reduction in cervical cancer incidence and mortality since implementation of screening programs in

developed countries.[13] However, minority women and women of lower socioeconomic status have the highest incidence rates and mortality rates from cervical cancer. [6] This is thought to be largely due to financial as well as sociocultural barriers to access to screening and subsequent treatment.[6] Although this disease is detectable and preventable, women who are not screened represent most of the cases of death due to cervical cancer.[11]

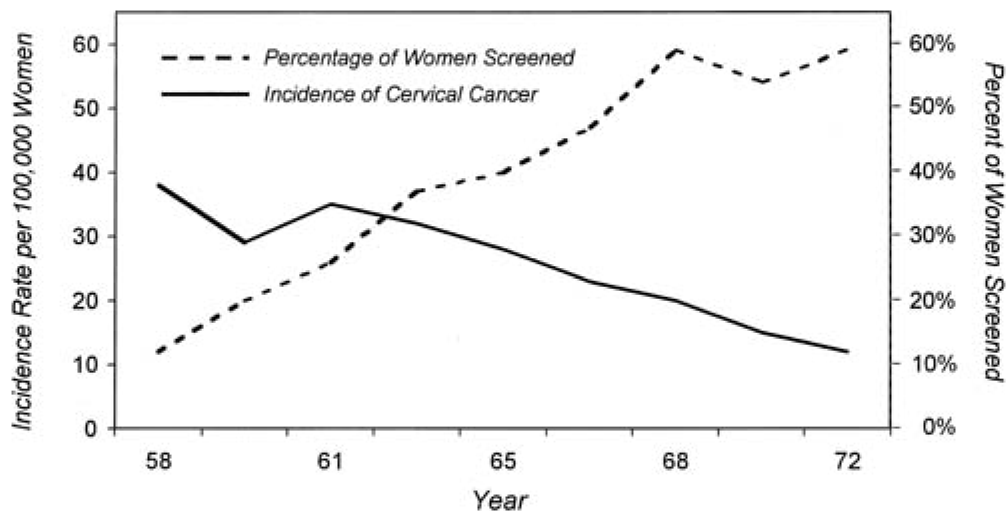

Figure 1: Effect of cervical cancer screening on the incidence of cervical cancer in the United States (Adapted from Wright T, Ferenczy A, Kurman R. *Blaustein's Pathology of the Female Genital Tract*. 5th ed. New York: Springer-Verlag; 2002).[12]

Pathophysiology of cervical cancer

The primary etiology of cervical cancer is infection with high-risk strains of human papillomavirus (HPV), a double-stranded DNA virus that infects epithelial cells of the cervix.[9] HPV is a common virus that many individuals contract throughout their lives, however, most women are able to clear HPV once infected.[14] Over 90% of women who are immunocompetent will clear their HPV infection within 2 years.[13] If not cleared, persistent infections with HPV can lead to cervical dysplasia.[6] Cervical dysplasia is defined as aberrant or disordered growth of the epithelial cells of the cervix.[15] HPV strains 16 and 18 are the most commonly implicated subtypes in causing cervical dysplasia and subsequent cervical cancer, however around 20 high-risk strains exist.[9] Low-risk strains of HPV are associated with genital warts.[15] If HPV infection is persistent, it typically takes years for cervical dysplasia to progress to invasive cervical cancer.[6] HPV infections may be cleared, may persist, or may progress to cervical dysplasia and cervical cancer depending on environmental factors, host genetics, and host immunity (Figure 2).[6]

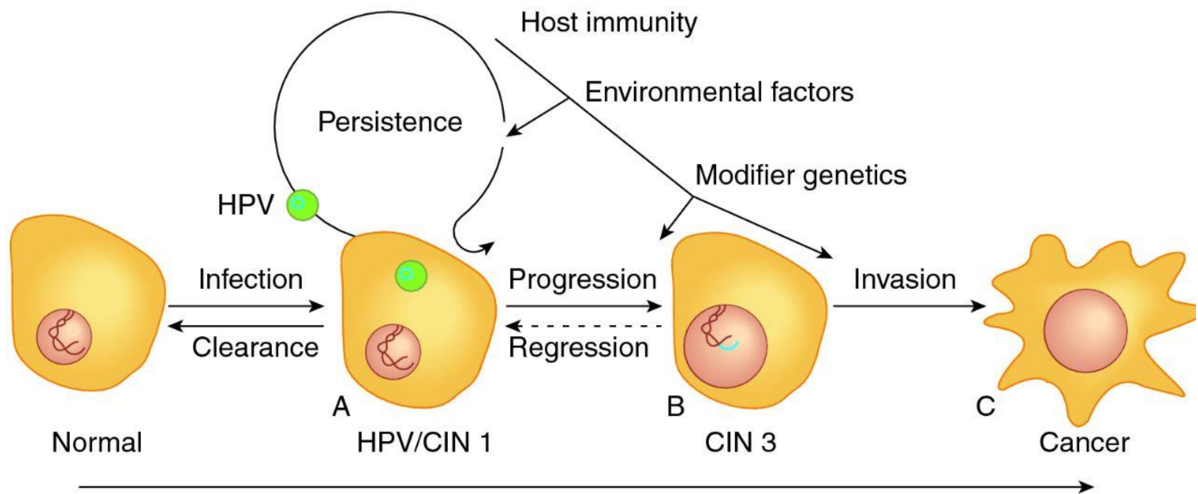

Figure 2: Progression from normal cervical epithelial cell to malignant cell (Adapted from Hoffman BL, Schorge JO, Bradshaw KD, Halvorson LM, Schaffer JI, Corton MM. Cervical Cancer. In: *Williams Gynecology*. 3rd ed. New York, NY: McGraw-Hill Education; 2016. Accessed February 9, 2019).[6]

Histologically, most cervical cancers are squamous cell carcinomas, however some are adenocarcinomas.[9] Both types of cervical cancers typically arise in the transformation zone of the endocervical canal, the junction between the squamous epithelium (ectocervix) and the glandular epithelium (endocervical canal). This transitional area may not be fully visualized during gross examination of the cervix during pelvic exams, posing a challenge to visually assessing for abnormalities concerning for cervical cancer.[9]

Screening for cervical cancer

The Papanicolaou (Pap) smear is the primary screening method for pre-invasive cervical dysplasia[9] and is the gold standard for screening in the United States and other developed countries.[10] Pap smears have a 53- to 80-percent sensitivity for detecting high-grade cervical lesions.[6] However, the dramatic decrease in cervical cancer incidence and death rates in countries that perform broad screening is considered to be sufficiently strong evidence for the Pap smear as an effective screening tool.[9] In some populations, HPV testing by polymerase chain reaction (PCR) is utilized to increase the detection of cervical pathology.[9] It takes years for cervical dysplasia to progress to cervical cancer, so periodic screening is relatively effective in identifying early pre-cancerous cells or pre-invasive cancers.[5]

Although there have been numerous revisions of cervical cancer screening guidelines in recent decades, the U.S. Preventive Services Task Force (USPSTF) as well as the American College of Obstetricians and Gynecologists (ACOG) currently recommend that asymptomatic women of average risk receive Pap smear screening starting at age 21, with subsequent screening every 3 years until age 29 if Pap smear results are normal.[15] The guidelines for women ages 30 to 65 years recommend Pap smear screening with HPV co-testing every 5 years if screening is normal and negative for HPV infection. Women with multiple sexual partners, a history of sexually transmitted infections (STIs), genital warts, or a history of abnormal Pap smears, as well as women on immunosuppressive therapy or women who were exposed to

diethylstilbestrol in utero are currently advised to be screened annually, consistent with previous guidelines.[15] For women who are age 65 years and older, providers may discontinue Pap smear screening if the patient has had at least 3 negative Pap smears consecutively, 2 consecutive negative HPV co-tests within the last 10 years, and provided that the woman is of average risk for cervical cancer.[15] If women are cytologically negative but HPV positive, it is recommended to repeat co-testing at one year or proceed with HPV DNA subtyping.[13] Women who are pregnant are advised to have a screening Pap smear as part of their initial prenatal visit evaluation.[13]

Clinical presentation, diagnosis, and treatment

Cervical cancer typically has a slow course of progression, and is asymptomatic in early stages. Once carcinomas have grown and become invasive, symptoms can include intermenstrual or post-coital vaginal spotting, abnormal vaginal discharge, pelvic pain, and pain with intercourse.[9] As the malignancy grows, vaginal spotting and bleeding typically worsens.[6] The most common objective physical exam finding in women with symptomatic cervical cancer is a visible malignancy on the ectocervix, and such lesions can be biopsied directly.[9]

While the Pap smear is an effective screening test, it cannot be diagnostic for cervical cancer.[15] An abnormal Pap smear merely indicates the need for additional evaluation. HPV testing can also be performed in conjunction with the Pap test to identify infection with high-risk strains of the virus, however presence of a high-risk strain of

HPV is also not diagnostic for cervical cancer.[15] A finding of abnormal cytology indicates a need for further evaluation with a colposcopy, endocervical curettage, cervical biopsy, or a loop electrosurgical excision procedure (LEEP).[15] Colposcopy is a procedure that involves direct visual examination of the cervix using a binocular microscope.[15] Chemical agents are utilized to enhance visualization of abnormal cells during this procedure.[15] This tool allows providers to see areas of dysplasia or other abnormalities on the ectocervix. LEEP is a technique that employs a low-voltage current to excise areas of cervical dysplasia and obtain biopsies of the cervix.[15] Cytologic and histologic specimens are described as either low-grade squamous intraepithelial lesions (LSIL) indicating mild dysplasia or high-grade squamous intraepithelial lesions (HSIL) indicating moderate to severe dysplasia or carcinoma-in-situ .[15] Staging of cervical cancer is based on the level of stromal invasion and extension to adjacent or distant organs (Figure 3).[6]

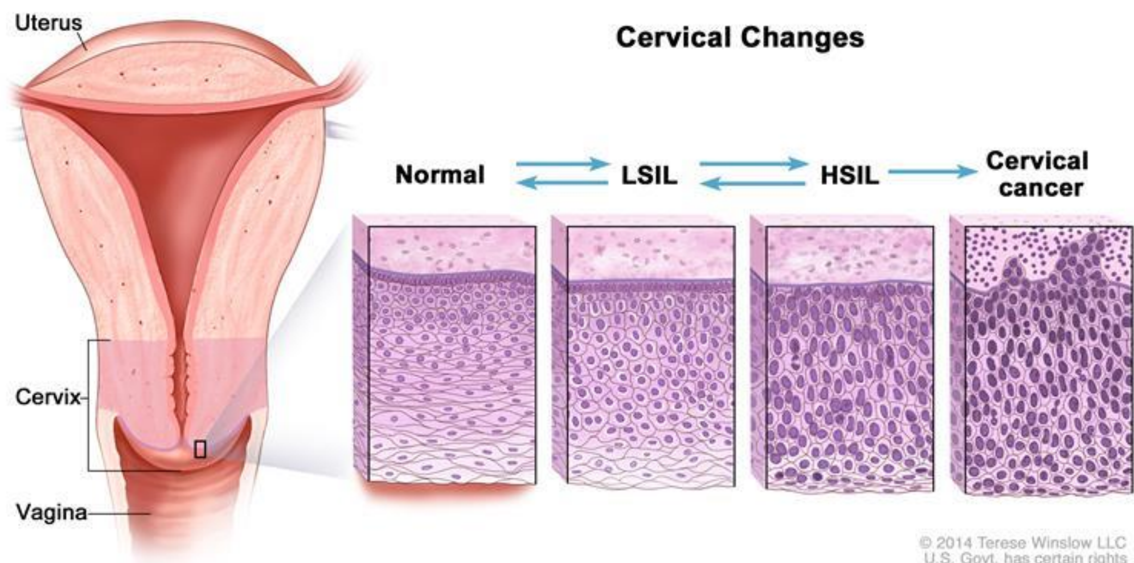

Figure 3: Stages of dysplasia in cervical cancer cells (Adapted from NCI Dictionary of Cancer Terms. National Cancer Institute. https://www.cancer.gov/publications/dictionaries/cancer-terms/def/lsil).[16]

According to the 2013 American Society for Colposcopy and Cervical Pathology (ASCCP) guidelines, when a woman is diagnosed with LSIL with a negative HPV test, expectant management with repeat cervical cytology and possible colposcopy at one year is appropriate.[17] Women with LSIL on cytology with a positive HPV test proceed with colposcopy for further evaluation.[17] All women with cytology results that cannot exclude HSIL or are confirmed HSIL proceed with either colposcopy with endocervical assessment or proceed directly to LEEP.[17] Guidelines for subsequent testing after colposcopy/LEEP and recommendations for evaluation of other findings on cytology are nuanced and will not be detailed in this review.

Treatments for malignant lesions utilizes ablative therapies, if invasive disease has been excluded.[13] Ablative therapies include laser ablation or cryotherapy.[13] If invasive disease has not been excluded, excisional treatment such as LEEP, laser cone excision, and cold knife conization are preferred to allow for further histologic study to determine if treatment has adequately targeted the area of malignancy.[13] Women with extensive or late-stage disease may proceed directly to radical hysterectomy with pelvic lymph node dissection.[6] Adjuvant chemotherapy or radiation therapy may also be considered based on staging and histologic factors of the disease.[6]

Once treated, there is an 80% success rate regardless of which treatment technique is utilized.[13] Most treatment failures are diagnosed within a few years of the initial therapy on subsequent follow-up cytology, cervical sampling, or colposcopy.[13] Treatment goals include reducing symptoms such as spotting and abnormal discharge, preserving fertility, and preventing mortality.[13]

HPV vaccination

HPV vaccines approved by the U.S. Food and Drug Administration (FDA) include Gardasil, a quadrivalent vaccine, Gardasil 9, a nine-valent vaccine, and Cervarix, a bivalent vaccine.[13] These vaccines provide inoculation against multiple strains of HPV, including the high-risk oncogenic strains 16 and 18.[9] The HPV vaccines have been shown to be 93-100% effective in preventing HSIL.[13] Currently, the Centers for Disease Control and Prevention recommend that these vaccines be offered to all children as young as 9 years old and should extend to females until age 26 and males until age 21. Vaccination is a primary prevention strategy can protect women from HPV infection and resulting dysplasia, however there is still benefit from regular Pap smear screening for vaccinated women.[9]

Overview of refugee women's health

The Office of the United Nations High Commissioner for Refugees (UNHCR) defines a refugee as a person who is outside of the country of his or her nationality due to a well-founded fear of being persecuted due to race, religion, nationality, membership of a social or political group, and who is unwilling or unable to return to the country of his or her nationality.[18] Asylum-seekers are defined as individuals who are seeking international protection, but whose claim has not yet been evaluated or decided upon by the host country.[18] According to the UNHCR 2017 Global Report, there are at least 68.5 million forcibly displaced people worldwide, encompassing internally displaced people, refugees, and asylum-seekers. This report states that there were 392,296 refugees and 701,455 asylum-seekers in North America and the Caribbean as of December 2017.[7]

According to the Massachusetts Department of Public Health (DPH), over 12,000 refugees have resettled in Massachusetts between the years of 2011-2016 (Table 1).[19] The largest groups of refugees in Massachusetts during this period have immigrated from Iraq, Bhutan, and Somalia.[20] Resettlement in a new country provides refugees with physically safe living conditions; however, refugees face other challenges relating to the resettlement process. Some of these challenges can include language barriers, acculturation difficulties, social isolation, and mourning of the loss of their native countries and cultures.[21] The Massachusetts Office for Refugees and Immigrants provides services such as case management, up to 8 months of cash assistance, employment

services, health assessments, and 8 months of health insurance coverage for refugees who are ineligible for Medicaid/MassHealth.[22]

Table 1. Refugee Arrivals in Massachusetts by Country of Origin (adapted from Massachusetts DPH, 2016[20] and Massachusetts DPH, 2017.)[19]

	2011	2012	2013	2014	2015	2016	Total:
Iraq	321	645	767	697	383	356	**3,169**
Bhutan	515	517	329	251	178	254	**2,044**
Somalia	141	238	249	332	356	232	**1,548**

Many displaced people suffer from a variety of acute and chronic diseases, which may go undiagnosed or untreated during periods of instability in native countries, during time spent in refugee camps with limited resources, and after resettlement due to barriers in accessing health care in new host countries.[23]

Federal refugee resettlement programs offer aid for refugees upon arrival in the United States.[23] Under the Refugee Act of 1980, the United States government provides medical, financial, and legal support to refugees.[21] Refugees in Massachusetts are universally eligible for health insurance that covers basic medical needs including primary care and preventive services.[24] Refugee Medical Assistance is health insurance that is available to newly-resettled refugees for up to 8 months after arrival, however given the burden of chronic diseases, refugees are still at risk for being inadequately insured and having adverse health outcomes.[21]

In the United States, newly arrived refugees undergo a domestic health assessment after arrival. These intake health assessments are typically focused on diagnosing and treating infectious diseases, and are less likely to focus on diagnosis and management of chronic disease, mental health issues, or on preventative health care.[23] Despite this initial health assessment, refugees experience limited access to health care services due to difficulty navigating the health care system or due to a range of other barriers.[21]

The Canadian Research Institute for the Advancement of Women (CRIAW) has reported that an average of seventy-five percent of displaced people worldwide are women and children.[8] Refugee women are a population that are particularly vulnerable to adverse physical and mental health outcomes relating to displacement and resettlement.[8] Many refugee women migrate from countries with high rates of cervical cancer incidence and mortality, with disparities in access to screening services continuing to persist after resettlement in the United States.[25]

Existing research

Numerous studies have evaluated the particular health care needs and outcomes for refugee and immigrant populations both in the United States and in other developed countries. There is existing research evaluating the sexual and reproductive health of refugee women in the United States, as well as in other host countries around the world. Much of this research has focused on the utilization of prenatal, antenatal, and postnatal care. In 2013, the CDC recommended that all refugee woman receive cervical cancer

screening after settling in the United States, however there are common barriers to accessing care for refugee women. These barriers include lack of knowledge of preventive care or primary care services, language barriers, financial barriers, and cultural barriers.[25]

One article by Lamb and Smith[26] discussed the problems with health care access that refugees experience when settling in developed countries such as Australia. This article noted that refugees are a particularly vulnerable population and may have specific health care needs related to their experiences of conflict, trauma, and forced exile from their home countries. If refugees are fleeing from countries with political instability or conflict, they may have experienced psychological trauma, physical harm, and poor access to health care services. The authors propose that possible barriers to accessing care for newly resettled refugees could include language barriers, financial constraints, limited trust in health care providers, and cultural differences. The authors note that health care providers can attempt to increase refugees' utilization of services through community outreach and educational campaigns, utilizing workers who are familiar with both cultures, and by collocating health care services with other services that refugees commonly use.

A qualitative study by Morris et al.[23] sought to gather information on health issues among refugees in San Diego County in order to assess the health care needs of refugees who had been settled in the U.S. for at least 1 year. To gather a wide variety of perspectives on refugee health issues, this study carried out 40 in-depth interviews with providers, aid organization employees, and recent refugees residing in the U.S. for at

least 1 year. The researchers noted a variety of barriers to accessing health care including language, transportation, logistical, financial barriers and difficulties with acculturation. Acculturation was defined as "the merging and adoption of behavior patterns between cultures as a result of prolonged contact."[23] This study noted that refugees' native cultures had a direct impact on their behaviors regarding preventative health care, expectations of health care in their host country, and stigma surrounding health conditions, particularly mental health conditions. The authors concluded that providers must focus on providing culturally tailored care to refugee populations.

Salman and Resick[8] carried out a qualitative descriptive study to gather data about the health of resettled Iraqi refugee women in the United States in order to inform how to provide culturally competent care to this population of women. They recruited 12 women between the ages of 21 and 67 years old who resettled in the United States after 2003. They conducted individual interviews with the goal of learning about women's description of health as a concept, assessment of their own health status in the context of resettling in the U.S., and their health experiences. Participants described health as a highly valued gift that many attributed to their strong faith and devotion to their religion. Women also described health as the absence of physical symptoms, indicating a potential lack of experience with preventive medicine. Many participants considered safety and security as high priorities and aspects of their overall health. This theme highlights that many refugee women have experienced trauma, violence, war, and instability in their native countries, and how such experiences directly influence their concepts of health and wellbeing. Participants described challenges with utilizing the health care system in the

U.S., and cited inexperience with health insurance, primary care, and navigating a complex and foreign health care system. Finally, participants noted language, cultural, and financial barriers to accessing health care services. Although the sample size of this study was small, the descriptive narratives provide insight into refugee women's experiences with health care.

Fink et al.[5] discussed refugee health through the lens of women's health issues. The authors note that women's health encompasses a broad spectrum of sexual and reproductive health issues. They discussed pre-migratory challenges including limited access to women's health care services in war- or conflict-affected native countries. Migratory stressors include living in refugee camps in which women may experience physical or sexual violence, as well as post-migratory stressors of resettlement, which can include poverty, social isolation, and acculturation challenges. Refugee women may underutilize primary and preventive care services due to lack of these services in native countries or unfamiliarity with the health care system of new host-countries. Regarding pelvic exams, the authors noted that these exams may be stressful or re-traumatizing for women who have histories of sexual violence, physical abuse, or history of female genital circumcision. These exams may also feel culturally inappropriate for refugee women who come from cultures that consider gynecologic exams immodest. The authors stated that same refugee women may have never had access to sexual and reproductive health services, including Pap smears and mammography, in their native countries. They noted that immigrant and refugee women tend to be under-screened in host countries due to

numerous barriers to access including lack of knowledge about cervical cancer and lack of familiarity with preventive care in general.

Haworth et al.[10] carried out a study to assess the knowledge, perceptions, and behaviors of cervical cancer screening among the Bhutanese refugee population in Omaha, Nebraska. The researchers provided 42 participating women with self-administered questionnaires and utilized focus groups to gather information. Women from the Bhutanese community were involved in recruiting participants. The majority of participating women reported resettling in the United States within the previous 2 years. Questionnaires and focus groups sought to determine women's knowledge and perception of cervical cancer, the role of screening, women's susceptibility to cervical cancer, and perceived barriers to screening. The study found that there was a lack of knowledge about cervical cancer and about screening recommendations, with only about 20% of participants having ever heard of Pap smears and even fewer ever undergoing a Pap smear. Women were also noted to have a low perceived susceptibility to cervical cancer. Researchers observed that women were interested in having community health workers who could facilitate cervical cancer educational initiatives. This study determined that some barriers to cervical cancer screening for participants included lack of knowledge, language, transportation, financial concerns, lack of trust in providers, cultural differences, and difficulty navigating the health system. This study also further highlighted that decreased utilization of cervical cancer screening is one clear health disparity affecting this population of refugee women.

Ornelas et al.[25] studied the barriers to cervical cancer screening in 40 Karen-Burmese and Nepali-Bhutanese women aged 21 to 65 years old in the United States. This study noted that refugee women face a myriad of barriers to screening that include limited knowledge of cervical cancer, poor understanding of screening recommendations, cultural barriers to access, and language barriers. Participants in this study noted a lack of understanding of female anatomy, cervical cancer screening and prevention, and lack of familiarity with Pap smears. Participants also mentioned that limited English proficiency, lack of insurance, and difficulties with cost and transportation all affected their ability to access health care services. This study piloted an educational video to promote screening among these refugee groups. Educational videos were narrative-based, featuring multi-generational characters to whom participants could relate, and were culturally tailored by methods such as using appropriate language translation, displaying photos from participants' countries of origin, highlighting native health practices, and playing traditional music from participants' native countries. Participants watched the videos at home with a health educator, and were given a pre-test and post-test evaluation. The authors found that women had increased knowledge of cervical cancer, screening guidelines, and greater intentions to obtain screening. Despite a relatively small sample size and involvement of two specific refugee communities for whom the results may not be generalizable, this study found that culturally sensitive educational materials and outreach from community health workers could increase knowledge and potentially influence behaviors regarding cervical cancer screening.

Piwowarczyk et al. evaluated an educational program entitled the UJAMBO project for Congolese and Somali immigrant and refugee women in Boston, Massachusetts.[27] Participants were invited to attend workshops that involved watching a culturally and linguistically tailored DVD that imparted information about women's health services including mammography, Pap smears, and other relevant services. These women completed self-administered surveys in order to provide pre- and post-test data. Prior to viewing the informational DVD, one-third of the participants reported having a lack of knowledge of Pap smears and other SRH services. Post-test analysis showed that these culturally sensitive education workshops improved knowledge of preventative SRH services and increased women's intentions to receive mammograms and Pap smears. As was noted in this study, women from a variety of ethnocultural groups could potentially benefit from access to culturally tailored information regarding SRH.

Mehta et al. performed a secondary analysis of the UJAMBO program.[28] In this study, the authors noted that immigrant women in general are less likely to have undergone a Pap smear in the last year and less likely to regularly access health care services. This secondary analysis utilized focus groups to evaluate behaviors regarding gynecologic care as well as barriers to access in Congolese and Somali immigrant communities. Thirty-one Somali and Congolese women in six focus groups were interviewed. One theme from these interviews was that Somali and Congolese women typically sought SRH care in the context of pregnancies, consistent with existing research regarding SRH care utilization in other refugee populations. They described a culture of seeking health care when pregnant or unwell, but not when they were asymptomatic or

otherwise well. Women endorsed the sentiment that one should seek health care when negative symptoms such as pain are present. This lack of familiarity with preventative care was seen less among younger participants. Another important theme that arose in these focus groups was that both Congolese and Somali women strongly preferred to receive SRH care from female providers. Women endorsed feelings of shame or discomfort with seeing male providers, as well as a desire to preserve modesty and avoid exposure of their female anatomy. Some women, more commonly Congolese participants, also noted that experiences of sexual violence and trauma played a role in their desire to see female providers. One additional theme that arose from this focus group analysis was the stigma of seeking gynecologic care. Women from all age groups noted concerns that family members, husbands, other community members would criticize women for seeking out gynecologic care. Particularly, unmarried women reported that seeking out gynecologic health care services may imply that a woman was engaging in pre-marital intercourse, which was stated to be culturally taboo. This desire to adhere to cultural norm was noted to be an important sociocultural barrier to seeking care. Mehta et al. succinctly highlight numerous barriers to seeking SRH services among immigrant and refugee women.[28]

Metusela et al.[29] performed a qualitative study examining the SRH experiences among migrant and refugee women who had recently resettled in Sydney, Australia and Vancouver, Canada. Participants were originally from multiple countries including Iraq, Afghanistan, Somalia, Sudan, India, Sri Lanka, and others. Researchers carried out 84 individual interviews as well as 16 focus groups involving an additional 85 participants.

Most of these interviews were conducted with the use of translator services and questioning focused on women's experiences with reproduction, sexuality, and SRH experiences and practices. Thematic analysis of the data from these interviews was used to identify major themes in refugee women's experiences with SRH services. The authors noted that for many refugee women, SRH needs were often lower priorities compared to other needs after resettlement with their main priorities being safety and security for women and their families. The authors mention that SRH topics are considered taboo in more conservative cultures. Patriarchal values in many societies may influence women's desire or ability to seek out SRH services. Lack of knowledge of SRH issues and inadequate utilization of SRH services can lead to a variety of adverse health outcomes for refugee women, including traumatic experiences of menarche, discomfort or pain with intercourse, STIs, undesired pregnancy, and delayed diagnosis of gynecologic malignancies. All of these adverse outcomes would affect women's overall quality of life. Across all cultural groups, women reported a lack of knowledge regarding SRH, including menstruation, fertility, menopause, contraception, STIs, cervical cancer screening, HPV testing, and HPV vaccination. Women described menstruation as being a shameful topic and stated that talking about intercourse was forbidden in their cultures. Women reported stigma around engaging in premarital intercourse, and stated that premarital sexual activity could result in social exclusion. One theme regarding cervical cancer screening was that it was immodest and a threat to a woman's virginity. This study identified many common themes regarding SRH knowledge and practices among a broad range of cultural groups. In this study, it was also noted that many participants showed an

interest in increasing their knowledge of SRH topics. One particular strength of this study was its inclusion of women from numerous cultural and ethnic groups, which allowed for comparison and elucidation of cross-cultural experiences regarding SRH.

Overall, the body of existing research has shown that refugees, in particular refugee women, are at risk of poor utilization of preventive health care services. The reasons for this are multifactorial with commonly identified barriers that include language, financial, sociocultural barriers, and lack of knowledge about SRH guidelines and practices. Refugee women represent a vulnerable sector of the population and there is evidence to support that these women experience significant health disparities in regards to SRH, including cervical cancer screening and gynecologic health outcomes.

METHODS

Study design

This study will be a qualitative study that will utilize open-ended, in-depth interviews with individual Iraqi, Bhutanese, and Somali refugee women from the greater Boston area. This study will seek to define and understand refugee women's knowledge of and experience with cervical cancer screening. Information will be gathered from one-on-one interviews. Interviews will be conducted in English or participants' native languages per participant preference. The goal of this study will be to characterize opinion and experience of cervical cancer screening among these specific refugee populations. Investigators will utilize a grounded theory approach, which is a method of qualitative research that draws theories from a pool of collected narrative data.[30] These theories will aim to better characterize refugee women's experiences with cervical cancer screening and potentially identify barriers to access.

Study population and sampling

Study subjects will be recruited from Boston Medical Center's Refugee Women's Health Clinic. Participants will be assessed based on specific inclusion and exclusion criteria (Table 2.)

Table 2. Inclusion Criteria for Participants.

Inclusion Criteria
▪ Female sex ▪ 21-65 years old ▪ Immigrated to the United States from Iraq, Bhutan, or Somalia within the past 10 years ▪ Applying for asylum or already granted refugee status ▪ Reside in Massachusetts within 30 miles of Boston ▪ Currently seek care at BMC ▪ Able to provide informed consent

If patients meet the defined inclusion criteria, they may be recruited to participate in an in-person interview.

In this qualitative study, the sample size will be based on theoretical saturation, meaning that an adequate sample size is reached when continued data collection no longer provides new or additional themes.[31] For this study, a minimum sample size of 30 participants will be established with the goal of reaching theoretic saturation.

Interview Structure

This qualitative study will consist of one-on-one, open-ended interviews conducted to record information about the study population's knowledge of and experiences with cervical cancer screening. Interviews will be conducted on-site at Boston Medical Center or at participants' homes based on preference and pending interpreter availability. Consent forms will be provided to all participants and interviews will be conducted once consent is obtained. Interviews will be conducted by a trained investigator. In-person

language interpreters will be provided per participant preferences. If no in-person interpreters are available, telephone interpreters may be utilized.

Investigators will utilize a demographic questionnaire to collect participant information including age, nationality, language, education level, socioeconomic status defined by household income, and refugee or asylee status. This information will be placed into a database which will also contain a code to identify participants. Participant interview transcripts will be labeled with only this identifying code to ensure confidentiality.

Investigators will then conduct interviews using a standardized set of questions, however the interviews will be informal and semi-structured; questions will be open-ended to allow participants to provide personalized narratives. As a qualitative study, the goal of these interviews will be to gather a variety of narratives in order to better understand the participant population in regards to knowledge and opinions of cervical cancer screening.

This study's interviews will seek to address the following topics:

a. Understanding of cervical cancer as a disease
b. Knowledge of symptoms of cervical cancer
c. Understanding of HPV as a causative agent of cervical cancer
d. Understanding of methods of transmission of HPV
e. Knowledge of HPV vaccine
f. Past experiences with Pap smears

g. Past experiences with HPV testing

h. Cultural perceptions of cervical cancer screening

i. Barriers to obtaining screening

Recruitment

Study candidates will be continuously recruited from Boston Medical Center's Refugee Women's Health Clinic. All female patients between the ages of 21 and 65 years old who are identified to be of Iraqi, Bhutanese, or Somali nationality and attend the BMC Refugee Women's Health Clinic from January 1, 2020 to June 30, 2020 will be invited to participate. Initial screening for these patients will be done in the form of a printed survey that will ask patients about their age, nationality, and whether or not they relocated to the United States as refugees or asylees. A definition of refugee and asylee status will be provided on this survey. If candidates meet these criteria according to survey responses and indicate a willingness to participate, they will be contacted by investigators by telephone for additional screening. Potential participants will be provided with an overview of the goals of this study. If candidates meet inclusion criteria and provide consent, they will be invited to participate in this study.

Data collection

Investigators and in-person interpreters will conduct interviews with participants for around 60 minutes. Interviews will be recorded and later transcribed with assistance from

interpreters. Information regarding patient demographics such as age, education level, refugee or asylee status, and socioeconomic status will also be collected.

Data analysis

Investigators will analyze this narrative data as it is being collected. Transcripts will be reviewed and coded by investigators. The goal of reviewing transcripts will be to identify themes in participants' knowledge of or opinions regarding cervical cancer and cervical cancer screening. The process of analyzing this qualitative data as it is collected will allow major themes and commonalities to arise. The data will be coded with an inductive analytic approach such that codes and themes will arise from the narratives. Transcripts will be double-coded so multiple researchers will independently assign codes to the data.

ATLAS.ti software will be used for data organization and analysis. ATLAS.ti is a program that allow researchers to code and annotate findings from primary qualitative data. Themes that arise frequently during interviews will be noted and used to guide subsequent interview sessions.

Timeline and resources

Investigators will conduct interviews and complete data collection and analysis. For this study, investigators will require access to BMC's interpreter services and appropriate compensation will be provided to interpreters. Investigators will develop a relationship with providers affiliated with BMC's Refugee Women's Health Clinic in order to facilitate participant recruitment. The recruitment and interview period will occur over

the course of 6 months, from January 1, 2020 to June 30, 2020. Coding and data analysis will occur throughout the interview period and will continue for a three month period from July 1, 2020 to September 30, 2020. Facilities in the Boston University Medical Campus will be required for on-site interviews and ATLAS.ti software will be required for data analysis.

Institutional Review Board

This study will be submitted to the Boston University Medical Campus IRB for expedited review under the 45 CFR 46.102 criteria, given that this proposed study will provide no more than minimal risk to participants.

CONCLUSION

Discussion

The results of this study will evaluate the specific barriers faced by Iraqi, Bhutanese, and Somali refugee women in the greater Boston area. Although there is a wide breadth of literature that examines sexual and reproductive health service uptake among refugee women, further research is needed on specific refugee populations. This study will allow further understanding of barriers to accessing care among major refugee populations within the Boston Medical Center patient population. The qualitative nature of this study will preserve the complexities of participants' experiences while allowing for major themes and commonalities to arise. The results of this study will help to inform future public health initiatives to increase uptake of preventative sexual health services.

Limitations of this study include lack of generalizability and question-order bias. Because this study will focus on three major refugee populations in the greater-Boston area, the findings of this study may not be generalizable to other refugee populations or the greater population in the United States. Because of the small sample size, findings also may not be fully generalizable to the populations included in the study, but will seek to characterize nuances in the data. Additionally, participants will be recruited from a clinical facility and will already have some engagement with the health care system. Therefore, the perceptions of women in this study may not accurately reflect the broader perceptions of women who are not currently engaged with health care services. This study will have question-order bias, as participants' responses to interview questions will likely influence subsequent questions that are posed by the investigator. This is to be

expected in semi-structured, open-ended interviews where the goal is to capture a personal narrative.

Summary

Immigrants and refugees are a rapidly growing sector in the United States population.[4] Female refugees face significant disparities in health care and an increased burden of adverse health outcomes. This is due to numerous barriers to accessing health care services including language, financial, and cultural barriers. Research shows that refugee women tend to have lower rates of utilization of preventative sexual health services in the United States.[5]

Public health campaigns to provide culturally-tailored education to refugee women may help to increase the uptake of cervical cancer screening services among the Boston Medical Center patient population. However, before such campaigns can be designed, it is critical to evaluate refugee women's perceptions and experiences of cervical cancer screening. The findings of this study may inform future development of targeted interventions to increase uptake of preventive cervical cancer screening, which will subsequently decrease cervical cancer morbidity and mortality among refugee women in this community.

The current body of research lacks a clear understanding of the refugee groups who seek care at BMC's Refugee Women's Health Clinic. It is important to gather specific knowledge about the refugee groups that are most prevalent in the greater Boston area. This study aims to utilize interviews with women from three major populations of

refugees in the Boston area in order to develop a broad understanding of this patient population's beliefs and experiences regarding cervical cancer screening and preventative sexual health care. As individual narratives are collected, data will be analyzed for major themes regarding cervical cancer screening. This knowledge will allow for the development of more targeted and personalized interventions to increase cervical cancer screening rates.

Clinical and/or public health significance

Cervical cancer can be fatal if not adequately screened for and treated. Although the morbidity and mortality associated with cervical cancer in the United States has decreased due to comprehensive guidelines for screening and treatments.[1] However, refugee women in the United States are often affected by both racial and socioeconomic disparities in health care, and therefore experience a disproportionate burden of adverse health outcomes. Numerous barriers have been identified that may contribute to this, including language, financial, and cultural barriers.

Studies have demonstrated that migrant women often experience lack of exposure to preventative health care services or cultural taboo surrounding sexual health services, depending on nationality. Increasing uptake of cervical cancer screening and preventative sexual health care will decrease the overall morbidity and mortality due to cervical cancer among refugee women. This study will improve understanding of refugee women's beliefs and experiences of cervical cancer screening, and this knowledge can be used to fuel future campaigns aimed at addressing barriers to cervical cancer screening.

LIST OF JOURNAL ABBREVIATIONS

Abbreviation	Journal
Arch Sex Behav	Archives of Sexual Behavior
Health Educ Behav	Health Education & Behavior
Int J Behav Med	International Journal of Behavioral Medicine
Int J Soc Sci Interdiscip Res	The International Journal of Interdisciplinary Social Sciences
J Community Health	Journal of Community Health
J Environ Public Health	Journal of Environmental and Public Health
J Immigr Minor Health	Journal of Immigrant and Minority Health
Matern Child Health J	Maternal and Child Health Journal
NSW Public Health Bull	New South Wales Public Health Bulletin
Obstet Gynecol	Obstetrics & Gynecology
Public Policy Adm Res	Public Policy and Administration Research

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