

CERVICAL CANCER CONTROL REFUGEE WOMEN

Examining Cervical Cancer Control for Refugee Women Living in the United States

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Dedication

To all of the newcomers. The diversity you bring to our country makes us stronger and infinitely more interesting.

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Doctoral work is a professional and academic endeavor for an individual, but success is not possible without the support of those who guide us through the experience.

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database, her willingness to answer my never-ending questions, her keen eye for editing and formatting, and her unrelenting positivity helped me feel like I was not alone during what could sometimes feel like solitary work. Plus, she always makes our dissemination products a bazillion times better.

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Daniel T. Wilson, MLS, at the UVA Health Sciences Library, has mentored me with numerous projects over the past four years, including the literature search strategy for Chapter 5 of this dissertation. I am grateful for his steady, thoughtful and kind expertise.

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who earned his own PhD at the age of 62. My siblings – Susan, Beth, and Jim – have also been a tremendous support over the years and I’m grateful that we have each other, especially during these years as we have cared for our aging parents, and together grieved the loss of our mother. I’m so grateful that my Mom was able to watch (virtually, by Zoom video call, thanks to the pandemic) my dissertation defense alongside my Dad, the month before she died, and that I was able to hear from both of them how proud they are of this accomplishment.

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Main Results (Chapter 3)

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CHAPTER 1: Introduction

“Why cervical cancer?” I have been asked this by friends and family over the past three years as I have been working on this research. Some have said to me, “I’ve never known anyone diagnosed with cervical cancer.” This unfamiliarity with the problem of cervical cancer is privilege born from living in a country where cervical cancer screening is routine and almost unremarkable, and where those with health insurance and the means to pay are able to receive fast and effective follow-up on their “abnormal Pap” without much more effort than having to schedule a routine appointment with their healthcare provider sooner than they had wanted.

But for women globally, cervical cancer is a big deal. Cervical cancer is the fourth most commonly diagnosed type of cancer worldwide and the fourth most common cause of cancer-related death in women.¹ Even for women born in countries like the United States, disparities exist driven by social determinants of health like education level, access to a usual source of healthcare, access to health insurance, and living in rural areas.²

The World Health Organization (WHO) has stated an ambitious goal to eliminate cervical cancer as a public health problem by 2030. Addressing the problem includes three necessary pillars of cancer control: prevention, screening and treatment.³ This dissertation focuses on the first two pillars: primary prevention through vaccination and secondary prevention through screening. That’s right: *We have a vaccine that prevents cervical cancer.*

The primary risk factor for cervical cancer is undetected and untreated persistent infection with high-risk human papillomavirus (hrHPV), with roughly 70% of cervical cancer cases attributed to hrHPV genotypes 16 and 18.^{1,4} In fact, HPV causes six types of cancer including cervical, vaginal, vulvar, anal, penile and oropharyngeal.⁵ In the United States, a 2-dose schedule of HPV vaccination is recommended before boys and girls turn 15 years old.⁶ It is

estimated that HPV vaccination could prevent more than 33,000 people from getting cancer each year in the United States.

With regard to cervical cancer, the only type of HPV cancer that we have reliable screening measures for, the evidence continues to mount. In 2018, U.S. guidelines were updated to reflect the primacy of HPV as a cause of cervical cancer. For women age 21–65 years old, the current guidelines include the option for hrHPV testing *alone*, every 5 years. The guidelines also carry forward those from 2012, which allowed for cytology every 3 years, and co-testing with cytology plus hrHPV testing every 5 years.⁷ The choice of which option to use is left to the woman and her healthcare provider. (Please note that the 2012 guidelines were in effect at the time this study began and were therefore used for the proposal and analysis in chapters 2 and 3.)

Cancer screening remains important and relevant, even in the midst of a global pandemic. A recent survey of a representative sample of adults ($n=5,412$) in the United States found that 31.5% reported delaying routine medical care because of concerns about COVID-19.⁸ The potential implications of this for cervical cancer control includes a substantial decrease in HPV vaccination uptake, fewer routine screenings, more cases of pre-cancerous or cancerous lesions identified at later stages, and a resulting increase in morbidity and mortality.^{9,10} One of the many public health challenges of this unprecedented time is the need to balance mitigation against the spread of the potentially deadly SARS-CoV-2 virus, while also ensuring that all people, including women, are able to access regular, routine preventative care for cervical cancer and many other common preventable health threats.

Format of the Dissertation

The dissertation follows the three-manuscript option, where chapters 3, 4 and 5 each represent a stand-alone publishable manuscript. Chapter 2 contains the study proposal, which

spells out the three aims of the study. Chapter 3 represents the main results of the secondary data analysis, and addresses aims one and two. Chapter 4 is a descriptive analysis of relevant country of origin policy, which addresses aim three. Finally, Chapter 5, is an integrative review that suggests one potential next step in this program of research. The last chapter presents a synthesis of all of the results and discusses overall strengths and limitations of the dissertation.

The order in which these chapters are presented are not the same order in which they were written. The integrative review found in Chapter 5, which focuses on self-collection of cervicovaginal samples, was written first. Self-collection, also called self-sampling, reflects the leading edge of the science because it has the potential to expand screening for those who may not otherwise be screened. Self-sampling is used for many other things in healthcare, including colon cancer screening, diabetes, and now COVID-19 testing. The work that went into writing Chapter 5 provided much of the necessary background for the work that followed. The original idea for the dissertation research was to conduct a trial of self-sampling at the University of Virginia Medical Center's International Family Medicine Clinic (IFMC). However, we soon realized that we needed to answer a basic question first: What proportion of women who attend the IFMC are up-to-date with current cervical cancer control guidelines? To answer that question first, I took a step back and proposed a study (Chapter 2) that would help us identify the baseline proportion of cervical cancer screening for women who attend the IFMC (Chapter 3).

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CHAPTER 2: Revised Proposal

Abstract

Despite advances in cervical cancer prevention, foreign-born women living in the United States are more than twice as likely to have never been screened for cervical cancer compared to U.S.-born women (18.5% vs. 6.8%, respectively). Refugees are a specific type of foreign-born group in the United States; an estimated 1.6 million female refugees have resettled in the United States since 1975; however, little research has examined factors that may predict cervical cancer screening adherence specifically for refugee populations living in the United States. This formative research will be completed in Charlottesville, Virginia, at the International Family Medicine Clinic, which has an 18-year history of providing interprofessional, culturally sensitive access to preventative care for refugees resettling in the community. Our multidisciplinary team will use a mixed-methods data analysis approach using a social ecological framework to achieve three aims: 1) determine the proportion of women who are up-to-date on cervical cancer screening; 2) examine predictors of cervical cancer screening adherence in the sample; 3) describe cervical cancer control policies and practices for countries of origin of women who resettle in the United States as refugees. The results of this study are expected to inform future research that will test and refine interventions to increase rates of cervical cancer screening for refugee women living in the United States.

Specific Aims

Despite advances in cervical cancer prevention, foreign-born women living in the United States are more than twice as likely to have never been screened for cervical cancer compared to U.S.-born women (18.5% vs. 6.8%).¹ Early detection of precancerous lesions and cancer through cervical screening has reduced mortality specifically because there are effective treatments available.² National data on cervical cancer screening (CCS) uptake show an age-adjusted screening rate of 80.7% for the overall U.S population; however, for foreign-born women who have lived in the United States for less than 10 years, the screening rate is only 66.0%.³ Known barriers to CCS for foreign-born women in the United States include lack of health insurance, lack of access to usual care, and language barriers,⁴ all of which put foreign-born women living in the United States at a disproportionate risk of disease progression compared to U.S.-born women.

Refugees are a specific type of foreign-born person living in the United States. Because of resettlement support, refugees have access to federal health insurance for the first 8 months after arrival, which provides for annual no-cost preventative healthcare.⁵ Refugees who resettle in Charlottesville, Virginia, are connected to a usual source of primary care through a referral by the resettlement agency to the University of Virginia Medical Center's International Family Medicine Clinic (IFMC). Although attendance is voluntary, nearly all (>99%) newly arriving refugees make at least one initial visit in the IFMC. The IFMC has served over 3,800 refugees from 40 countries in its 18-year history. The IFMC model of care is focused on interprofessional collaboration within the clinic, across the health system, and with community partners, and includes care coordination by a registered nurse (RN) and no-cost language interpretation services.⁶

The World Health Organization (WHO) guidance for cervical cancer control (CCC) includes three necessary pillars: prevention, screening and treatment.⁷ Given that the primary risk factor for cervical cancer is undetected and untreated persistent infection with certain genotypes of human papillomavirus (HPV),⁸ primary prevention of cervical cancer is achieved by HPV vaccination. Secondary prevention is achieved through cervical screening.

The broad goal of this program of research is to identify, describe and find ways to mitigate barriers to preventative care for refugees living in the United States in order to reduce health disparities. The major objectives of this study are to identify whether a disparity in CCS exists for these refugee women, to identify factors that are predictive of being up-to-date (UTD) with CCS, and to consider the potential influence of primary and secondary prevention measures utilized in their countries of origin. Using a retrospective cohort of refugee women over the age of 21 who have not had a hysterectomy and have attended the IFMC in Charlottesville in the past 3 years, this study will do the following:

AIM 1: Determine the proportion of women who are UTD on CCS;

AIM 2: Examine predictors of CCS adherence;

AIM 3: Describe CCC policies and practices for countries of origin of women who resettle in the United States as refugees.

The social ecological model (SEM) has been used in cancer control programs generally, and in cervical cancer and HPV research more specifically, as a framework for understanding how multiple layers of dynamic relationships—including individual factors, interpersonal factors, organizational factors, factors within local communities, and national policies embedded within a global context—impact the health of individuals.^{9–19} This framework is useful for thinking about how factors at various levels influence intermediate health outcomes like

adherence with cancer screening, and in the case of modifiable factors, help to identify and inform the kinds of interventions that could be implemented to improve CCS for refugee women living in the United States.²⁰

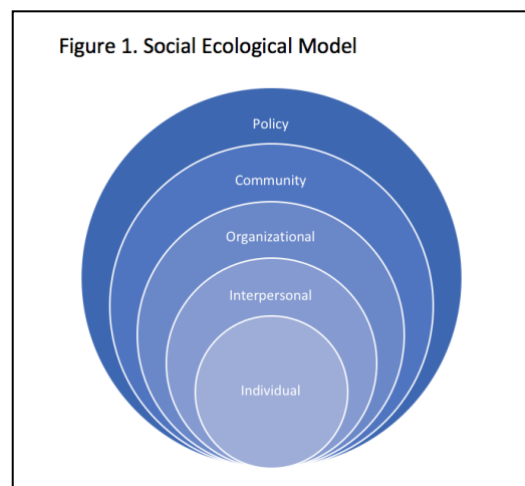
As formative research, the proposed study aligns with the National Institute on Minority Health and Health Disparities' mission of improving minority health and reducing health disparities.²¹ It will inform future studies intended to address national nursing research strategic priorities of promoting health and preventing disease, particularly for minority and underserved populations.²² This study also meets the National Academy of Medicine (formerly called the Institute of Medicine) recommendation that research should focus on diverse sub-populations of the conventionally defined larger racial and ethnic groups.²⁰ There has never been a better time than now for health professionals in the United States to focus on and learn about the unique aspects of caring for diverse groups of people, including foreign-born immigrants and refugees. Given its population estimates, the U.S. Census Bureau projects that by the year 2030 population growth will be driven more by international immigration than by native birth.²³ Recognizing that there are clearly important differences both within and between sub-groups, refugees are a population with a unique set of needs. As healthcare providers, we do not always know what the unique needs are or fully understand how to address them. This study aims to begin filling this knowledge gap. By doing this, we will have a better understanding of which factors predict CCS adherence for refugee women who resettle in the United States, and how country-of-origin policies and practices may influence adherence to CCC measures. We expect this new knowledge to lead to future research that will test and refine clinical interventions that will increase rates of CCS and improve health equity for this diverse group of individuals living in the United States.²⁴

Research Strategy

Significance

Worldwide, cervical cancer is the fourth most commonly diagnosed type of cancer and the fourth most common cause of cancer-related death in women.²⁵ The primary risk factor for cervical cancer is undetected and untreated persistent infection with high-risk human papillomavirus (hrHPV), with roughly 70% of cases attributed to hrHPV genotypes 16 and 18.^{8,25} Early detection of precancerous lesions and cancer through cervical screening has reduced mortality specifically because there are effective treatments available.² For women with cervical cancer, country of origin matters: 90% of cervical cancer deaths occur in developing countries, in part because low availability of screening in these countries means that cervical cancer has a chance to progress to more advanced and more deadly stages before it is identified.^{25,26} Women who are foreign-born and immigrate to the United States are more likely to have never been screened for cervical cancer (18.5%) compared to women who are born in the United States (6.8%), even after adjusting for covariates (including age, marital status, education, and/or country of birth).^{1,27} When women immigrate to countries that have national screening programs, like the United States, there is an opportunity to improve screening rates and thereby reduce mortality.

This study will use the SEM as a framework for data analysis. The SEM (**Figure 1**) has been used in cancer control programs as a framework for thinking about how multiple layers of dynamic relationships—including individual factors,



interpersonal factors, organizational factors, factors within local communities, and national policies embedded within a global context—impact the health of individuals.^{9–19} Foreign-born women in the United States continue to face barriers to cancer screening, including individual factors (e.g., lack of knowledge, fear of embarrassment, fear of pain, or fear of positive diagnosis); interpersonal factors (e.g., lack of provider recommendation, provider gender, provider insensitivity to culture or religious beliefs); organizational factors (e.g., lack of interpreters); community factors (e.g., limited access to healthcare); and policy factors (e.g., availability of health insurance, type of national screening program—opportunistic vs. registry based and national screening program coverage).⁴ This puts foreign-born women living in the United States at a disproportionate risk of cervical cancer disease progression compared to U.S.-born women.

Refugees are a specific type of foreign-born person in the United States; their legal status is defined by the United Nations High Commissioner for Refugees (UNHCR) as any person who has been forced to flee their country because of persecution, war or violence for reasons of race, religion, nationality, political opinion or membership in a particular social group.²⁸ Women who have arrived in the United States as refugees often come from less developed countries, where cervical cancer results in the death of nearly a quarter of a million women per year.²⁵ Since 1975, the United States has resettled over 3.3 million refugees, with an estimated 50% of these being women.²⁹ However, because the scant data available on U.S. refugee resettlement focuses on self-sufficiency and integration and does not track any health indicators, more research is needed to investigate the magnitude of this problem for refugee women, all of whom would be at risk of developing the preventable and treatable disease of cervical cancer.^{30,31} Limited research has

examined factors associated with CCS for refugee populations in the United States; this proposed study seeks to fill that gap.

Innovation

The proposed study will be innovative in two ways: 1) This study proposes an innovative method of determining the binary outcome variable of interest based on actual laboratory results obtained from electronic medical records (EMR) (Aim 1). 2) While there have been a few studies looking at CCS adherence in refugee women in the United States, this study considers policy-level factors from the woman's country of origin as important variables in a way that other studies to date have not, as far as we are aware (Aim 3).

Approach

Overall design. This study will use a secondary data analysis approach to achieve three aims: 1) determine the proportion of women who are UTD on CCS; 2) examine predictors of CCS adherence; and 3) describe CCC policies and practices for countries of origin of women who resettle in the United States as refugees.

Study setting. The setting for this study is the IFMC, a primary care clinic that is located in Charlottesville, Virginia, a municipal area with a population of approximately 150,000 people. The IFMC is physically located within the University of Virginia Medical Center's Family Medicine Clinic and is open to all residents who live in the surrounding catchment area. The area is home to a federal refugee resettlement agency that is responsible for aiding individuals and families who come to the United States under refugee status. Until recently, approximately 200 new refugees per year have resettled in the area. Refugees who resettle here are all connected to a usual source of primary care at the IFMC through a referral by the resettlement agency. Since 2002, the IFMC has registered over 3,800 new refugee and international patients from over 40

countries. To give a sense of the diversity of the patient population, the ten most common languages spoken by patients of the IFMC include Nepali, Arabic, Burmese, Dari, Karen, Swahili, Russian, Farsi, Mai-Mai (Somali) and Turkish.³²

As part of federal resettlement support, refugees reside in the United States under a legal status and initially receive 8 months of public health insurance (Medicaid). Also, of note, as a state teaching hospital, the university medical center has an indigent care program, which allows individuals and families whose gross household income is less than 200% of the federal poverty level (based on family size) to obtain free or discounted healthcare, regardless of their insurance status. In this way, patients who have established care at this clinic *may* have overcome at least two common barriers to care: (a) having access to a primary care provider at a clinic, and (b) being able to afford care either because they have private or public health insurance or because they qualify for free or reduced cost care through the state's indigent care program.

The IFMC consists of an interprofessional team of care providers—including physicians (residents and medical school faculty), Nurse Practitioners, a Registered Nurse Care Coordinator, a Clinical Pharmacist, a Social Worker, and other administrative support staff—who each receive training and mentorship in the culturally competent care of refugee patients.⁶ This includes training on how to perform a standardized initial clinic visit, during which providers collect medical and social history using a semi-structured interview guide and record their findings in the patient's EMR. These interviews are conducted in the patient's native language using interpreters. For all languages spoken by patients in the IFMC, no-cost, professional medical language interpretation is readily accessible by either pre-scheduled in-person interpreters, or over-the-phone interpreters who are available 24 hours a day/7 days a week. Data collected during this initial visit is stored in a University of Virginia Institutional Review Board-approved

(IRB HSR # 17539) database used by the IFMC (hereinafter referred to as the “IFMC database”), which allows for the identification of individuals who meet the main inclusion criteria for this study, that is, women who have arrived in the United States as refugees.

Sample for Aims 1 and 2

The data for this study were collected for women who have arrived in the United States as refugees, age 21 and older, who had been seen by a provider in the IFMC in the past 3 years. The clinic considers patients who have been seen in the past 3

Table 1. *Study eligibility criteria*

Study Inclusion
Women who arrived as refugees
Ages ≥ 21
Attended IFMC in past 3 years
Study Exclusion
Hx of hysterectomy ($n = 25$)
Deceased at time of chart review

years to be current patients of the practice (dates of last IFMC visit for the sample ranged from March 23, 2015 to March 20, 2018). **Table 1** summarizes the inclusion and exclusion criteria for the sample. An initial list of 606 potentially eligible cases was pulled from the IFMC database.

After a review of all 606 charts, cases were excluded if they were foreign-born but had not arrived under refugee status, or if they were deceased at the time of chart review. While a total of 550 women met all initial inclusion criteria, an additional 25 women were excluded due to hysterectomy, leaving a total sample size of 525 for this study’s secondary data analysis.

Preliminary descriptive statistics for the sample ($n=525$) are found in **Table 2**. The mean age of women in the study sample is 41.2 years (range 21–89). Mean number of years living in the United States is 6.1 (range <1 year–20.5 years).

Sample for Aim 3

The top ten most frequent countries of origin in our study sample, and the top 10 most frequent countries of origin for individuals resettling in the United States as refugees in Fiscal

Year 2019³³ will be considered. We will also consider four specific countries of origin as examples on each extreme end of the spectrum of CCC.

Measures for Aim 1

The objective of Aim 1 includes determining the primary outcome of interest (the dependent variable) for the study; that

Table 2. Descriptive Statistics

	Mean	Min	Max
Age	41.2	21	89
Years in U.S.	6.1	<1	20.5
Countries of Origin (Top 10 of 31)	Frequency	%	Cum. %
Afghanistan	130	24.8	24.8
Bhutan	109	20.8	45.6
Iraq	73	13.9	59.5
Congo	35	6.7	66.2
Burma	33	6.3	72.5
Nepal	20	3.8	76.3
Syria	18	3.4	79.7
Colombia	11	2.1	81.8
Iran	9	1.7	83.5
Russia	9	1.7	85.2
Primary Languages (Top 10 of 40)	Frequency	%	Cum. %
Nepali	129	24.6	24.6
Arabic	94	17.9	42.5
Dari	74	14.1	56.6
English	34	6.5	63.1
Farsi (Persian)	27	5.1	68.2
Swahili	25	4.8	73
Pashto	20	3.8	76.8
Burmese	16	3.1	79.9
Russian	16	3.1	83
Karen	13	2.5	85.5

is, whether or not each woman is UTD on CCS. For this study, being UTD means that women who are age-eligible for CCS have received screening within the recommended time interval, as of a given point in time—in this case, as of the study’s Institutional Review Board (IRB) approval date.³⁴ Being UTD is a binary outcome (either YES [1] or NO [0]), which is determined based on the 2012 U.S. Preventative Services Task Force (USPSTF) guidelines for CCS (**Table 3**), which were current as of the study’s IRB approval date.³⁵ Specifically, the guidelines recommended that for women age 21 and older screening should be completed with cytology (meaning identification of abnormal cervical cells using a microscope, called “Pap testing”) every 3

Table 3. 2012 USPSTF CCS

Age Group	Test(s)	Interval
21 - 65	Cytology (Pap)	3 years
30 - 65	Pap + HPV	5 years

years, or for women age 30–65 the option to extend their screening interval to every 5 years if screened using a combination of cytology plus HPV genotype testing (called “co-testing”). HPV testing is now recommended as part of CCS because certain high-risk types of HPV are a known cause of cervical cancer.³⁶ In Epic, the EMR software system being used at the IFMC, there is no single data field that would provide the answer to this specific question. Therefore, in order to determine the study’s dependent variable, raw data was collected from the EMR of each woman including date of birth, date of last cervical cancer screening, and the type(s) and result(s) of the last screening test(s).

Data Analysis for Aim 1

While the raw data was being collected from each woman’s EMR, a preliminary decision was made by the researcher about whether the woman was UTD as of the date of the study’s IRB approval—and the preliminary decision (yes/no) was put in a new column “Researcher Decision.” However, to ensure validity and reliability, Aim 1 relies on a series of indicator variables, equations, and “if, then, else” expressions using Microsoft Excel to test and confirm the researcher’s decision, and determine the final binary outcome variable. These precise steps (illustrated in **Appendix B, Figure 2A** and **Figure 2B**) are used:

- 1) Date of birth is used to determine the woman’s **age** as of the IRB study approval date.
See Figure 2B, columns A and G.
- 2) Then three indicator variables were created that allowed a simple **count of negative (i.e., normal) tests** (cytology and/or HPV testing) for each woman at her last CCS, if any. See Figure 2B, columns H, I and J.
- 3) Then a logical if-then-else expression uses age and the number of negative tests to indicate which **screening interval** applied to each woman (See Figure 2A and 2B,

variable/column K). If the woman had one or two negative tests, there will be a straightforward screening interval result of either 3 years or 5 years. And, if not, for example, if there were no test results (i.e., no screening had been completed) or if one of the test results was abnormal, there would be an indicator value of [-1] alerting to the need for deeper review of the individual case.

- 4) Then, a calculation is made of how much **time passed since the date of the last screening** as of the study IRB approval date (converted to years). See Figure 2B, column M.
- 5) Next, the **number of years since last screening is compared to the calculated recommended screening interval**. If years since last screening is greater than the screening interval, or if there is no last CCS date, then NO [0]—she is not UTD. Otherwise, YES [1], she is UTD.

Women with abnormal screening results may require follow-up testing and shortened screening intervals.³⁶ We accounted for this by reviewing each case with an abnormal screening result (any result other than negative or normal), referencing the American College of Obstetricians and Gynecologists follow-up guidelines³⁷ to determine the recommended screening interval, inputting this screening interval into the spreadsheet manually (see Figure 2B, column L), then comparing the recommended interval to the time since last screened, and allowing Excel to calculate the final binary outcome variable.

Figures 2A and 2B show the steps, along with the equations and logical if-then-else expressions, used to determine the outcome variable, satisfying Aim 1. Note Figure 2B column O—here, a calculated if-then-else expression alerts the researcher to any case where the preliminary Researcher Decision did not match the Calculated Decision about UTD status. In

any case where there was a mismatch (coded as [1]), the researcher investigated the case to determine why a mismatch existed. As an example, in Figure 2B, for case ID # Z629, the reason for the mismatch was that the cervical sample sent to the lab for Pap testing was insufficient or unsatisfactory and the test was not completed.

While it is typically not best practice to have subsequent specific aims depend on earlier ones in a research study, in this case, because the outcome of interest was not readily available in the EMR, Aim 1 is a required first step for subsequent analysis. Because we have completed thorough, preliminary validity and accuracy testing of the methods described for Aim 1, we have a high level of confidence in successfully completing Aim 1 as a necessary stepping-stone to the analysis for Aim 2. As shown in Figure 2B, Microsoft Excel will be used to finalize the results of Aim 1.

Measures for Aim 2

The goal of Aim 2 is to identify predictors (independent variables) of CCS for the sample. The independent variables 1–15 (shown in **Table 4**) were collected directly from the EMR, stored in the IFMC database and were included in the data file when the potential eligible cases were identified.

When the EMR was reviewed for inclusion eligibility and data collection for Aim 1, if data was missing from the IFMC database, an additional systematic search to fill in missing independent variable data was completed. Variables 1–6 are collected at the time of registration for all patients who attend the university medical center. Data fields for variables 1–6 are selected by using a drop-down menu of pre-determined categories.

Regarding race and ethnicity data, exploratory data analysis revealed that 52% of the sample had a race category marked as “Other” in the EMR. In this diverse sample of individuals,

the fact that over half would have a non-specific racial category used to identify them, calls into question either the usefulness and legitimacy of U.S.-based race categories for foreign-born individuals living in the United States, or perhaps even how the race category was selected and entered into the EMR for these individuals. Because of this, race and ethnicity variables will be

Table 4. Operationalization of Independent Variables with Corresponding Social-Ecological Level of Influence

Raw Data Variable Name	Variable Type	SEM Level of Influence				
		Ind	IP	Com	Org	Pol
1. Age	Continuous	•	•	•	•	•
2. Race	Categorical	•	•	•	•	•
3. Ethnicity	Categorical	•	•	•	•	•
4. Marital Status	Categorical	•	•	•		
5. Religion	Categorical	•	•	•		
6. Primary language	Categorical	•	•	•	•	
7. Country of origin	Categorical			•		•
8. Country of exit	Categorical			•		•
9. Date of arrival in the U.S.	Date					
10. Ability to speak English	Binary	•	•	•	•	•
11. Literate in primary language	Binary	•	•	•	•	•
12. Years of education	Ordinal	•	•	•		•
13. Number of children	Continuous	•	•		•	
14. Years lived in a refugee camp	Continuous	•		•		•
15. History of trauma	Qualitative	•	•	•		
New Variable Name						
16. Age at time of arrival in U.S.	Continuous	•				
17. Years lived in U.S.	Continuous	•	•			•
18. Years lived in U.S.	Categorical (4 levels)	•	•			
19. Percentage of lifetime lived in U.S.	Categorical (+/-25%)	•	•			
20. Completed secondary school	Binary	•	•	•		•
21. Education	Categorical (2 levels)	•	•	•		•
22. One or more children	Binary	•	•		•	
23. Ever lived in refugee camp	Binary	•		•		•
24. Experience of trauma	Categorical (3 levels)	•	•	•		
<i>Note.</i> SEM = Social Ecological Model. Ind = Individual; IP = Interpersonal; Com = Community; Org = Organizational; Pol = Policy						

excluded from statistical analysis for this sample. Additional discussion of this issue is included in **Appendix A**.

Variables 7–15 comprise the IFMC database and are collected by a healthcare provider during the refugee patient's visit to the IFMC using a semi-structured interview guide. Most commonly, this semi-structured interview takes place during the patient's first visit to the IFMC when additional time is allotted to getting to know the patient, and the information is updated as

needed. It is important to note that these data rely primarily on patient self-report. Variables 7–15 allow free-text entry—these were cleaned and recoded into categorical variables and are available in the data set in both the original and recoded form. In addition to raw data variables, new variables have been created. For example, variables 16–19 were created by taking the participant’s age and date of arrival in the United States to determine age at time of arrival, total number of years lived in the United States and percentage of lifetime lived in the United States. The IFMC database provides rich detail because providers will often complete free-text data fields with verbatim accounts from the patient; therefore, the data set also includes qualitative data for participants who were not UTD with CCS if there was evidence in the EMR that a conversation between provider and patient had occurred and the provider made notes in the chart about why the patient declined or deferred the screening.

Data Analysis for Aim 2

Descriptive statistics will be used to summarize the sample. Bivariate relationships between independent variables and the outcome of interest will be examined using t-tests for

Table 5: Proposed Logistic Regression Models

	Model 1	Model 2	Model 3
Variables that apply to all women			
Age	•	•	•
Ever married	•	•	•
Religion	•	•	•
Literacy in native language	•	•	•
Years of education	•	•	•
Having at least one child	•	•	•
Variables that apply to all immigrant women			
Age at time of arrival in U.S.		•	•
Years lived in U.S.		•	•
Percentage of lifetime lived in U.S.		•	•
Speaks English		•	•
Variables that apply only to refugee women			
Ever lived in a refugee camp			•
History of trauma			•

continuous variables and chi-square statistic for categorical variables. Multivariate logistic regression models will be fitted (**Table 5**). The first model will include independent variables that would be applicable to *any* woman; the second model will add variables that would apply to all *immigrant* women; the third model will add variables that apply only to *refugee* women.

Robust standard errors will be used. The data will be assessed for missing values, and any missing data will be explored to look for patterns. For data that is either *missing completely at random* or *missing at random* we will use multiple imputation using chained equations ($m=25$) to account for missing data³⁸; otherwise, complete case analysis will be used. An alpha (α) level of 0.05 will be considered significant, and odds ratios will be reported with 95% confidence intervals. Data analysis for Aim 2 will use Stata Version 16.

Measures for Aim 3

Data will include 1) the presence (yes/no) and type (organized population-based screening vs. opportunistic screening) of a national CCS program; 2) the percentage of screening coverage of the population; 3) the type of screening being done (e.g., cytology, HPV genotyping, Visual Inspection of the cervix with Acetic Acid (VIA); and 4) the presence (yes/no) and percentage of HPV vaccination coverage. This data is available for all 31 countries of origin represented in the IFMC database, and can be found on the WHO Global Health Observatory data repository³⁹ and through the ICO/IARC Information Centre on HPV and Cancer.⁴⁰ With regard to the four specific exemplar countries of origin, the discussion will be supported with a review of scientific and gray literature using PubMed and Google Custom Search, and the search terms “cervical cancer screening AND national policy AND [country of origin]” to identify additional country level CCC policy information.

Data Analysis for Aim 3

We will collect and tabulate descriptive data related to each measure and use narrative summaries to describe how country-level policies and practices related to CCC may also be informed by other key features of each country's health system.

Study Team

Our **interprofessional study team** will be comprised of a Primary Investigator (PI), a Co-Investigator (Co-I) who will serve as dissertation chair, three additional dissertation committee members, and two consultants. **Catherine Elmore, MSN, CNL, RN** (PI) is a PhD doctoral candidate at the University of Virginia (UVA) School of Nursing and will be the study's PI. Ms. Elmore is a master's prepared RN with a bachelor's degree in cultural anthropology. She has been involved with the IFMC since 2014. For more than 3 years, she served as RN Care Coordinator in the IFMC and has extensive clinical experience with the study population. For the past 3 years, she has been a student investigator collecting and cleaning the retrospective data set to be used in this proposed study. Ms. Elmore has 21 graduate credit hours in quantitative research methods, including logistic regression and multiple imputation, and has experience using STATA, SPSS and R data analysis software. **Emma Mitchell, PhD, MSN, RN** (Co-I and chair of the dissertation committee) has extensive experience with qualitative and mixed-methods approaches to researching barriers to CCS in vulnerable women, as well as in researching innovative technology, strategies, and delivery models to mitigate those disparities.^{12,41} She has been a faculty member at UVA School of Nursing and Associate Member of the UVA Cancer Center's Cancer Control Program, for six years. Dr. Mitchell has two current clinical trials in rural and remote settings exploring CCS access in vulnerable

women. Ms. Elmore and Dr. Mitchell are two of three co-authors on an integrative review focusing on CCS for foreign-born women, which is currently being revised for resubmission.⁴²

Katrina Debnam, PhD, MPH will serve as a dissertation committee member. Dr. Debnam is an Assistant Professor with a joint appointment in the UVA School of Education and the UVA School of Nursing. She has a background in family and community health, is an expert in mixed methods, with an interest in health equity research. Dr. Debnam will serve as the Dean's representative on the committee. **Kathryn Laughon, PhD, RN, FAAN** will serve as a dissertation committee member. Dr. Laughon is an Associate Professor and Director of the PhD program in the UVA School of Nursing; her research foci include improving the health and safety of women. **Jess Keim-Malpass, PhD, RN** will serve as a dissertation committee member. Dr. Keim-Malpass is an Associate Professor in the UVA School of Nursing with a joint appointment in the UVA School of Medicine. She is an expert in quantitative research methods, and she will advise on the quantitative analysis of the data. **Fern Hauck, MD, MS**, will serve as a faculty consultant on the project. Dr. Hauck is a physician and founding Medical Director of the IFMC, which was established in 2002. In addition to providing clinical care for refugees for the past two decades, she has mentored students from medicine, pharmacy and nursing in conducting research focused on the IFMC.^{6,43-48} Ms. Elmore and Dr. Hauck are two of several co-authors on a descriptive paper focusing on interprofessional collaboration within the IFMC, which has been published in *Family Medicine and Community Health*, a peer-reviewed, open access journal.⁶ **Kawai Tanabe, MPH**, formerly a data analyst in the Department of Family Medicine at UVA, is currently an epidemiologist with the UVA Department of Student Health. Ms. Tanabe has extensive experience with research projects related to the IFMC's refugee population, is an expert in data management of the IFMC database, and will be involved as a

data consultant for the project.^{43,44,46,47} Dr. Mitchell, Dr. Hauck, Ms. Tanabe and Ms. Elmore have previously worked together to design, implement and disseminate the retrospective cohort study which provided the parent data set for this proposal.

Timeline

Dissertation Research - Proposed Timeline	2018			2019				2020				2021	
Tasks/Aims	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2
Approval of IRB protocol													
Data Collection													
Data Cleaning													
Aim 1: Determine the proportion who are up-to-date on CCS													
Aim 2: Examine predictors of CCS adherence in the sample													
Aim 3: Describe CCC policies and practices for countries of origin													
Dissemination to local, regional and national scholarly community													
Manuscript writing and revising													
Anticipated dissertation defense													
Anticipated graduation													

Limitations

One limitation of both secondary data analyses and retrospective cohort studies includes a lack of control over who is included in the sample. In this case, inclusion criteria for the parent data set included only patients who had attended the clinic in the past 3 years; this was based on how the clinic defines a “current” patient. This potentially biases the sample and provides no insights into issues affecting women who have not attended the clinic within the preceding three years. There is a further limitation that the cohort data could have been incomplete with regard to screening status—namely, that women may have been screened elsewhere, but either lacked medical records to demonstrate this, or were unable to recall having had the screening.

In addition, the original raw data found in the IFMC database is collected during provider interactions with patients during clinical encounters, so not only do they rely on the patient’s ability to recall personal medical history, but they could be subject to missing or incomplete data, or improperly recorded data. During the original collection of the data set used for this study,

when possible, the entire EMR—across all past visits across the health system—was searched using multiple keywords in a global search function in an attempt to find data that was missing from the original IFMC database report.

The data set includes many independent variables pertinent to the outcome, however, it does not include information on citizenship status, current health insurance status as of the date of the last CCS, income levels or employment status, which have been identified as significant factors influencing the odds of foreign-born women having completed CCS.⁴⁹

Finally, the findings may not be generalizable to all refugee populations in the United States or in other countries of resettlement because of the unique nature of the IFMC, the setting of the study, which, over its 18-year history, has been dedicated to providing high-quality, culturally-competent interprofessional care for individuals who arrived in the United States as refugees.

Protection of Human Subjects

This study was approved under the University of Virginia's IRB for Human Subjects Research (#20724) as last modified on July 27, 2018. Because it only involves the collection and analysis of data that was previously collected for clinical (non-research) purposes, this study is anticipated to pose no more than minimal risk to individual participants.

Appendix A: Using ethnicity and race data in a diverse international sample

In the United States, public agencies are mandated to record and report specific demographic information, including ethnicity and race data.⁵⁰ The U.S. Office of Management and Budget (OMB) sets guidelines for ethnicity and race reporting. The two standard categories for ethnicity are “Hispanic or Latino” and “Not Hispanic or Latino.” The five minimum standard categories for race are (1) American Indian or Alaska Native, (2) Asian, (3) Black or African American, (4) Native Hawaiian or Other Pacific Islander and (5) White. These ethnic and racial categories are unique to the particular historical, social and political context of the United States and change over time. Beginning in 2000, the U.S. Census allowed participants to select “Some other race,” to select multiple categories and to write-in responses. In a committee report from 2009, the National Academies of Medicine developed a template for a national standard for “granular ethnicity categories” that was inclusive of approximately 540 different ethnicities, and encouraged researchers to use locally relevant categories to capture more personally meaningful differences among population groups.⁵¹

With regard to how race and ethnicity data are collected for use (for example, when a person fills out new patient registration at a doctor’s office), the OMB has issued several specific recommendations including the order in which the two questions of ethnicity and race are asked (i.e., first ethnicity, then race). OMB guidelines also emphasize that “*self-identification* is the preferred means of obtaining information about an individual’s race and ethnicity” (emphasis added) and that individuals collecting this information should “*not* tell an individual who he or she is, or specify how an individual should classify himself or herself” (emphasis added).⁵⁰

In U.S. health research, ethnicity and race data are used in order to identify and reduce health disparities.^{52–54} The concept of *health disparities* has been defined by the National

Academy of Medicine as differences in the quality of healthcare by race and ethnicity.²⁰ U.S. researchers who are interested in populations that may suffer from health disparities and who place value on ethnicity and racial categories to parse out differences, rely on accurate *self-reported* ethnicity and race information in order to better understand how these characteristics may be associated with poor health outcomes. Indeed, the Journal of the American Medical Association requires researchers who submit manuscripts for publication to “provide an explanation ... about who classified individuals as to race, ethnicity, or both; the classifications and classification framework used; and whether the options were defined by the investigator or self-reported by the study participants.”⁵⁵ However, scientists are rightly growing increasingly critical about the use of race as a useful predictor of risk, when it is clear that there are no underlying genetic reasons that race would play a role.⁵⁶ Indeed, we know that it is really racism—or perhaps in the case of this study, *xenophobia*, an intense dislike or fear of people from other countries—that plays the more important role in creating and perpetuating health inequities.

Future research should consider how refugee newcomers make decisions about self-identifying from the preset selection of U.S.-based ethnicity and race categories as they begin to navigate many personal business transactions during the early period of resettlement, including signing leases, filling out employment applications, registering for social and public services, and enrolling in care in clinics and hospitals, particularly when they may identify themselves using other more granular and relevant descriptors, for example, based on ancestry or tribal identity in their home country. Given that refugees to the United States often arrive with limited English proficiency (LEP), and are provided with robust resettlement support upon arrival, a useful entry point into this question would be to begin with observations by and the role of

professional language interpreters. Public hospitals and other agencies in the United States are mandated to provide meaningful language access according to Title VI of the 1964 Civil Rights Act. Professional interpreters, therefore, often help LEP individuals resettling as refugees navigate these personal business transactions during the early period of resettlement. The role of professional interpreters has been debated in the scholarly literature, with some saying that interpreters should act merely as conduits of language.⁵⁷ However, sociolinguistic and communication scholars have rightfully pointed out that, in addition to performing the task of direct transmission of words between languages, professional interpreters act as social agents and participants in discourse⁵⁸; as communication collaborators and co-constructors⁵⁹; as clarifiers and cultural brokers who negotiate shared meaning⁶⁰; and as mediators who attempt to ensure culturally appropriate and sensitive interactions.^{57,61,62} It is plausible, then, that during the course of their daily work, professional interpreters may have participated in conversations in which foreign-born newcomers were asked to indicate their race and ethnicity by choosing from U.S.-based categories. Without critical scrutiny and deeper understanding about how these categories are selected and applied in, say, an EMR of a refugee, the use of ethnicity and race as factors in an analysis like the one conducted in this study is wholly inappropriate.

Appendix B: Figures

Figure 2A. Determining the dependent variable. This figure shows a listing of original raw data collected from the EMR, along with a display of the new calculated variables.

Determining CCS Status

Data Collected

- A) Date of birth
- B) History of hysterectomy (exclusion criteria)
- C) Date of last CCS
- D) Type of test(s)
- E) Results of test(s)
- F) Researcher decision UTD?

New Variables Created

- G) Age = $\text{INT}([\text{IRB Date}] - [\text{DOB}]) / 365$
- H) Pap result negative (1 or 0)
=IF(OR([@[Pap result]] = "Negative", [@[Pap result]] = "...") = TRUE, 1, 0)
- I) HPV result negative (1 or 0)
=IF(OR([@[HPV result]] = "Negative", [@[HPV result]] = "...") = TRUE, 1, 0)
- J) Number of negative test(s)
=([@[Pap Test Negative]] + [@[HPV Test Negative]])
- K) Appropriate screening interval based on age and type of last test(s)¹
=IF([@[Age]] < 30, 3, IF(AND([@[Age]] < 65, [@[Number of Negative Tests]] = 2), 5, IF([@[Age]] < 65, 3, IF([@[Number of Negative Tests]] = 0, -1, 999))))
- L) Appropriate interval for abnormal screenings² entered manually
- M) Years since last CCS (as of study IRB approval date)
=IF([@[Date of Last CCS]] = "None", -1, ([@[IRB Date]] - [@[Date of Last CCS]]) / 365)
- N) Computer calculated UTD?
=IF(OR([@[Years Since Last CCS]] > [@[USPSTF Screening Interval]], [@[Date of Last CCS]] = "None"), "NO", "YES")

Figure 2B. Screenshot of Microsoft Excel spreadsheet used to manage data collection and to implement the if-then-else expressions used to determine the outcome variable (Aim 1).

	A	G	B	C	D	D	E	H	E	I	J	M	K	L	N	F	O	P
ID	DOB	Age	No of Hysterectomies	Date of Last CCS	Type of Last CCS	Result of Last CCS	Pap result	Pap Test Negative	HPV result	HPV Test Negative	Number of Negative Tests	Years Since	USPSTF	Screening Interval	Computer Calculated	Researcher Decision	Unsatified	Reason for unsatified
2621	xx/xx/1952	41	None	xx/xx/2014	Cytology/Gynecological	NGUS, but included HPV	Negative	1	Negative	1	2	5/22/2018	4.93668992	5	YES	Yes	0	
2622	xx/xx/1973	44	None	xx/xx/2016	Cyto gen > 30yo	Co-test with PAP and HPV	Negative	1	Negative	1	2	5/22/2018	1.742403753	5	YES	Yes	0	
2623	xx/xx/1989	29	None	xx/xx/2017	Cyto gen 21-30yo	HPV - reflex if PAP is ASCUS	Negative	1	n/a	0	1	5/22/2018	2.257534247	3	YES	Yes	0	
2624	xx/xx/1980	38	None	xx/xx/xxxx	Cyto gen > 30yo	Co-test with PAP and HPV	Negative	1	Negative	1	2	5/22/2018	0.578682592	5	YES	Yes	0	
2625	xx/xx/1943	75	None	None	n/a	n/a	0	n/a	0	0	0	5/22/2018	-1	-1	NO	No	0	
2626	xx/xx/1932	86	None	None	None	n/a	0	n/a	0	0	0	5/22/2018	-1	-1	NO	No	0	
2627	xx/xx/1976	42	None	xx/xx/2017	Cyto gen > 30yo	Co-test with PAP and HPV	Negative	1	Negative	1	2	5/22/2018	1.583621938	5	YES	Yes	0	
2628	xx/xx/1991	27	None	xx/xx/2019	Cyto gen 21-30yo	Co-test with PAP and HPV	ASCUS	0	Negative	1	1	5/22/2018	2.587215286	5	YES	Yes	0	
2629	xx/xx/1984	33	None	xx/xx/2018	Cyto gen > 30yo	Co-test with PAP and HPV	UNSATISFACTORY	0	"If the Pap test is	0	0	5/22/2018	0.260277873	3	YES	No	1	needs repeat due to unsatisf
2630	xx/xx/1977	41	None	xx/xx/2017	Cytology, pap smear	Cytology Co-test with PAP and HPV	Negative	1	Negative	1	2	5/22/2018	0.742403753	5	YES	Yes	0	

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**CHAPTER 3: Predictors of cervical cancer screening for refugee women attending an
international family medicine clinic in the United States**

Under Review

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Conflicts of interest/Competing interests

The authors have no conflicts of interest to disclose.

Availability of data and material

The deidentified data set generated and analyzed during the current study is available from the corresponding author on reasonable request, after review by the Institutional Review Board and through a Data Use Agreement.

Code availability

Stata/IC 16.1 was used to analyze this data and code is available from the corresponding author on reasonable request.

Authors' contributions

C.E.E. contributed to the conception of the study; collecting, cleaning, and analyzing the data; and drafting and revising the article critically for important intellectual content. E.M.M. contributed to the conception of the study, provided advice and direction for the study design and data interpretation, verified a random sub-set for accuracy of the outcome variable, and revised the article critically for important intellectual content. K.D., J.K.M. and K.L. provided advice and direction for the study design and data interpretation and revised the article critically for important intellectual content. K.O.T. contributed to the conception of the study; collecting and cleaning the data; and revised the article critically for important intellectual content. F.R.H. contributed to the conception of the study, provided advice and direction for the study design and data interpretation, and revised the article critically for important intellectual content. All authors gave final approval of the version to be published and agree to be accountable for all aspects of the work.

Abstract

Purpose

Cervical cancer screening rates are lower for foreign-born women in the United States compared with the overall population. This study aimed to determine the cervical cancer screening rate and predictors among refugee women attending a family medicine clinic.

Methods

A retrospective chart review included refugee women ages 21+, seen within 3 years, without hysterectomy ($n=525$). Lab results determined cervical cancer screening rate and logistic regression models assessed predictors of cervical cancer screening.

Results

Overall, 60.0% were up-to-date on cervical cancer screening. Women ages 30–49, married, and with ≥ 1 child had higher odds of being up-to-date. Ten or more years living in the United States was a significant univariate predictor of cervical cancer screening for refugee women with 10 or more years approaching significance in the multivariate model.

Conclusion

This study begins to fill gaps in knowledge about cervical cancer control among refugee women resettled in the United States.

Keywords

cervix cancer; cancer screening; refugees; healthcare disparities

Purpose

Worldwide, cervical cancer is the fourth most commonly diagnosed type of cancer and cause of cancer-related death in women.¹ One of the key objectives of *Healthy People 2020* is to increase the cervical cancer screening (CCS) participation rate among women living in the United States from 80.7%² to an overall rate of 93.0%.³ Analysis of National Health Interview Survey (NHIS) data identified predictors that lead to disparities in CCS for women generally: notably, women in the youngest (21–29) and oldest (40–49 and 50–65) age groups had significantly lower odds of being screened for cervical cancer, as did those with less than a college education, with family income <400% of the poverty level, not having a usual source of healthcare, and having either Medicaid or other public insurance or being uninsured.⁴

NHIS data also show that foreign-born women are more than twice as likely to have *never* had a Pap test, and to have not had a Pap test in the past 3 years, compared to U.S.-born women.⁵ Indeed, the CCS rates for foreign-born women are persistently and significantly lower,^{6,7} specifically for those living in the United States for less than 10 years (66% [61.5–70.1 95% CI]),⁸ and for non-citizens who have lived in the United States for less than 5 years (OR = 0.65 [0.54–0.78]).⁹

Refugees are a specific type of foreign-born person living in the United States. An estimated 1.6 million female refugees have resettled in the United States since 1975¹⁰; however, relatively few studies have examined factors that predict CCS adherence specifically for refugee women living in the United States. The objectives of this study are to determine the overall CCS rate and predictors of CCS among a sample of refugee women attending an international family medicine clinic in Central Virginia. This study aims to identify whether a disparity in CCS exists

for these women who arrived in the United States as refugees, and will inform directions for future research and clinical practice.

Conceptual Framework

A 2019 systematic review that examined facilitators and barriers to breast and cervical cancer screening among immigrant women living in the United States identified relevant factors on every level of the social ecological model (SEM) including: lack of knowledge, fear of embarrassment, fear of pain, or fear of positive diagnosis (individual factors); lack of provider recommendation, provider gender mismatch, providers who are insensitive to cultural or religious beliefs (interpersonal factors); lack of language interpreters, lack of clinic-based outreach to under-screened women (organizational factors); limited access to affordable healthcare options (community factors); and lack of health insurance (policy factors).¹¹ These factors include or are derived from upstream factors—social determinants of health—that cross multiple levels of the SEM.^{12,13} Some factors may be unique to the immigrant experience, such as language concordance or acculturation in their new communities. We recognize immigration itself as a social determinant of health.¹⁴ Other factors may be unique to the experience of refugee women in particular, such as having lived in a refugee camp, or having experienced specific traumas that forced them to flee their home country to seek asylum and eventually achieve refugee status.¹⁰

Methods

We conducted a retrospective electronic medical record (EMR) review to determine the rate and predictors of CCS among women attending an international family medicine clinic (hereafter referred to as “the Clinic”) in Central Virginia. The Clinic is located at an academic medical center and has served over 3,800 refugees and special immigrant visa holders (hereafter

referred to collectively as “refugees”) from 60 countries since it was established in 2002.¹⁵ All refugees who resettle in the area are referred by the local refugee resettlement agency to establish care at the Clinic, and close to 100% attend at least one initial visit. This research study was approved by the Human Subjects Research Institutional Review Board (HSR-IRB) of the University of Virginia on May 22, 2018 (HSR-IRB #20724).

Sample

Data were collected for women who had arrived in the United States as refugees, were ages 21 and older at the time of EMR review and had been seen by a provider in the Clinic in the past 3 years ($n=547$). The Clinic considers those seen at least once in the past 3 years to be current patients of the practice; dates of last clinic visit for the sample ranged from March 23, 2015 to March 20, 2018. Cases were excluded if there was evidence of a hysterectomy ($n=22$). A total of 525 cases met all inclusion criteria.

Data Collection

Eligible subjects were identified using an IRB-approved database previously established for the Clinic to conduct research on this population. The data extracted from the database included demographic variables, and these were exported as a CSV file. Additional data collected from EMR review were manually added to the CSV file.

Measures

Dependent variable

The outcome of interest was whether a woman was up-to-date (UTD) on CCS as of the date of study initiation. UTD refers to women who are eligible for CCS and have received screening within the recommended time interval.¹⁶ This is a binary outcome (yes/no), based on the 2012 U.S. Preventative Services Task Force (USPSTF) guidelines for CCS (detailed in **Table**

1), which were current at the time of IRB approval.¹⁷ Raw data collected included: date of birth, date of last CCS, and the type(s) and result(s) of the last screening test(s). New variables were created that calculated the woman's age at time of screening, indicated the result of a cytology (Papanicolaou or Pap) test and/or human papillomavirus (HPV) test, and counted the number of negative tests. A series of "if, then, else" expressions were used in Microsoft Excel to determine the appropriate screening interval based on age and type of testing. A new variable was created that calculated whether the time interval since date of last CCS was *less than* the recommended screening interval. If so, then the case was coded as being UTD on CCS.

Every case with any abnormal screening result ($n=29$) was reviewed individually. Screening intervals were adjusted based on American College of Obstetricians and Gynecologists (ACOG) guidelines appropriate for abnormal results.¹⁸ A second study team member verified 10% of cases to determine agreement (100%) of UTD status.

Independent variables

Independent variables or predictors of CCS were grouped into three categories: 1) factors that would apply to all women generally, 2) factors that would apply to foreign-born immigrant women generally, and 3) factors that would apply uniquely to women who have arrived in the United States under refugee status. Definitions and variable type for each independent variable are found in **Table 2**.

Factors that apply to all women include age by 10-year groups (limited by the youngest and oldest ages in the screening guidelines), marital status, literacy in a native language, education, and parity, since opportunities for CCS may arise during prenatal care. Factors that would apply to foreign-born immigrant women generally include age at time of arrival, years lived in the United States, percentage of lifetime lived in the United States, and ability to speak

English as either a primary or secondary language. Factors that would apply uniquely to women who arrived in the United States under refugee status include whether she has ever lived in a refugee camp and history of trauma related to their status as refugees (not specifically limited to sexual trauma).

Analysis

Univariate descriptive statistics and cross tabulations were calculated. Bivariate relationships between each independent variable and the outcome were analyzed using Pearson's Chi-square. Then, three multivariate logistic regression models were tested based on groupings of the independent variables; each model building on the previous. The models were examined first using only complete cases, and then again using multiple imputation with chained equations to account for independent variables with missing data.¹⁹

Data were analyzed using Stata I/C version 16.1, using robust standard errors.²⁰ Results are reported in Odds Ratios (OR), with 95% confidence intervals (CI).

Results

Demographic Characteristics

Demographics of the study population are summarized in **Table 3**. The mean age of the sample was 41.2 years (range 21–89). Mean years living in the United States was 6.1, (range <1–20 years). There were 32 unique countries of origin represented in the sample; the top 8 countries represent ~82% of the sample; after that each country of origin was represented by fewer than ten individuals. The ten most frequent languages represent 85% of the sample; 43 languages were represented.

Overall CCS Rate and Univariate Analysis

Overall, 60.0% (315 of 525) of women were UTD on CCS. Cross tabulations and bivariate relationships between each independent variable and the outcome are reported using Pearson's Chi-square analysis (**Table 4**). There were significant differences in the outcome related to age group, marital status, having at least one child, and number of years lived in the United States.

Multivariate Logistic Regression Models

Three multivariate logistic regression models were run, first using only complete cases (Model 1 $n=170$; Model 2 $n=164$; Model 3 $n=88$), and then using multiple imputation (MI) with chained equations; in both cases robust standard errors were used. There was consistency in terms of magnitude, direction and significance of each predictor when comparing complete cases versus MI models. The MI models gave the most conservative estimates, and are reported in **Table 5**. While controlling for all other variables, the models consistently showed that women in the 30–49, and 40–49 age groups had statistically higher odds of being UTD on CCS compared to the youngest age group. Having ever been married doubled the odds of a woman being UTD on CCS, compared to women who were never married. Having had at least one child increased the odds of a woman being UTD two-and-a-half fold compared to women with no children. We found that *years lived in the United States* was a significant predictor in the univariate model; in the multivariate model, it approached significance for the group of women who had lived in the United States for 10 years or longer, while controlling for all other variables.

Conclusion

This study demonstrated that several known predictors of CCS for women in general were also found for refugee women. The one exception is that years lived in the United States—a factor that would apply only to immigrant and refugee women—is a significant predictor in the univariate model; in the multivariate models, it approached significance for the group of women who had lived in the United States for 10 years or longer. This is consistent with another population-based study, which found increased odds of reporting a Pap test within 3 years if the period of residence in the U.S. was 10 years or longer.²¹ This finding can be explained by the fact that women who have lived longer in a country of resettlement may be more established in their jobs and thus may be more likely to afford care or have health insurance, and may have had more opportunities to be offered screening, particularly for women who stay attached to the same usual source of care for a long period of time. While number of years or percentage of lifetime living in the United States has sometimes been used as a proxy for acculturation,²² future studies should use validated measures for acculturation to assess whether this is a significant factor for refugee women who attend this Clinic.²³

We hypothesized that religion would be a significant predictor when controlling for age and marital status. Our clinical experience suggests that many younger women who practice Islam often decline CCS before marriage, when they claim to not be sexually active. In this sample, we found that 61.8% of Muslim women (the largest religious group represented) were UTD on CCS, which is statistically equivalent to the sample's overall rate of 60.0%. However, an unexpected finding was that women who practice Buddhism were *less likely* to be UTD, as found in Model 1 of the multivariate regression (OR 0.44, $p < 0.05$). In post-hoc analysis, we

found no significant differences in marital status or mean age across religious groups in our sample. Further, while some have suggested that the more acculturated women are to the country of resettlement, the less significant religion is as a factor in CCS uptake,²⁴ we found no significant difference in mean *percentage of life lived* in the United States by religious group ($F_{4,359}=1.54$, $p=0.19$). International studies have shown that Buddhist women have higher CCS rates compared to women practicing other religions.^{25,26} One U.S.-based study of Cambodian-American women suggested that while Buddhism itself was not a predictor of previous or recent CCS, Buddhist beliefs that illness is a matter of karma could play a role in decisions to participate in CCS and other preventative care.²⁷ These mixed findings suggest that particular attitudes and beliefs of diverse sub-groups generally, and of patients as unique individuals, are important factors to be assessed in clinical settings, and that more research is needed to better understand differences among refugee women who practice different religions.

The findings that women who have ever been married and have at least one child are more likely to be UTD is consistent with other published literature²⁴ and our experience with women who attend the Clinic.

We hypothesized that women who reported a history of direct trauma related to their refugee status would have lower rates of CCS adherence; in the univariate analysis, we found that 69.3% of those who reported direct trauma were UTD on CCS, which is statistically equivalent to the overall proportion of the sample (see **Table 4**). While extant literature on associations between violence against women and CCS is mixed,²⁸ one provider who cares for women in the Clinic has observed an eagerness to pursue screenings as women seek reassurance that their past trauma will not put them at risk for future physical morbidities (R. Thompson,

personal communication, March 3, 2020). However, given that the trauma variable in this analysis was non-specific, and not statistically different, we interpret this finding with caution.

As shown by Beavis and colleagues,²⁹ in order to provide reasonable estimates of CCS adherence, analysis should exclude women who have had a hysterectomy. Although we took this into consideration, our analysis was limited by scarce surgical history detail, because most of the hysterectomies had been completed prior to the patients seeking care in the Clinic, including those reportedly done overseas. In some cases, women with a hysterectomy should continue being screened for cervical cancer, so having clear records about how much of the cervix was removed and the indications for the surgery are important to ensure appropriate preventative care.¹⁸

Strengths and Limitations

This analysis was strengthened by the fact that we used EMR data to determine the outcome variable. In this case, details about screening tests and results came directly from the medical record, which means that determining the outcome variable did not rely on participant recall.¹⁶ However, it is possible that individuals in the sample may have received testing elsewhere (for example, young women who have moved away for college), which means that our findings may have underestimated the proportion of women in the Clinic's population who are UTD. At the same time, our sample included only women who have actively sought medical care in our Clinic in the past 3 years, which may bias the overall rate of being UTD on CCS upward.

EMR data were lacking for some variables with known influence on CCS uptake: household income; employment status; current health insurance status; and knowledge, attitudes, beliefs about cervical cancer and CCS. Also, despite specific training on data collection pertaining to independent variables for the Clinic database, we cannot account for missing data

in cases where the provider did not ask questions, didn't record answers to questions, or where there may have been a systematic reason for data to be missing not-at-random. However, we found that results from the model using only complete cases was consistent with the models presented here that used multiple imputation to fill in missing data.

There are cultural nuances across countries of origin and language that are difficult to capture in quantitative analysis, and we recognize these limitations. For example, the life experiences of young women born in a refugee camp in Nepal would likely have been different from those of their mothers, who were born in Bhutan, and therefore should be considered separately. For women from Afghanistan, speaking Pashto or Dari may suggest differences in socio-economic status or educational opportunities in their home country. For reasons like these, and because there were so many countries of origin represented in the sample, we did not include country-specific variables in the regression models.

Factors related to countries of origin—the existence and type of CCS programs, percentage of population covered by programs where they exist, the type of CCS tests used, and existence of HPV vaccination programs for primary prevention—would all be potentially relevant factors for women who have arrived in the United States as refugees. We intended to use these variables in the logistic regression models, but found the large majority of women in this sample come from low-resource countries where CCS is opportunistic, there are no data about overall percentage of screening coverage, and HPV vaccination programs do not exist.³⁰ We therefore believe that these women are likely to have never heard of, or been offered, CCS prior to arrival in the United States. Because of this, it is essential that providers assess their foreign-born patients for knowledge, attitudes and beliefs about prevention, cancer screening, and CCS in particular.

Finally, the Clinic's patient population is unique and reflects trends in refugee resettlement in our particular city, while in different parts of the country, the diversity of residents who arrived as refugees may look quite different. Therefore, these results may not be generalizable to groups of women who arrive as refugees in other parts of the United States or to women who were not otherwise represented by the sample.

New Contribution to the Literature

This study contributes to existing knowledge by using an established refugee clinic database to examine rates and predictors of CCS for refugee women living in the United States. To our knowledge, our study represents the largest sample of refugee women residing in the United States that examines the question of CCS adherence using clinical laboratory results. The findings suggest that women in the sample are similar to U.S.-born women in terms of the following CCS-adherence predictors: being older, married, and having at least one child all increase adherence. Time lived in the United States potentially increased the odds that a woman was UTD on CCS. Healthcare providers should be aware that in most refugee countries of origin CCS is not widely available, and focused attention should be paid particularly to younger, unmarried, childless refugee women who have lived in the United States less than 10 years.

In other qualitative analysis from this data set, we found that providers in this Clinic are recommending screening, and are considering cultural preferences by offering screening by female providers³¹; this should be continued. Providers should also consider how the delivery of culturally specific education around both CCS and HPV vaccination could improve cervical cancer control for this population into the future.³² In our Clinic, an initiative to provide culturally sensitive education around colon cancer screening, utilizing the role of a registered nurse as an educator and advocate along with a specially made video, has bolstered successful

colon cancer screening completion for refugees. A similar strategy may also improve both CCS and HPV vaccination uptake.

The National Academy of Medicine and the National Institute on Minority Health and Health Disparities have issued calls for researchers to produce knowledge that can inform our understanding of risk and protective factors for unique sub-groups of the population living in the United States, and to seek and implement context specific approaches to address disparities in care for affected sub-groups.^{33,34} There are certainly knowledge gaps about immigrants in general in the United States, but for refugees in particular there are very few data sets that allow researchers to uniquely identify refugees, particularly when it comes to assessing cancer control measures.³⁵ There is also the need for more research focused on understanding barriers and facilitators to CCS for refugees. This study lays the groundwork for additional mixed-method research focused on understanding particular barriers and facilitators unique to refugee populations and sub-populations living in the United States, with the eventual goal of developing tailored interventions that will decrease disparities in screening.

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Table 1

Cervical Cancer Screening Intervals for Women by Age and Type of Test(s)*

Age Group	Test(s)	Screening Interval
21–65	Cytology (Pap)	3 years
30–65	Cytology + HPV	5 years

Note. *Based on 2012 USPSTF guidelines. Pap = Papanicolaou Test. HPV = Human papillomavirus.

Table 2

Definitions and variable type for each independent variable.

Independent Variable	Variable Type	Definition
Factors that would apply to all women generally		
Age	Categorical	10-year age groups, limited by the youngest and oldest ages in the CCS guidelines.
Marital Status	Binary	Defined by whether the woman has <i>ever been</i> married (including divorced and widowed women) or <i>never</i> married.
Religion	Categorical	Self-reported and was historically asked at all initial visits to the Clinic, and more recently is asked of all patients who register at the medical center where the Clinic is located. This variable includes the category of “none” where the patient reported not practicing any religion; this is distinct from cases with missing data.
Literacy in Native Language	Binary	Self-reported during any relevant encounter at the medical center. Open text responses were grouped into two categories, literate and not literate, which included any report that literacy was limited, poor, or with deficits including loss of vision or hearing.
Completed Secondary School	Ordinal	Open text responses about number of years of education were classified into the categories of less than secondary school (defined as completion of U.S. grade 12 or high school) or \geq secondary school
Number of Children	Binary	Using documented data on parity and self-reported number of children, whether a woman had at least one child or no children
Factors that apply to foreign-born immigrant women generally		
Age at time of arrival	Continuous	Calculated based on current age and year of arrival.
Years lived in U.S.	Categorical	Continuous data was categorized into 5-year increments based on previous studies
Percentage of lifetime lived in U.S.	Categorical	Categorized into $\geq 25\%$ of lifetime based on previous studies
English fluency	Binary	Self-reported ability to speak English as either primary or secondary language

Factors that would apply uniquely to women who have arrived in the U.S. as refugees		
Ever lived in refugee camp	Binary	Whether women have ever lived in a refugee camp. Self-reported data was categorized into a binary yes-or-no variable.
Experience of Trauma	Categorical	History of trauma was self-reported and was collected from any relevant encounter at the medical center. Qualitative data about trauma directly related to their status as refugees were recoded into three categories: 1) direct trauma, or violence that was inflicted directly on the woman herself, 2) indirect trauma that was either witnessed or targeted towards a family member or friend, and 3) or no trauma, when a woman denied experiencing any trauma. This variable is not specifically limited to sexual trauma.

Table 3*Demographics including age, years in U.S. and 10 most frequent countries of origin and language*

	Mean	Min	Max		Mean	Min	Max
Age	41.2	21	89	Years in U.S.	6.1	0	20.5
Countries of Origin (Top 10)	Frequency	%	Cum. %	Primary Languages (Top 10)	Frequency	%	Cum. %
Afghanistan	130	24.8	24.8	Nepali	129	24.6	24.6
Bhutan*	109	20.8	45.6	Arabic	94	17.9	42.5
Iraq	73	13.9	59.5	Dari**	74	14.1	56.6
Congo	35	6.7	66.2	English	34	6.5	63.1
Burma	33	6.3	72.5	Farsi (Persian)	27	5.1	68.2
Nepal*	20	3.8	76.3	Swahili	25	4.8	73
Syria	18	3.4	79.7	Pashto**	20	3.8	76.8
Colombia	11	2.1	81.8	Burmese^	16	3.1	79.9
Iran	9	1.7	83.5	Russian	16	3.1	83
Russia	9	1.7	85.2	Karen^	13	2.5	85.5

Note. Individuals who report a country of origin of either Bhutan or Nepal are ethnically Bhutanese, and spent time living in refugee camps in Nepal. **Dari and Pashto speakers are from Afghanistan. ^Burmese and Karen speakers are from Burma.

Table 4

Cervical cancer screening adherence by independent variable (percentages and Pearson χ^2)

	<i>n</i>	Yes (%)	No (%)	χ^2
Age Group				46.12*
21-29	136	42.6	57.4	
30-39	142	73.9	26.1	
40-49	112	73.2	26.8	
50-59	63	60.3	39.7	
60-65	25	56.0	44.0	
>65	47	38.3	61.7	
Marital Status				36.13*
Never Married	145	39.3	60.7	
Married/Widowed/Divorced	376	68.1	31.9	
Religion				7.24
Muslim	178	61.8	38.2	
Christian	83	62.7	37.3	
None	63	65.1	34.9	
Buddhist	41	43.9	56.1	
Other	23	73.9	26.1	
Literacy in Native Language				0.91
Not literate	79	54.4	45.6	
Literate	176	60.8	39.2	
Completed Secondary School				0.24
No	202	61.4	38.6	
Yes	148	58.8	41.2	
Number of Children				33.24*
No children	72	30.6	69.4	
1 or more children	395	66.6	33.4	
Years lived in U.S.				11.52**
≤ 1 year	20	50.0	50.0	
1-5 years	206	64.1	35.9	
6-10 years	176	54.6	45.4	
>10 years	77	75.3	24.7	

CERVICAL CANCER CONTROL REFUGEE WOMEN

Percentage of lifetime lived in U.S.				1.27
<25%	384	61.5	38.5	
≥25%	141	56.0	44.0	
English as primary or secondary language				0.00
No	415	60.0	40.0	
Yes	110	60.0	40.0	
Ever lived in a refugee camp				3.58
No	88	75.0	25.0	
Yes	172	63.4	36.6	
History of Trauma				4.18
Denied	166	58.4	41.6	
Indirect	19	52.6	47.4	
Direct	114	69.3	30.7	

Note. * $p<0.001$, ** $p<0.01$

Percentages in **bold** are less than the overall percentage for the sample.

Table 5.

Logistic Regression Models using Multiple Imputation (m=25) with Chained Equations and Robust Standard Errors

	Model 1	Model 2	Model 3	
	OR	OR	OR	95% CI
Variables that apply to all women				
Age Group				
21-29	1.00	1.00	1.00	
30-39	2.98**	3.06**	3.05**	[1.65, 5.64]
40-49	2.87**	2.82*	2.80*	[1.25, 6.32]
50-59	1.82	1.83	1.78	[0.62, 5.12]
60-65	1.60	1.77	1.80	[0.43, 7.52]
>65	0.93	1.11	1.10	[0.22, 5.47]
Ever married				
No	1.00	1.00	1.00	
Yes (Married / Divorced / Widowed)	1.96**	2.62**	2.05**	[1.20, 3.51]
Religion				
Muslim	1.00	1.00	1.00	
Christian	1.05	1.06	1.16	[0.63, 2.15]
None	1.02	1.05	1.18	[0.60, 2.34]
Buddhist	0.44*	0.48	0.59	[0.23, 1.47]
Other	1.24	1.22	1.36	[0.45, 4.13]
Literacy in native language				
No	1.00	1.00	1.00	
Yes	1.47	1.29	1.21	[0.60, 2.48]
Completed secondary education				
No	1.00	1.00	1.00	
Yes	0.97	.098	0.96	[0.53, 1.74]
Having at least one child				
No	1.00	1.00	1.00	
Yes	2.49**	2.52**	2.46*	[1.23, 4.91]
Variables that apply to all immigrant women				
Age at time of arrival in U.S.		0.99	0.99	[0.96, 1.03]
Years lived in U.S.				
≤ 1 year		1.00	1.00	
1-5 years		2.15	2.41	[0.85, 6.85]
6-10 years		1.60	1.86	[0.59, 5.90]
>10 years		3.34*	3.81	[0.98, 14.79]
Percentage of lifetime lived in U.S.				
<25%		1.00	1.00	
≥25%		0.66	0.67	[0.36, 1.25]
Speaks English as primary or secondary language				
No		1.00	1.00	
Yes		1.11	1.10	[0.65, 1.90]

Variables that apply only to refugee women		
Ever lived in a refugee camp		
No	1.00	
Yes	0.72	[0.37, 1.39]
History of trauma		
Denied	1.00	
Indirect	0.96	[0.34, 2.70]
Direct	1.24	[0.72, 2.14]

Note. OR = Odds Ratio, CI = Confidence Interval, * $p < 0.05$. ** $p < 0.01$.

Appendix

We closely examined the data set to consider missing data (**Table 6**). Assuming that missing data are missing completely at random, we used the <mi> command in Stata to create 25 imputed data sets using chained equations. In order to solve the problem of perfect predictors on the logit and mlogit commands we used the option <,augment>. A summary of the variables having imputed observations are detailed in **Table 7**.

Multivariate Logistic Regression Model Comparison: Complete Case vs. Multiple Imputation

We first ran the three multivariate logistic regression models on only complete cases using robust standard errors (Model 1 $n=170$; Model 2 $n=164$; Model 3 $n=88$). In the complete case Model 3, number of children and percentage of lifetime lived in the United States were omitted due to collinearity; years lived in the United States and trauma were dropped because they were perfect predictors. We then ran the three models after Stata imputed missing data (25 times) using chained equations, again using robust standard errors. There was consistency in terms of magnitude, direction and significance of each predictor when comparing the models using only complete cases and the models using multiple imputation. The models using multiple imputations gave the most conservative estimates, and are reported in the main manuscript (Table 5).

Table 6*Examination of variables for missing data*

Variable Name	Missing	Total	Percent Missing
Uptodate	0	525	0.00
Age10	0	525	0.00
Spouse	4	525	0.76
religion	137	525	26.10
literate	270	525	51.43
SecondaryEdu	175	525	33.33
NumChildren	58	525	11.05
agearrival	48	525	9.14
years	46	525	8.76
percent	0	525	0.00
english	0	525	0.00
camp	265	525	50.48
trauma	226	525	43.05

Table 7*Multiple imputations completed per variable*

Variable Name	Observations per <i>m</i>			Total
	Complete	Incomplete	Imputed	
agearrival	477	48	48	525
Spouse	521	4	4	525
literate	255	270	270	525
SecondaryEdu	350	175	175	525
NumChildren	467	58	58	525
camp	260	265	265	525
religion	388	137	137	525
trauma	299	226	226	525
years	479	46	46	525

(complete + incomplete = total; imputed is the minimum across *m* of the number of filled-in observations.)

**CHAPTER 4: Health inequity in cervical cancer control among refugee women in the
United States by country of origin**

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Abstract

Purpose

To describe cervical cancer control (CCC) policies and strategies for countries of origin of women who resettle in the United States as refugees.

Methods

Using publicly available data, describe the presence/type of national CCC program, screening coverage percentage, and HPV vaccination program presence and coverage in 15 countries.

Results

Nine of fifteen included countries screen opportunistically. Most countries do not use high-performing tests and estimates of screening coverage was limited. One country offers HPV vaccination.

Conclusion

Countries of origin for refugee women may lack effective national CCC prevention programs. To meet the WHO's call to eliminate cervical cancer by 2030, continued focus on culturally-tailored education and research is paramount.

Purpose

Worldwide cervical cancer continues to be the fourth leading cause of cancer incidence and death for women¹ and the burden is highest in low and middle income countries (LMICs).¹ In the United States, foreign-born women are significantly more likely to have *never* been screened for cervical cancer, and are significantly more likely to be *past-due* for cervical cancer screening (CCS) compared to native-born women.^{2–5} Many refugees entering the United States come from LMICs where screening programs for cervical cancer are inaccessible and/or under-resourced.^{6,7} Even where CCS programs exist, many refugees' countries of origin have no active invitation to screening, meaning they are opportunistic and do not track data using screening registries.⁸ We posit that refugee women resettle in the United States with knowledge, attitudes, and beliefs about preventive care in general, and screening for cervical cancer in particular, that are informed by policies and strategies of their countries of origin.

The aim of this short report is to describe country-level cervical cancer control (CCC) policies and strategies from common countries of origin for women who resettle in the United States as refugees in order to highlight this persistent health inequity.

Methods

We conducted a retrospective cohort study of women (n=525) who arrived in the United States as refugees and are current patients at a family medicine clinic to determine predictors of CCS adherence (Elmore et al. 2020 in preparation). For this review of country level CCC policy and strategies, we consider the ten most frequent countries of origin from our study sample (found in Table 1). We also include the ten most frequent countries of origin for U.S. refugee admissions from Fiscal Year 2019⁹ (found in Table 2) in order to expand the generalizability of our findings. Five countries overlap; therefore, data from 15 countries are used to examine how

countries of origin may influence CCC for refugee populations resettled in the United States. We consider in more detail the CCC policy and strategy for four specific countries of origin (Afghanistan, Democratic Republic of Congo, Colombia and El Salvador) as examples on the extreme ends of the CCC spectrum.

We collected and tabulated descriptive data including 1) the presence (yes/no) and type (organized population-based screening vs. opportunistic screening) of a national CCS program; 2) the percentage of screening coverage of the population; 3) the type of screening being done (e.g., Cytology, HPV genotyping, Visual Inspection of the cervix with Acetic Acid [VIA], visual inspection with Lugol's iodine [VILI]); and 4) the presence (yes/no) and percentage of HPV vaccination coverage.

Data were obtained from:

- 1) Review of most frequent countries of origin in our study sample (Table 1). This includes only females over the age of 21 who are current attendees of a family medicine clinic (n=525), average years in the United States is 6.1 (range <1 to 20.5 years).
- 2) Review of Worldwide Refugee Admissions Processing System data on most frequent countries of origin for Fiscal Year 2019 (Table 2). This data includes individuals of all genders and all ages (n=11,814), and provides a snapshot of recent refugee resettlement trends in the United States.
- 3) Review of data from HPV Information Centre.⁸ We examined “Human Papillomavirus and Related Diseases” full reports by countries of origin (last updated 17 June 2019). HPV Centre is a collaboration between Catalan Institute of Oncology (ICO) and International Agency for Research on Cancer (IARC) that compiles data from systematic review and meta-analysis of published literature and from official reports by the World Health Organization (WHO), the United Nations, The World Bank, and IARC's *Globocan* and *Cancer Incidence in Five Continents*.

- 4) Review of data from Gavi: The Vaccine Alliance country hub website,¹⁰ examining whether or not the country was receiving Gavi support specifically for HPV vaccination. Gavi is an international, public-private organization that seeks to create equal access to vaccines especially in low-income countries.

We reviewed scientific and grey literature using PubMed and Google Custom Search to identify additional information on the current state of the respective health systems and CCC policy information on the four exemplar countries (Afghanistan, Democratic Republic of Congo, El Salvador, and Colombia).

Results

According to HPV Centre data, nine of the 15 countries have CCS programs; of these, all are opportunistic, meaning there is no active program by which women are invited to be seen for screening (Table 3). Six national programs use Cytology alone; one uses VIA alone, one uses Cytology and VIA, and only one country (Colombia) uses either Cytology, VIA-VILI or HPV genotyping based on age.

Available data estimating screening coverage was often based on relatively small samples (noted in Table 3), and age eligibility for screening varied across countries. Some countries without national programs (such as Bhutan, which has had a VIA demonstration project) did offer estimates of CCS coverage, though this data was limited and sometimes based on single studies with small sample sizes. None of the countries have HPV vaccination programs, and only Moldova has been supported (in 2017 & 2018) by Gavi for HPV vaccination demonstration projects.

Discussion

To add additional context, we briefly consider the broader health system contexts for four specific countries of origin. These four countries represent examples on either ends of the

spectrum of national CCC programs. As examples of countries where programs are emerging or not yet in existence, Afghanistan and Democratic Republic of the Congo (DRC), are represented by nearly 25% of refugees residing in the United States (see Tables 1 and 2). Both countries are classified by the World Bank as low income countries, defined as an economy where the Gross National Income (GNI) is USD\$1,035 or less in 2019.¹¹

The health care system in Afghanistan, which has been affected by decades of war and conflict, experienced a turning point with the fall of the Taliban in 2001.^{12–14} At that time, the people of Afghanistan suffered with some of the worst health indices in the world, including staggering maternal and infant mortality rates, low life expectancy, and extremely poor access to health services.¹⁵ In 2001, the Ministry of Public Health (MOPH), with the support of significant international guidance and financial aid, established the Basic Package of Health Services (BPHS) on the principals that high quality care would be provided to all persons regardless of their ability to pay.¹² The BPHS included a focus on improved access to reproductive health services for women, and increasing the number of women in the health care workforce.^{12,13} Increasing the number of women in health care is a critical goal for Afghanistan because of long-standing cultural norms that forbid women from being treated by male health workers. This is particularly significant because of the country's long history of marginalizing women and limiting access to basic education and literacy, and to more advanced or specialized education and training as doctors, midwives or nurses.¹⁶

In 2016, the Afghanistan MOPH established the National Reproductive Health Policy which expanded the policies in the BPHS to finally initiate a country-wide breast and cervical cancer diagnosis and treatment plan.¹⁷ Despite significant strides in improving the overall health care system, the country is still on the cusp of widespread implementation of CCC strategies.

The initial goal included implementing VIA, though HPV Centre reports that the main test used is Cytology for women 15-49 years old with a screening interval of every 5 years. In

Afghanistan, there are no estimates of coverage for CCS, and no national HPV immunization program.^{18,19} A lack of reliable population-level data, including those relevant to CCC, continues to present challenges to assessing the overall status of health indices in Afghanistan.¹³

The DRC, the second largest country on the African continent, was taken as a colony by Belgium in 1908, and regained independence in 1960.²⁰ More recently it has been impacted by decades of violent conflict and instability since the country's civil war (1997-2003).²¹⁻²³ While the country has a tradition of primary health care-based district health system,²³ health system infrastructure has eroded in the past two decades. Government spending on health per capita is well short of the WHO recommendation for supporting the health of a population.^{20,23} The DRC currently ranks 175 out of 189 countries on the Human Development Index, a global summary measure which considers measures of health, education and economics.²¹ The country has been receiving assistance across governmental sectors, including health, from United States Agency for International Development (USAID) since the mid-1970s.²⁴

Sexual- and gender-based violence (SGBV) remains one of the most important health problems in the DRC.^{20,22} There are estimates that nearly 40% of women in the DRC have experienced SGBV; these crimes have reportedly been committed by paramilitary personnel and soldiers, however nationally representative surveys revealed that an estimated 35% of women in the DRC have also suffered from intimate partner sexual violence.²²

In the DRC, there reportedly is a published "National strategy to combat the cancer of the uterine, neck and breast", however according to the authors of a policy analysis published in 2020, the document does not appear to be legally binding.²⁵ (At the time of this writing, the primary document as referenced by Njunguna and colleagues was not available, nor did an independent grey literature search reveal the

document.) Njuguna et al. reported that the DRC strategy document does adhere to WHO recommendations related to HPV vaccination, screening, and treatment for precancerous lesions; however, the document does not appear to address treatment for invasive cancer or referral systems. The authors also report that DRC has screening capability using HPV DNA testing, and also uses VIA and VILI, which are screen-and-treat approaches. However, recent studies conducted in the DRC report an ongoing lack of equipment and qualified medical and laboratory personnel, resulting in practically no access to preventative and curative services such as cervical cancer screening and treatment.²⁶ These findings and the general paucity of scientific and grey literature on CCC in the DRC are consistent with the IARC and WHO reports that the DRC has no effectual national program for primary¹⁹ or secondary prevention.⁸

As examples of countries with extant programs, El Salvador and Colombia are represented by only 2-3 % of cases in our samples. El Salvador is classified by the World Bank as a lower-middle income economy (USD\$1,036 - \$4,045 GNI per capita); Colombia is classified as an upper-middle income economy (USD\$4,046 - \$12,535 GNI per capita).¹¹

El Salvador has experienced decades of political and economic instability, characterized by authoritarian control, coups, civil unrest, and a civil war (1979-1992).²⁷ The country continues to deal with significant gang-related crime, gender-based violence, and depressed economic opportunity, which has driven citizens to seek asylum and apply for refugee status.^{28,29} The national health system has seen improvements since 2010 when the National Health Forum was created, during a period of national public health system reform which focused on the principals of primary health care.³⁰ In the same year, a public-private partnership between the El Salvador Ministry of Health and non-governmental organizations began a successful demonstration project aimed at implementing HPV-testing programs over several phases.³¹⁻³³ Based on the success of the demonstrate project, and estimated cost-effectiveness, in 2014, the

Salvadorian national guidelines for cervical cancer and treatment were updated to include recommendations for HPV testing, plus immediate treatment of precancerous lesions at the time of screening, which is recommended as a preferred approach, particularly in low-resources settings where referrals and follow up options are limited.³¹ Estimates of population coverage of CCS in El Salvador is relatively high, around 67%, while having an opportunistic screening program just like the United States. There is no data estimating HPV vaccination coverage for El Salvador, published by either WHO-UNICEF, GAVI, or HPV Centre.^{8,10,19}

Despite being one of the oldest democracies in Latin America, Colombia has struggled with decades of violence and instability related to illegal drug production and trafficking.³⁴ In addition to being the world's top country of origin for internally displaced people (IDP), in recent years the country, including health infrastructure, has also been strained as a receiving country for IDP from neighboring countries.³⁴⁻³⁶ In the 1990s, Colombia first introduced cervical screening with cytology, but with uneven benefits to women, due to disparate access to follow up for abnormal results, depending on whether women had private or public health insurance.³⁶ Like many other countries globally, women in Colombia also experience morbidity and mortality from cervical cancer disproportionately due to socioeconomic inequalities.^{36,37} To its credit, in the past decade Colombia has continued pushing for improvements in the health system: by publishing a 10-year Public Health Plan; passing the 2015 Statutory Health Law, which recognizes health as a basic human right; and in 2016 passing a Comprehensive Health Care Policy, which recognized cancers (including cervical cancer) as an area of concern and focus.^{35,38} Colombia has also been on the leading edge of HPV research, including participating in one of the earliest population-based studies causally linking high risk HPV genotypes with cervical cancer.^{36,39} Cervical cancer mortality has continued to decline in Colombia since HPV testing

and screen-and-treat approaches like VIA and VILI were implemented about 10 years ago.³⁶ In Colombia, HPV vaccines were approved for use even before they were incorporated into the national immunization plan in 2012.³⁶ According to WHO data from 2018, 56% of females 15 years and older have completed full HPV vaccine series; while 85% have received the first dose.¹⁹ Colombia stands out as an exception among the four countries examined here, but represents a small fraction (0.002% in Fiscal Year 2019) of new refugee arrivals in the United States.⁹

Conclusions

Countries of origin for those who resettle as refugees are markedly different than countries of origin for other types of immigrants to the United States. By definition, refugee countries of origin suffer from unstable governmental infrastructure and under-resourced economies, which often corresponds with weakened health care systems.^{11,40} Examining CCC practices from these fifteen countries, it becomes clear that women who arrive in the United States as refugees are likely to have countries of origin where national programs for primary prevention of cervical cancer by HPV vaccination and secondary prevention through cervical screening do not exist. Furthermore, given the general lack of HPV genotyping, it is possible that any screening done in a country of origin could have been inadequate. This is because high-performing HPV testing (alone or with Cytology) is more effective in identifying pre-cancerous lesions and invasive cancers than screening with Cytology alone or by VIA, and is scantily used in the countries considered here.⁴¹

When we considered four specific countries of origin, we see examples of the spectrum of possibilities: for the largest groups of refugees resettling in the United States, CCC in countries of origin (e.g., Afghanistan and DRC) is generally poor. On the other hand, countries

of origin with more robust programs (e.g., El Salvador and Colombia) are represented by small numbers of women resettling in the United States. Contextualizing the state of CCC programs within a broader description of each country's government and health system further illuminates the challenges of providing care to women from these countries.

The WHO's ambitious goal to eliminate cervical cancer as a public health problem by 2030 includes three necessary pillars of cancer control: prevention, screening and treatment.⁶ The specific global goals to achieve elimination include 90% coverage of HPV vaccination, 70% coverage of screening with high-performance tests, and 90% access to treatment for cervical pre-cancer and cancer. This study uses country of origin data that focuses on the first two pillars, prevention and screening, to demonstrate how and why CCC represents a persistent source of health inequity for refugee women in the United States. While high-income countries like the United States are close to these goals for the overall population, in order to improve health equity in CCC, we must pay focused attention to women who migrate and resettle here because they represent a vulnerable and under-screened group.

Individuals who resettle as refugees benefit from relationships with healthcare providers who are supportive, can anticipate unique needs, and can provide clear, culturally responsive information about disease prevention and early detection guidelines, including those related to CCC.⁴² Individual knowledge, attitudes and beliefs about health and health care are also situated in a particular cultural context which is informed by country of origin. As providers caring for these women, our responsibility is to recognize the existence of the global disparity in CCC and be responsive to this in order to improve health equity.^{43,44} We can do this by assessing our migrant and refugee patients' need for culturally tailored education around prevention and screening for cervical cancer, and by continuing to research novel ways of increasing screening

for this vulnerable population.^{45,46} While this brief report focuses only on cervical cancer control, it may also serve as a bellwether for increased awareness about disparities related to other cancers and non-communicable diseases for refugee populations.

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Table 1. Top 10 countries of origin for our sample* (n=525)

Countries of Origin (Top 10)	Frequency	%	Cum. %
Afghanistan	130	24.8	24.8
Bhutan**	109	20.8	45.6
Iraq	73	13.9	59.5
DRC	35	6.7	66.2
Burma	33	6.3	72.5
Nepal**	20	3.8	76.3
Syria	18	3.4	79.7
Colombia	11	2.1	81.8
Iran	9	1.7	83.5
Russia	9	1.7	85.2

Note. *Includes only women, 21+ years old. DRC = Democratic Republic of the Congo. **Women who report country of origin as either Bhutan or Nepal are ethnically Bhutanese and have lived in refugee camps in Nepal for many years.

Table 2. Top 10 countries of origin for refugee resettlement in United States FY 2019 (n=11,814)

Countries of Origin (Top 10)	Frequency*	%	Cum. %
DRC‡	2868	24.3	24.3
Burma‡	2115	17.9	42.2
Ukraine	1927	16.3	58.5
Afghanistan‡	604	5.1	63.6
Iraq‡	537	4.5	68.1
Syria‡	481	4.1	72.2
Eritrea	475	4.0	76.2
El Salvador	365	3.1	79.3
Moldova	364	3.1	82.4
Sudan	254	2.1	84.5

Note. *Number of individuals, includes all genders and ages. ‡Country overlaps with those in Table 1. DRC = Democratic Republic of the Congo. FY = Fiscal Year.

Source: <https://www.wrapsnet.org>

Table 3. Comparison of primary and secondary prevention strategies for cervical cancer for 15

most common countries of origin of refugees who resettle in the United States

Country of Origin	National Screening Program	Type of National Program	Percentage of screening coverage	Most widely used screening method	National HPV Vaccination Program Percentage Coverage	Receiving support from Gavi for HPV Vaccination
USA	Yes	Opportunistic	80.7%*	Cytology/HPV	64.2% 44.5% ‡	No
Afghanistan	Yes	Opportunistic	—	Cytology	—	No
Bhutan	No	—	40.9% ^c	VIA ^a	—	No
Burma	No	—	—	VIA	—	No
Colombia	Yes	Opportunistic	69.9% ^d	Cytology/VIA/HPV ^b	85% 56% ‡‡—	No
Congo, DR	No	—	—	—	—	No
El Salvador	Yes	Opportunistic	66.7% ^e	Cytology/VIA	—	No
Eritrea	No	—	—	—	—	No
Iran	Yes	Opportunistic	49.4% ^f	Cytology	—	No
Iraq	Yes	—	12.6% ^g	Unknown	—	No
Moldova	Yes	Opportunistic	30% ^h	Cytology	—	Yes
Nepal	Yes	Opportunistic	2.8% ⁱ	VIA	—	No
Russia	Yes	Opportunistic	72% ^j	Cytology	—	No
Sudan	No	—	—	VIA ^a	—	No
Syria	Yes	Opportunistic	—	Cytology	—	No
Ukraine	Yes	Opportunistic	73.7% ^k	Cytology	—	No

Note. USA = United States of America, USA is included as reference country. HPV = human papillomavirus, VIA = Visual inspection of the cervix with acetic acid. Congo, DR = Democratic Republic of the Congo.

“—” indicates no data found or reported.

*Based on 2013 population-based survey, n = 11,857, age 21-65, within last 3 years.

^a Demonstration project only.

^b Method depends on screening age: age 25-69 (cytology), 30-50 (VIA), 30-69 (HPV).

^c Based on 2012 population-based survey, n = 13,852, age 20-59, ever screened.

^d Based on 2010 population-based survey, n = 6,339, age 18-69, every 1 year.

^e Based on 2003 population-based survey, n = 8,777, age 15-49, within last 2 years.

^f Based on single 2015 urban study, n = 441, age 18-49, ever screened.

^g Based on single 2012 urban study, n = 222, ≥20, ever screened.

^h Based on statistical modeling from 2013, ever screened.

ⁱ Based on 2003 population-based survey, n = 3,486, age 25-64, every 3 years.

^j Based on 2012 population-based survey, n = unknown, age 14-55, every 3 years.

^k Based on 2003 population-based survey, n = 1,007, age 25-64, every 3 years.

‡ 1994 birth cohort has the highest percentage coverage: 64.2% for one dose and 44.5% for the full-course.

‡‡2018 Females 15 years and older: 85% first dose and 56% full HPV vaccine series.
Data Sources: HPV Centre Human Papillomavirus and Related Diseases Report for respective countries, version 17 June 2019; Gavi: The Vaccine Alliance country hub data; WHO.

**CHAPTER 5: Self-collection of samples for HPV testing to increase participation in
cervical cancer screening by immigrant women: An integrative review**

This is the accepted version of the following article: Elmore CE, Laughon K, Mitchell EM. Self-collection of samples for HPV testing to increase participation in cervical cancer screening by immigrant women: An integrative review. *Public Health Nursing*. 2020;37(5):677-695, which has been published in final form at <https://doi.org/10.1111/phn.12782>. This article may be used for non-commercial purposes in accordance with the Wiley Self-Archiving Policy [<http://www.wileyauthors.com/self-archiving>].

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Abstract

Objective

To examine methods and results of studies assessing self-collection of cervicovaginal samples for human papillomavirus (HPV) testing by immigrant women for insights into how future research using this method with unique sub-populations of women may improve rates of cervical cancer screening compared to current strategies.

Data Sources

Four electronic databases were systematically searched through March 2020, with no limits applied. A manual review of reference lists was also completed.

Study Selection

The search resulted in 63 articles. After removal of duplicates, 36 were reviewed against inclusion criteria. A manual review of reference lists yielded two additional studies. The final sample included 15 relevant publications representing 13 unique empirical studies.

Data Extraction

Data related to study methodology and empirical results were extracted into table form.

Data Synthesis

The methods of the studies were summarized and synthesized, including diversity of participants, community engagement, including collaboration with public health nurses or community health workers. In addition, methods and findings related to the educational components of the studies, and empirical findings related to various cultural groups, were described.

Conclusion

To reduce health disparities in cervical cancer screening, researchers should focus on diverse groups, such as immigrant women, to understand important individual and group-specific factors

that may influence screening, including whether self-collection of samples for HPV testing, along with appropriate education and support for follow-up, will address these factors.

Keywords

cervical cancer screening, self-collection, immigrants, integrative review

Background

Cervical cancer is the fourth most commonly diagnosed cancer in women worldwide, and 90% of cervical cancer deaths occur in developing countries.¹ When immigrant women resettle in developed countries, they may still be at risk for cervical cancer mortality if they are not able to participate in screening programs in their country of resettlement. Women who are foreign-born living in the United States (U.S.) are nearly three times as likely to have *never been screened* for cervical cancer than women who are U.S.-born (18.6% vs 6.7%).² Other recent studies using U.S. population-level data also support the fact that immigrants have a significantly lower odds of adherence to CCS compared to U.S.-born women.^{3,4} Miranda et al.⁴ found that these disparities persist regardless of citizenship status in the United States, noting in particular significantly lower odds of CCS adherence for non-citizens who have lived in the United States for less than five years, compared to U.S. born citizens (OR=0.65 [0.54-0.78 95%CI]).

Early detection of precancerous and cancerous lesions through cervical cancer screening has reduced mortality specifically because there are effective treatments available.⁵ The primary risk factor for cervical cancer is undetected human papillomavirus (HPV) infection, particularly the high risk HPV (hrHPV) sub-types 16 and 18.¹ Because high risk genotypes of HPV cause cervical cancer, primary HPV-DNA testing is now approved for use in cervical cancer screening (CCS) in the United States, but only when collected by a provider in a clinical setting and only for women ages 30–65.^{6,7} Researchers around the world are exploring whether self-collection of samples by women for HPV testing can be used as a potential method for overcoming barriers to screening.^{8–10} *Self-collection*, also called *self-sampling*, is a test in which women collect their own specimens by inserting a collection device into the vagina and following other specific instructions according to the device manufacturer to collect cells from the cervix. Numerous

research findings, including meta-analyses, have demonstrated that self-collected cervico-vaginal samples are at least as sensitive as provider-collected cervical samples for cytology or hrHPV testing when it comes to detecting potentially cancerous lesions.^{8,11–13} Researchers also have found that a large majority of women find self-collection both acceptable and feasible.^{8,14,15} Currently in the United States, self-collection of samples for HPV testing is only approved for use in research settings, however it is emerging as a way to improve equity in CCS if implemented in person-centered, culturally-sensitive ways.

The aim of this review was to critique research design and results of studies assessing self-collection of samples for HPV testing by immigrant women for insights into how future research using this emerging approach with unique sub-populations of women may improve rates of CCS compared to current standards of care. Although there have been other reviews that examined CCS among under-screened, never-screened, or otherwise “hard to reach” groups,^{10,15} we add to the literature by examining the methods and results from studies examining self-collection by immigrant women in order to guide future research design that will inform culturally tailored approaches to self-collection, and to consider the ways in which public health nurses can facilitate the use of this emerging strategy with these unique populations. Although we are aware that experiences vary widely and are dependent on numerous factors including immigration or citizenship status, we use the term *immigrant* broadly to refer to all foreign-born women residing in a country of resettlement.

Search Strategy

We conducted a systematic literature search in PubMed, CINHALL, Web of Science, and Cochrane Library databases. We also searched both PsychNET and Social Sciences Database which yielded no relevant results. The keyword terms used in the search were ("cervical cancer"

OR cervix OR uterus OR uterine) AND screen* AND (self-administ* OR self-collect* OR self-sample) AND (immigrant* OR emigrant* OR refugee*). MESH terms were used in PubMed. Because initial probes into the literature using these terms resulted in a relatively small number of articles, we completed the search with no date, language, or publication type limits. The search was conducted in March 2020.

Articles met inclusion criteria if they (a) addressed methods of self-collection of samples for cancer screening, (b) included immigrant populations, and (c) were original research. Articles were excluded if they were abstracts of conference presentations, study protocols without published results, or reviews with no original empirical results.

The search resulted in 63 articles. Among these there were 27 duplicate articles that were excluded. A manual review of the reference lists of included articles yielded two additional studies that met all inclusion criteria. Titles and abstracts of the 38 remaining articles were reviewed for all inclusion criteria. Twenty-three articles failed to meet inclusion. Figure 1 shows a PRISMA flow diagram of the systematic collection of relevant studies included in our review.

Fifteen articles met all inclusion criteria for our review, representing 13 empirical research studies; in two pairs of papers, authors reported results from different aspects of the same research study.^{16–19} Table 1 (found in published version) includes a matrix of each study's purpose; research design; sample size and characteristics; intervention description; outcome measures; main findings; and limitations. Table 2 (found in published version) includes country where study was conducted, participant language, and location of self-sampling if completed. Given that the studies had different types of research designs (i.e., mixed methods, qualitative methods), our approach was to conduct an integrative review which focused on both the methodology and results of the included studies.²⁰

Review of Study Methodologies

Study Purpose

The purpose of most studies included in this review was to determine feasibility and acceptability of self-collection which was operationalized in varied ways, from qualitative only studies that focused on sub-group specific attitudes and beliefs about self-collection.^{16–18,21–25} all the way through to regional and national implementation with sub-group analysis for differences in uptake depending on delivery method.^{26,27} Three studies focused on CCS completion rates in the self-collection group vs. standard clinic-based collection.^{19,28,29} Two studies also considered whether pairing self-collection with the support of Community Health Workers (CHWs) was culturally acceptable.^{30,31}

Study Design

The majority of the included studies were descriptive, mixed methods design and used purposive sampling. At least 3 studies explicitly used a Community Based Participatory Research (CBPR) approach, and others reported collaboration with community partner organizations. Five studies were randomized controlled trials (RCTs); two were country-wide implementation trials. Research designs, sample size and characteristics, and other study features are summarized in Table 1.

Heterogeneity of Participant Demographics

Among the 10 studies that did not use population-based screening registries for recruitment, there were 2,110 total participants identified as immigrants. Across studies there was heterogeneity of participants demographic characteristics, and in how these characteristics were reported, limiting our ability to draw conclusions about immigrants as a group.

Study location. Seven of the studies were conducted in the United States, two in Canada, two in Finland, and one each in the United Kingdom and Denmark (Table 2).

Countries of origin and languages spoken. In terms of countries of origin (i.e., country of birth) and languages spoken, most researchers provided some detail although there was a lack of specificity in some cases. The most well represented immigrant groups include Creole speaking Haitians and Spanish speaking Hispanics living in Miami, Florida, United States.^{24,26,30,31} The vast majority of Spanish speaking participants in the studies reviewed came from Mexico^{21,25}, but other countries in Central and South America were represented in small numbers.^{21,23–25} Somali speaking individuals were represented in two small studies.^{23,28}

Howard and colleagues²³ conducted focus groups with women representing six ethnolinguistic groups. These groups included Canadian-born English speakers, plus an English-speaking group and a native language group of native speakers of Arabic, Cantonese, Somali, Dari and Spanish where the sample size for each group was nine or fewer; for this study the researchers only specified the country of origin for the Cantonese language speakers from China, and the Dari language speakers from Afghanistan. Authors noted that the Spanish speakers were from “Central America,” and no countries of origin were noted for the Arabic speakers.²³ In all of the above-mentioned studies, language interpretation and translation were provided for participants. In a study focusing on self-identified Muslim women, where country of origin was noted as being either from Iran, Pakistan or India, participants were required to speak English “well”, though it is important to note that no measure of English fluency was given.¹⁶ Counts of languages represented in the studies are found in Table 2.

Defining “immigrant”. In the Danish study, immigrants were only generally classified as either “Western” ($n = 682$; top 3 countries of origin: Poland 18.3%, Romania 14.8%,

Lithuania 8.2%) or “non-Western” ($n = 962$; top 3 countries of origin: Syria 12.6%, Turkey 10.5%, Lebanon 7.9%).²⁷ In the studies conducted in Finland using population-based screening registries, immigrants were distinguished only by the fact that their native language was *not* either Finnish or Swedish, the two official languages of the study country.^{18,19,29} Virtanen¹⁸ noted that of those presumed to be immigrants ($n = 375$), the five most common languages (representing 63% of 375) were Russian, Estonian, Thai, Chinese and Japanese; in this study, materials were provided only in Finnish or Swedish.

Length of residence in country of resettlement. Some authors reported how long participants had lived in their country of resettlement, but they did not all use the same time frames, making comparisons challenging. The most frequently noted time frame was 10 years, more or less, living in the country of resettlement.^{16,25,28,30} Only Ilangovan and colleagues reported on the citizenship status of their study participants.²⁴ Authors from only two of the 15 studies provided analysis of the relationship between length of time a participant had lived in the country of resettlement, or citizenship status, with specific outcome measures.^{28,30}

Ages. Across the 13 studies (and 15 manuscripts), there were nine distinct age ranges (noted in Table 1) used for participant inclusion criteria; the variation appears to reflect either study setting, study design, or both; or concurrent CCS guidelines in the country where the study was conducted.

Data collection instruments. There was inconsistency in instruments used to collect data from participants making it difficult to compare these findings across studies. Authors of three studies reported that the qualitative questions about health behaviors used were adapted from previous surveys and translated into the appropriate language(s) for their study participants.^{18,24,30}

Type of Self-collection Device

There are several devices that have been approved for research using self-collection for HPV testing. Table 3 (found in published version) summarizes the types of devices used in included studies, plus whether participants actually used, or were only shown, the devices. In three of the studies, the authors did not specify which type of self-collection device was being considered^{16, 28, 31}; in two studies, cotton swabs with transport media²¹ or fixative solution²³ were used. In two studies the POI/NIH self-sampler^{24,26} and the Delphi Screener^{TM18,29} were used respectively. Further, one study each utilized cytology broom²⁵; the Digene kit²² (Forrest et al, 2004); and the Evalyn® Brush²⁷ respectively.

Reporting on HPV Testing & Results Notification

In the ten studies in which participants self-collected a sample (77% of studies wherein self-sampling was employed and not just shown/discussed), four research groups reported the number of samples received that were adequate versus inadequate for HPV testing: ([n = 246, 97%]³⁰; [n = 121, 98%]²⁴; [n=263, 99%]³¹; and [n=920, 98%]¹⁹ There was no information on adequacy of the samples self-collected by the participants in the other studies.

Of the studies with participant self-collection, Barbee et al.³⁰ and Ilangovan et al.²⁴ reported that CHWs were involved in notifying participants of abnormal results and assisting those participants with positive results needing subsequent follow-up. Several other studies contained non-specific information on follow-up. In one study, authors indicated that participants were notified of results within one week and invited all participants to a clinic at a local hospital for Pap test (whether or not the HPV result was positive or negative, since self-collection for HPV testing was done as part of a research study, and is not the currently approved standard of care in the United States), but did not say who notified the participants or what follow-up support was provide.d²¹ Montealegre et al.²⁵ indicated that participants were notified about their hrHPV

results by telephone in 3-5 days or through certified mail²⁵ and all participants were advised to obtain a Papanicolaou test (or co-test) since it was the contemporary screening recommendation. Only 2% of the participants were unable to be reached about the results of their self-collected sample. Notably, this was the only study in which a nurse case manager who assisted with helping to schedule appointments for follow-up was mentioned. In the third study, Sewali et al (2015) simply reported that participants “will be notified” and will be “strongly encouraged” to get follow-up with a clinic based Pap test with no other details provided.²⁸

Researchers’ Partnerships with Community

In the study settings where a national screening registry was not used for recruitment, one commonality that emerged was the involvement of community members or organizations to identify and recruit participants, and to conduct aspects of the study itself. Several research teams used existing networks of CHWs, or lay health workers, to recruit participants and conduct the study.^{21,24,26,30,31} As previously described, a nurse case manager was a key part of one study after test results were reported.²⁵ Howard et al.²³ included fieldworkers that belonged to the included immigrant groups, while another research team incorporated research assistants who self-identified as belonging to the same group as the participants and had existing relationships within the community.^{16,17} Similarly, Forrest et al. engaged ethnically matched community researchers to recruit participants from social and community groups.²² Of the two remaining studies, one partnered with a national consulate which assists underserved immigrants from that nation²⁵, and one partnered with a community based organization.²⁸

Methodology and Findings from Educational Components

Each report provided some level of detail about the quality and extent of education (specific to either cervical cancer, HPV, and/or self-collection) provided to participants during

the study. Some of the studies also contained information about what women expressed either directly (in open-ended question responses) or indirectly (using measures that assessed attitudes and beliefs) about their confidence and comfort with self-collection. In one study, the researchers noted that well-trained CHWs instructed women using detailed pictures (which were included in the manuscript).³⁰ In this study, despite 97.5% of women saying that they felt comfortable with self-collection and 98.4% of participants saying they would recommend it to a friend, some participants also expressed concern that they were not sampling from the right place inside their bodies and also expressed that they had more confidence in a doctor's ability to do the test correctly than they had in their own ability.

For a diverse group of Spanish speaking participants, the majority of whom (89.4%) were from Mexico, authors reported that instructions were provided in Spanish and then lay health workers verbally instructed the women on self-collection.²¹ This study used a four-point Likert scale to assess degree of satisfaction in four categories. The researchers reported that younger, more educated, and non-Mexican origin Hispanics were more likely to express excellent satisfaction with self-collection compared to provider-collected Pap testing. Most women (>80% of the sample) reported excellent or very good clarity of instructions, ease of use, and understanding what the results of the screening meant, though it's not clear that women were given an opportunity to express open-ended feedback about the experience.

In one qualitative study with small groups diverse participants meeting in focus groups, women were shown the self-collection swabs and collection tubes, in addition to a diagram and written instructions.²³ In that study, the researchers reported that some women were concerned about obtaining accurate results and that women specifically suggested that they improve the diagram and instructions before implementing self-collection. Similar results were found in the

study by Forrest et al. where each participant was provided with basic information about HPV and shown a self-test kit.²² In this study, 55% of women reported that they would worry they had not done the test properly. These researchers also found statistically significant differences by national origin on the question about worry that the test had not been done properly (66% of Indian and 70% of African-Caribbean women compared to 33% of White and 49% of Pakistani women, Chi-square $p = 0.005$).²²

In one study conducted in a clinic setting, CHWs provided a short information session with flipcharts, explaining both Pap testing and self-collection for HPV testing; the authors noted that this was done also in the context of explaining the study design which included follow-up and navigation support for any positive results.²⁴ Women were asked for feedback using a 12-item acceptability survey which was based on a three-point Likert scale; of the 121 women who tried self-collection, 97% found the device easy to use and would recommend it to others, and 96% agreed that they felt they performed the self-collection test correctly.

In one early qualitative study to assess acceptability, self-collection for HPV testing was defined in written materials and women were given demonstrations of self-collection kits, which were circulated among women in groups so they could hold and examine them, though they did not try self-collection themselves. The researchers reported that several women said how important it would be to have clear, simple instructions, in one's native language, on how to perform the test, while other women said they lacked confidence in their ability to self-collect.^{16,17}

Montealegre and colleagues provided information to participants in a Spanish language instructional brochure with pictures and step-by-step instructions (which were included in the published report).²⁵ Despite initially reporting concerns about fear, safety, cleanliness, not

feeling comfortable touching themselves and not knowing how to do the self-collection, after self-collection 91% reported being very willing to use it regularly, and 98% felt the instructions were easy to understand. After receiving this instruction and trying it themselves, 69.2% reported that it is *more convenient* than a Pap test, while 87.2% reported that a Pap test is *more stressful* than self-sampling; this further supports the finding of positive attitudes towards the self-sampling.

As part of their study design, Sewali et al. provided hour-long information sessions about at-home self-collection and clinic-based Pap test collection using printed materials with both text and illustration.²⁸ These researchers reported that of those who were randomized to self-collect samples, all participants indicated that the instructions were easy to follow and they had no difficulties in collecting the samples. Sewali et al. found that Somali immigrants who had lived in the United States longer were more likely to complete screening (OR per 1 year longer: 1.23; [95% CI: 1.05-1.44], $p = 0.011$).²⁸

Virtanen et al. reported that over 90% of participants felt self-collection was easy and instructions were clear, although instruction provided to the participants was not described.¹⁸ However, they also noted that the group presumed to be immigrants in their study were statistically more likely to experience anxiety and fear during self-collection, and a non-significant difference in experiences of discomfort or unpleasantness while self-collecting.

Of the four larger randomized controlled trials, one mentioned that the use of written and picture-based instructions all in Danish²⁷; two studies reported that they assessed cervical cancer knowledge,^{26,31} but since the primary outcome was uptake of self-collection in settings where acceptability had already been assessed, there was little detail about educational components or women's feedback on confidence and comfort. Lastly, Virtanen and colleagues reported that the

self-collection arm received a data sheet about HPV infections and CCS (which would have also been shared during a routine clinic screening visit), along with the self-collection kit and informed consent; no specific details about how instructions for use of the kit were included.²⁹

Empirical Findings Related to Culture or Acculturation

Culture or acculturation of immigrant sub-groups may impact acceptability of self-collection. Barbee and colleagues noted that the Haitian immigrants in the Miami area had very consistent positive responses to questions asking about acceptability of self-collection.³⁰ However, there was variation in participant reports of pain or discomfort in using the device (40.8% had pain or discomfort compared to 59.2% who did not). The researchers, therefore, conducted additional analysis and found that factors including years lived in the United States, a frequently used proxy measurement for acculturation, were not statistically significantly related to this experience of pain or discomfort. In addition to noting that future research would need to examine this difference more carefully, the researchers speculated that the use of culturally-specific feminine hygiene practices intended to clean, dry and tighten the vagina may have affected the experience of self-collection for some participants. This is an important observation which seems a direct result of the researchers' familiarity with this cultural group: the awareness that there are unique qualitative factors that may influence pain or discomfort would not have been revealed through the generic questions asking about acceptance and feasibility of self-sampling, or through doing statistical analysis on variables derived from such questions.

Forrest et al. found significant differences in demographic characteristics such as marital status, age at which they left education, and previous Pap test between the four groups they surveyed (White, Indian, Pakistani and African-Caribbean) and despite this, only 2% of their entire sample reported that self-sampling would go against religious or cultural beliefs.²² This

suggests that, in general, self-sampling may be widely accepted across cultural groups even when they have varied characteristics.

Howard and colleagues interviewed women from various ethnolinguistic groups, and at the recommendation of community partners in certain groups (not otherwise specified), invited only women who were married and had children, as it was felt that they would be the only group for whom it would be culturally acceptable to have conversations on topics generally considered to be private bodily issues.²³ The Chinese speaking women in this same study noted that because of cultural unfamiliarity with tampon use, participants in this group would not find self-sampling as acceptable as another group might. Arabic speaking women in this study expressed a strong preference for female providers (whether nurses or doctors) when seeking care, particularly if related to women's health visits.

In one study which focused on self-identified Muslim women, country of origin resulted in some differences in attitudes: 85% of women from Iran indicated that they would prefer self-sampling over clinic-based Pap test, whereas only 23% of women from Pakistan/India preferred self-sampling ($p = 0.002$).¹⁷ This study did not provide sufficient detail about other differences between these two geographically distinct groups of Muslim women (like level of education, employment status or annual household income) which might account for the difference in preference. However, the same study noted that younger women aged 21–39 years were more likely to prefer self-sampling compared to older women age 40–61 (93% vs 44% ($p = 0.007$)) citing privacy and convenience as the primary reason for the preference.¹⁶

In another study, a few participants were unable or unwilling to obtain follow-up because of fear of disclosing their undocumented status.²⁵ Lastly, women from a Somali speaking cultural

group revealed that they did not know about cervical cancer, about risk factors for getting cervical cancers, or about why screening for cervical cancer is important.²⁸

Discussion

Beyond the studies included in this review which focused on immigrant women, ample research has demonstrated that self-collection for HPV testing, regardless of device, is generally both feasible and acceptable for women across the globe.^{13,14,33} The researchers whose papers were included in this review have begun to explore whether self-collection for HPV testing could help to overcome barriers to CCS for immigrant women who are persistently at risk for being under-screened in their countries of resettlement. Of note, each of the studies included in this review were conducted in developed countries with national CCS guidelines (UK, Canada or United States).

The large majority of the studies reviewed used descriptive research designs, with purposive, non-random sampling strategies. Participant characteristics, like length of residence in country of resettlement, age, and the way “immigrant” was defined were heterogeneous across studies, making comparisons difficult. The sample size of represented countries of origin and language was often small, and language seemed sometimes to be used as a proxy for country or cultural group of origin. While primary language has been used as a proxy for ethnic or cultural group in other studies, this can be a problematic assumption when languages are globally widespread, as in the case of Spanish and Arabic. The same limitation applies when a religious grouping is used as a proxy for cultural or ethnic differences, as can be seen in the variation among participants in the study assessing Muslim women’s attitudes.¹⁶ That there is not enough group specific detail (for example, about countries of origin of Spanish speakers), or that these studies don’t include large samples sizes for certain sub-groups, like the 7 Arabic speakers

(country of origin unknown), highlights the fact that we have only a sprinkling of information about certain groups of immigrants, and are lacking detail about other sub-groups, indicating that more research is still needed.

Most of the authors of these studies provided some information on the questions asked of participants, however the lack of consistency in both quantitative and qualitative data across studies limits direct comparisons. None of the reports contained specifics about instruments used for measuring participant characteristics like language proficiency (for the primary language in the country of resettlement), health literacy, or acculturation, which have all been found to be facilitators or barriers to obtaining appropriate preventative and follow-up care for immigrant populations.^{34–36} Length of time residing in the country of resettlement has been shown to have an impact on completion of cancer screenings,^{4,37} and was a demographic variable that was documented in some of the reviewed studies, but lack of standardized categories made it difficult to draw conclusions of the effect of this characteristic as well. Future studies could improve validity and reproducibility by using standard, validated measures when available,^{38,39} and by reporting on these measures when findings are disseminated.

While self-sampling of samples for HPV testing among immigrant women was the intervention being considered in this review, there was variation across studies as to whether participants only received information about self-collection, or whether they actually collected a sample themselves to assess their willingness to use this method of screening. In these studies, self-collection was done primarily in a home or community setting, though in one study self-collection was done in a clinic setting. If one of the primary barriers to CCS is making a visit to a healthcare provider's office, self-sampling outside of a clinic setting may help to overcome this barrier. The studies in this review did not provide sufficient evidence to draw conclusions about

this, so we suggest that future studies should establish whether location mitigates barriers specifically for women who are immigrants.

The study authors did not consistently report on whether the self-collected sample contained an adequate specimen which could be tested for HPV-DNA. It is worth noting that even those researchers who reported the adequacy of samples did not provide enough evidence to make the case that immigrant women in particular were or were not able to capture adequate samples while self-collecting. However, studies across other more general populations have demonstrated this capability sufficiently and there is no reason to believe that immigrant women can't do this well.¹² While urine-based tests are being considered as a potential method for CCS, they are not yet approved for primary cervical cancer screening and are beyond the scope of this review.⁴⁰

Reporting was inconsistent regarding how follow-up was conducted after results of samples were obtained, in cases where samples were actually self-collected. Screening can be effective only when women who have abnormal results are able to access required follow-up care, and this should hold true in research settings as well as clinical settings. Although some of the published reports did not contain full details, the character of follow-up and support after screening with self-collection in some studies appeared to be related to how the researchers were connected with community groups. Most of the studies benefited from strong community partnerships and researchers who were very familiar with the communities. Indeed, all of the researchers who recruited participants engaged members of the local community in the study design and assessment of outcome measures. Appropriate approaches to solving issues related to health disparities among diverse groups will likely be found when they are informed by community members and reflect specific, local knowledge about particular groups and

individuals. Future research on CCS among immigrant women should include plans for follow-up, test effective follow-up support strategies using public health nurses in collaboration with professional or lay health workers, and report on these findings.

Importantly, the synthesis of the educational components of the studies revealed that women expressed the need for clear, simple instructions in their native language. Further, the findings suggest that providing information to immigrant women around the importance of CCS, the value of HPV testing, and how to properly perform self-sampling could improve the confidence of women in doing the test, which would further support their willingness to complete CCS. Providing clear and appropriate education to individuals and communities is an important role for which public health nurses are uniquely trained.

Lastly, the precise legal status of immigrants in a country of resettlement can have an impact on local conditions that may facilitate or inhibit access to care regardless of other factors, and therefore change participation in preventative health care programs like cancer screening. For example, women who arrive in the United States under the legally defined status of *refugee* generally receive guaranteed access to public health insurance for at least the first 8 months after arrival.⁴¹ This automatic access to public health insurance is not guaranteed for other types of immigrants in the United States and may not be available in other countries of resettlement. Kobetz et al. noted that concerns about immigration status may have kept women who participated in their study from using mailed self-collection kits because of discomfort in using a government-run post office.²⁶ As a matter of social justice, future research should consider how

CCS can be implemented for all residents, regardless of legal status.

In addition, countries of origin of different immigrant groups may not have nationally recognized screening guidelines or screening programs,⁴² so individual women may be unfamiliar with this

and other preventative care strategies. In order to better understand the needs of immigrant women, it is important for public health nurses to know whether participants in research settings and patients in clinical settings may have been exposed to CCS in their countries of origin, including whether a national CCS program existed and what percentage of the age-eligible female population would have been covered by screening. This knowledge is an important first step in assessing potential gaps in knowledge and past screening behaviors of specific sub-groups of immigrant women.

Despite some limitations, the studies included in this review did provide valuable insights into some culture specific aspects of CCS, and the acceptability and feasibility of self-collection among diverse women. There are numerous and varied barriers which impact access to health care for immigrants, including lawful residence in the country, ability to obtain insurance, limited proficiency in the language of the resettlement country, along with a host of other factors common to all women including difficulty with transportation or childcare, and difficulty taking time off work. These studies reveal that there will likely be heterogeneity even within groups, which should be expected. This reinforces the fact that stereotyping racial, ethnic or cultural groups to find a one-size-fits-all approach to improve CCS is not advisable.⁴³

Conclusion

In the National Academy of Medicine report on health disparities, one important recommendation was that future research should focus on sub-populations of conventionally defined larger racial and ethnic groups, recognizing that for these sub-groups, health and health care is affected by language and cultural differences, legal or immigration status, having a usual source of care or not (i.e. having a primary care doctor), having health insurance or not, and other factors that impact access to care.⁴⁴ It is noteworthy that the researchers who conducted the

studies reviewed herein have focused in on very specific sub-groups to reveal important group-specific factors that may influence rates of CCS through HPV testing of self-collected samples. Although research focusing on the potential for self-collection by women who are immigrants is notably limited now, findings from each study reviewed revealed important cultural dimensions that reflect the rich diversity of patient populations and can help to inform future research aimed at reducing disparities in CCS for individual patients and the unique cultural groups to which they belong.

Future research on health disparities in CCS for immigrant populations should continue to include how factors (like country of origin, age, educational level, to name a few) influence women's adherence to current CCS guidelines. Similarly, the U.S. Preventative Services Task Force recommends further research into whether self-collection for HPV testing is acceptable and feasible in a variety of settings and populations.⁴⁵ It is important to understand the answer to these questions so that clinicians can understand with some certainty whether self-collection methods will address these barriers. A necessary component of screening programs includes insuring that all who are screened are able to obtain follow-up for abnormal results. Future research should explore how participation by public health nurses, professional CHWs, lay health workers, case managers and others can assist immigrant women to overcome barriers to follow-up once screening is completed.

Public health nursing is at the nexus of health promotion and disease prevention, and framed by a health equity lens. As cervical cancer is largely preventable, and as the World Health Organization is currently aiming toward eradication of cervical cancer, public health nursing research in the United States focused on innovations in CCS is imperative. Additionally,

focusing on sub-populations who experience additional barriers to accessing existing services is key to improving health equity.

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CHAPTER 6: Conclusion

Synthesis of Results

Aim #1 Summary

Overall, 60.0% of the sample were up-to-date (UTD) on cervical cancer screening (CCS). This compares to 80.7% of all women living in the United States and to an overall target rate of 93.0% set by *Healthy People 2020*.

Aim #2 Summary

Considering only bivariate relationships between independent variables and the outcome, there were significant differences in the outcome related to age group, marital status, having at least one child, and number of years lived in the United States. While controlling for all other variables, logistic regression models consistently showed that women in the 30–49, and 40–49 age groups had statistically higher odds of being UTD on CCS compared to the youngest age group. Having ever been married doubled the odds of a woman being UTD on CCS, compared to women who were never married. Having had at least one child increased the odds of a woman being UTD two-and-a-half fold compared to women with no children. We found that *years lived in the United States* was a significant predictor in the univariate model; in the multivariate model, it approached significance for the group of women who had lived in the United States for ≥ 10 years, while controlling for all other variables.

Aim #3 Summary

When we explored cervical cancer control (CCC) policies and strategies for countries of origin of women who resettle in the United States as refugees, we found that women who arrive in the United States as refugees are likely to have countries of origin where national programs for secondary prevention through cervical screening are not robust, do not use high-performing

screening tests, and have low coverage of the population. Only one of the examined countries offers primary prevention of cervical cancer by HPV vaccination.

Full Dissertation Summary

This dissertation adds additional evidence that foreign-born women in the United States, including those who resettle as refugees, represent an underserved group when it comes to CCS. Based on the results of this study, focused attention should be paid to increasing opportunities for CCS for sexually active women in their twenties, including those who have never married and have no children; plus, to women over the age of 50 who may have not been adequately screened in their lifetime. Other notable factors for this sample include practicing Buddhism and living in the United States for less than 10 years. However, we note that there are mixed findings about these factors, which suggest that particular attitudes and beliefs of diverse sub-groups generally, and of patients as unique individuals more specifically, should continue to be assessed in clinical settings and in research.

Strengths of the Dissertation

This analysis was strengthened by the fact that we used electronic medical record (EMR) data to determine the outcome variable, which means that determining the outcome variable of Aim 2 did not rely on participant recall. This study contributes to existing knowledge by using an established refugee clinic database to examine rates and predictors of CCS for refugee women living in the United States. To our knowledge, our study represents the largest sample of refugee women residing in the United States that examines the question of cervical cancer screening adherence using clinical laboratory results. In addition, the dissertation describes country-level factors that may influence participation in CCC measures, whether by primary prevention through HPV immunization or secondary prevention through cervical screening.

Limitations of the Dissertation

It is possible that individuals in the sample may have received testing elsewhere (for example, young women who have moved away for college) which means that our findings may have underestimated the proportion of women in the Clinic's population who are UTD. At the same time, our sample included only women who have actively sought medical care in our Clinic in the past 3 years, which may bias the overall rate of being UTD on CCS upward. EMR data were lacking for some variables with known influence on CCS uptake: household income; employment status; current health insurance status; and knowledge, attitudes, beliefs about cervical cancer and CCS.

There are cultural nuances across countries of origin and language that are difficult to capture in quantitative analysis, and we recognize these limitations. We also recognize that some variables commonly used in quantitative analysis in the United States – like ethnicity and race – are not appropriate for foreign-born individuals.

Finally, the Clinic's patient population is unique and reflects trends in refugee resettlement in Charlottesville, Virginia, while in different parts of the country the diversity of residents who arrive as refugees may be quite different. Therefore, these results may not be generalizable to groups of women who arrive as refugees in other parts of the United States or to women who were not otherwise represented by the sample.

Future Directions for Research and Practice

This study lays the groundwork for additional mixed-method research focused on understanding particular barriers and facilitators that are unique to refugee populations and sub-populations living in the United States, with the eventual goal of developing tailored interventions that will decrease disparities in primary and secondary prevention of cervical

cancer. Future directions could include testing interventions at multiple social ecological levels of influence. A focus on patient knowledge, attitudes and beliefs could be paired with culturally specific education on both CCS and HPV vaccination. Community members and stakeholders, including the women themselves along with community support workers and healthcare providers, could be provided with additional training around awareness of CCS disparities, particularly for women who are in their early years of resettlement in the United States under refugee status. Organizationally, the IFMC and other clinics and health systems could begin to include tracking of CCC metrics using the EMR as part of their larger focus on population health, if they have not already begun to do so. Policies that support equitable healthcare access, like providing extended health insurance coverage and consistent professional medical language interpretation, should be prioritized at the local, state and federal levels. Finally, the science supports self-collection of cervical samples as an effective way to improve access to screening for this population and for many other under-screened groups. Additional studies with unique sub-groups like the ones included in this study's sample could add support for policy that would make self-sampling for CCS available for routine use.

Final Conclusion

The ultimate aim of this research is to help ensure that women who arrive in the United States as refugees are able to achieve equity in their health status relative to other women who live in the United States and enjoy the highest quality of life for the longest time. My hope is that this work will allow us to take a few steps forward toward equity, not only for the women who live nearest to me, but for women across the country and across the globe.