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Beyond Resettlement: Sociocultural Factors of Preventive Health and Cancer Screening among Afghan Refugee Women

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in Nursing

by

Hafifa Siddiq Shabaik

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ABSTRACT OF THE DISSERTATION

Beyond Resettlement: Sociocultural Factors of Preventive Health and Cancer Screening among Afghan Refugee Women

by

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Doctor of Philosophy in Nursing
University of California, Los Angeles, 2018
Professor Eunice Eunkyung Lee, Co-Chair
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Afghan refugee women who have been resettling in the US since the 1980's are now aging and may face multiple layers of disadvantage, experience increased burden of disease, and face challenges to equitable access to preventive health screening. While research with refugee women's health prioritizes the assessment and treatment of communicable diseases, there is a paucity of research which seeks to understand social and cultural factors influencing preventive health behaviors beyond their initial resettlement. This study used focused ethnography methodology to explore women's perceptions of influences on health, mammography, and colonoscopy screening among a sample of Afghan women over the age of 50. Fourteen women participated in open-ended, semi-structured interviews. Interviews with their family members (n

= 5) and key informants (n = 8) from the Afghan community provided richer descriptions of women's context and social influences.

The findings of this research are presented in three manuscripts. The first manuscript is an integrative review of published literature of Afghan and other Muslim refugee women's preventive cancer screening behaviors in high-income countries of resettlement. This study found multi-level influences on women's screening behaviors and lower rates of mammography, colonoscopy and Pap smear use among refugee women compared to rates among the general host country's population. Findings also establish that resettled refugees from Muslim majority countries are understudied and underrepresented in health promotion interventions. The second manuscript is a qualitative study of Afghan women's perceptions about health and sociocultural influences on health-related behaviors. Afghan women reported holistic health beliefs as well as family-centered and religion-informed motivation for healthy behaviors. This study offers new insights on Afghan women's health concerns and health experiences as they continue to age in the US. The third manuscript is a qualitative study exploring sociocultural factors on women's perceptions of breast and colorectal cancer and screening. Screening behaviors were influenced by culturally-informed beliefs about cancer, poor and inadequate communication with providers and the need for support from family and community in navigating the US health system. This study offers new insights into patient empowerment factors for Afghan women to obtain screening repeatedly, including religious coping and family support. Future screening and health promotion interventions should incorporate women's cultural explanatory models of illness and religious and family-centered approaches.

The dissertation of Hafifa Siddiq Shabaik is approved.

Janet C. Mentes

Qais Alemi

Carol L. Pavlish, Committee Co-Chair

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2018

Dedication

Bismillah ir-Rahman ir-Rahim,

This work is dedicated to my family and the Afghan men and women who participated in this study. I am deeply honored to carry your words.

Remembering
Steaming green tea and cardamom
Your grief and longing for what was
Gentle and never-ending offers for something sweet
A voice that carries the weight of the world
Tearful eyes that long for family, unseen
Comforting arthritic hands
This is a gathering of memories
Your worries
Never ending

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I. INTRODUCTION

II. CHAPTER ONE

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PEER REVIEWED PUBLICATIONS

Alemi, Q., **Siddiq, H.,** Baek, K., Sana, H., Stempel, C., Aziz, N. & Montgomery, S. (2015). Effects of perceived discrimination on depressive symptoms in 1st- and 2nd-generation Afghan-Americans. *The Journal of Primary Prevention*. Accepted Sep 2015.

Alemi, Q., Sigrid, J., **Siddiq, H.** & Montgomery, S. (2016) Correlates and Predictors of Psychological Distress among Afghan Refugees in San Diego County. *International Journal of Culture and Mental Health*. doi: 10.1080/17542863.2015.1006647. Accepted May 2015.

Introduction

This study explores factors influencing health and preventive cancer screening of resettled Afghan women in the United States (US). This investigation is an attempt to understand resettled refugee women's health behaviors, years beyond their initial resettlement. The perceptions and experiences of Afghan women's health and screening behaviors are explored and discussed in three manuscripts. Directions for future research as well as recommendations on how to enhance and strengthen existing services and policies for immigrant and refugee women will also be discussed.

Background and Context

Since 1975, the United States (US) has resettled over 3 million refugees and is the largest resettlement program in the world (US Department of State, 2018). Growing conflicts in the Middle East and Africa has driven millions of refugees to seek shelter in neighboring countries, Europe and the United States (US), with over half of the entire refugee population from Muslim-majority countries (United Nations High Commissioner for Refugees [UNHCR], 2016). As the refugee crisis continue to reach unpresented numbers since World War II, and has been increasing since the start of this dissertation, permanent resettlement continues to be the only viable solution for many refugees unable to return to their country of origin (UNHCR, 2018). Limited research suggests that resettled refugees are even more disadvantaged as they face a triple burden of disease, with an increased risk for developing communicable diseases (CDs) endemic in their country of origin, mental health issues from experiences of war, trauma and displacement and an increased risk for developing non-communicable diseases (NCDs) endemic to their host country, putting them at risk for poorer health outcomes (Palinkas et al., 2003; Gerritsen et al., 2006; Morris et al., 2009; McDonald et al., 2017). Despite these concerns, there is a paucity in research that explores social and cultural influences on the health and health-seeking behaviors of resettled refugees, years beyond resettlement.

Who is a Refugee?

In 2017, an unprecedented number of 65.6 million people were forcibly displaced from their homes (United Nations High Commissioner for Refugees [UNHCR], 2017). According to UNHCR (2017), “refugee” is a term used for people who flee war or persecution across an international border. This study refers to Afghan refugees as nationals of Afghanistan who left their country as a result of war or persecution, and Afghan immigrants who choose not to return because of a direct threat of persecution or death, but mainly to improve their lives by finding work, in some cases for education, family reunification or other reasons (Hosseini & Burkle, 2017; UNHCR, 2017). The terms refugee and immigrant are used interchangeably in some of the reviewed literature. It should be noted that the term “refugee” is a blanketed statement that denies the inherent diversity of this population. Refugees are differentiated along intersecting dimensions of gender, age, socio-economic status, and ethnicity. Furthermore, the label “refugee” may be interpreted in a manner that ignores their agency and depicts them as helpless or dependent. Individuals often differ vastly from the labels affixed to them and may disagree with these labels (Lammers, 1999).

Afghan Diaspora

For over four decades, Afghans have been fleeing their country from on-going war and instability, identified as waves of migration: (1) 1980’s Soviet war, (2) 1990’s Civil War and Taliban military rule, (3) post 9/11 US intervention and (4) 2010 as the war in Afghanistan continued (Koser, 2014). The largest wave of Afghan refugees arrived in the United States in the 1980's fleeing the Soviet invasion, with the largest concentration of Afghan refugees settling in the San Francisco Bay Area. (Morioka- Douglas, Sacks, & Yeo, 2004). A general estimate of Afghan Americans range between 100,000 to 300,000, with an estimated 60,000 in California alone, making California home to the largest Afghan American population in the US (U.S. Census Bureau, 2014). Because majority of Afghans who have resettled in the US since the 1980s are now aging, research with resettled Afghans provides an excellent opportunity to examine sociocultural factors on perceived health and the adoption of preventive cancer screening behaviors.

Limited research has been conducted regarding Afghan refugees' health and health behaviors, with notable lack of research among resettled Afghan refugee women. Studies on communicable diseases among Afghan refugees in both developed and developing countries dominate the literature. Established literature of the health needs of Afghan refugees have found a higher prevalence of mental health issues (Alemi et al., 2015) and lower help-seeking behaviors (Slewa-Younan et al., 2017; Alemi et al., 2017). In addition to the prevalence of mental health issues that refugees face, emerging research of the physical health profile of Afghan refugees in developed (Gerritsen et al., 2006) and developing countries suggest that this population may also face increasing rates of chronic diseases (Hosseini & Burkle, 2017).

Afghan Refugee Women

A review of published journal articles and non-peer reviewed dissertation studies confirm that the health behaviors of Afghan refugee women residing in high-income countries is largely understudied. Previous research examined Afghan refugee women's health issues (Lipson et al., 1995), adjustment in San Francisco Bay Area (Lipson & Miller, 1994), intergenerational conflict of Afghan families in California (Omidian, 1992), as well as concepts of gender of Afghan refugees in Pakistan (Hemming et al., 1997). These earlier research findings support existing research in other established refugee groups which suggests that resettled refugee women experience multiple challenges to healthcare access and experience difficult adjustment to life in the US. Recent research regarding Afghan refugee women's health issues focus on gendered experiences of mental health (Alemi et al., 2016; Cole et al., 2013; Stempel et al., 2016), reproductive health (Balsara, 2010; McGinn et al., 2004; O'heir et al., 2004), particularly in early resettlement (Harrison et al., 2004), maternal mortality (Purdin et al., 2009), access to reproductive health services in developing countries (Raheel et al., 2012; Piran, 2004) and integration in Canada (Beg, 2005). There is a need for further research which examines resettled refugee women beyond their identities as a traumatized by war and of child-bearing age, but also, address issues around women's life holistically and contextually. Previous research of refugees resettled in San Diego, provides a strong rationale for conducting new research on the health of resettled refugee women which explores social and cultural factors that influence health behaviors post-resettlement and on culturally appropriate ways to improve their long-term health (Morris et al., 2009). Thus, refugee agencies, policymakers, educators, service providers and other stakeholders may identify culturally-tailored approaches and develop effective health promotion programs to ultimately improve the community health of resettled refugees in general (Krieger et al., 2002).

Breast and Colorectal Cancer and Screening

Research among ethnic minority women residing in high-income countries reports that they are more likely to be diagnosed with advanced-stage cancer and poorer survival rates when compared to the host country's general population (Esnaola & Ford, 2014). This has been attributed to a lack of knowledge about preventive health care services, language barriers, health literacy, socio-economic problems may inhibit refugees to better manage chronic conditions compared to non-refugees (McKeary & Newbold, 2010; Morris et al., 2009). Breast cancer (BC), cervical cancer (CC) and colorectal cancers (CRC) are among the most common and preventable chronic diseases among women, regardless of race or ethnicity, in the US and globally (American Cancer Society [ACS], 2018; Centers for Disease Control and Prevention, 2018). Early detection through screening and timely treatment of BC, CC, and CRC could substantially decrease cancer-related mortality (ACS, 2018). Consequently, expert medical groups, including the US Preventive Services Task Force (USPSTF), National Cancer Institute (NCI) and American Cancer Society (ACS), strongly recommend regular screening for BC and CRC for women, especially over the age of 50 (ACS, 2018; NCI, 2018; Smith et al., 2016; USPSTF, 2018). Despite the evidence that reductions in cancer morbidity and mortality can be achieved through early detection and screening, immigrant and refugee women continue to present with advanced disease (Yi et al., 2011; Suvaja et al., 2015). It is particularly concerning considering refugees may be likely to underutilize preventive health services than their non-refugee counterparts (Barnes and Harrison, 2004; Morris et al., 2009).

Social and Cultural Influences

Islam, the second largest religion worldwide may impact many aspects of Muslim women's health including the use of preventive cancer screening. In the US, the Muslim population is the fastest growing and the treatment of Muslims in the American healthcare system is, as may be expected, often lacking (Ali, Milstein, & Marzuk, 2005; Salman, 2012). Muslim populations have specific beliefs, attitudes, and perceptions that may directly impact healthcare received within a westernized health care system that may not share the unique sensitivities of the Islamic culture (Padela & Zaidi, 2018). It is important to explore the beliefs of Muslim women to fully meet the health care needs of this community (Belut and Ebaugh, 2013).

As a religion, Islam defines social realities and roles which then determine how patients may interact with their providers and how religion may influence their behaviors. For example, several studies find Islam as a factor influencing Muslim women's health behaviors (Walton et al., 2014) as well as reproductive health (Arousell et al., 2016; Budhwani et al., 2018). Islam, then, can be a dominant factor in the interaction of Muslim women within any healthcare system. The relevance of Islam to healthcare is well demonstrated by medical anthropologist, Dr. Arthur Kleinman, who argues that the way that individuals experience health and illness is very much shaped by cultural factors, such as religion, which in part determine when and how they choose to label illness, evaluate its severity, and seek care within a healthcare system (1980). Health care providers can better advocate for their Muslim patients when they have an awareness of the unique beliefs and preferences of their patients (Wandler, 2012).

Family, are also likely to have an important influence on Muslim women's health behaviors and is particularly relevant to Afghan women (Lipson et al., 1995). The influence of family on individual health has been established through studies examining its implication for health (Reblin & Uchino, 2008). Several studies have assessed husband's involvement in reproductive health, family planning and cancer screening (Lee et al., 2013; Shirazi et al., 2013). However, information about family members' involvement in Afghan women's health is limited, especially with regards to preventive health and cancer screening. Seminal research in Afghan women found that husbands' role as gatekeepers were a barrier to receiving healthcare and that husbands had a significant impact on women's access to healthcare and mammography screening due to women's reliance on family members for transportation and interpretation (Lipson et al., 1995; Shirazi et al., 2013). To serve the needs of patients from diverse cultural backgrounds, it is imperative that nursing research and interventions consider factors from ethnic minority women's social and cultural context that may influence health behaviors.

Theoretical Perspective

Social ecology is a useful perspective to help us understand health behavior as determined by a set of interconnected individual and contextual factors (Bronfenbrenner, 1992). The ecological perspective developed from earlier research in biology where researchers were first examining the symbiotic relationships between organisms and their environments, then was further developed in studies of health behavior that considered individual, interpersonal, community, institutional and policy level influences on health behaviors. The model developed by Bronfenbrenner (1992) is particularly relevant to this study because he considered additional contexts that may be relevant to refugee women's health behaviors. The ecological system is the environment divided into five different levels: 1) the microsystem, the most influential, has the closest relationship to the person, and is the one where direct contact occurs, 2) the mesosystem, where interactions between microsystems, 3) exo-system, links between the social setting that is further from personal experiences, 4) the macro-system, described as the cultural context, and 5) chronosystem, where events and transitions occur over the life course (Bronfenbrenner, 1992). This model may be useful in the development of future intervention studies addressing screening disparities, as the SEM has formed the basis for frameworks for violence prevention (Centers for Disease Control and Prevention), the assessment of HIV risk, agricultural safety and barriers to accessing sexual and reproductive health among many others. Therefore, addressing the context of health issues and behaviors of refugees from an ecological perspective may be useful in the development and implementation of multi-level health promotion and disease prevention programs that remains a high priority for this population.

Purpose of the Study

The dissertation study was an effort to address the gaps research in resettled refugee women from a Muslim majority country, Afghanistan, by expanding researchers' and health providers' understanding of the social and cultural context surrounding Afghan women's preventive health: specifically, their perceptions of health, personal health behaviors and cancer screening behaviors. This dissertation has focused upon the development of the first manuscript, an integrative systematic review of studies on the preventive cancer screening behaviors of resettled Muslim refugees in high-income countries. The second manuscript is a qualitative study of Afghan women's perceptions of health and healthcare experiences, collected through interviews between Afghan women, their family members, and key informants. The third manuscript examines sociocultural factors of breast and colorectal cancer screening among Afghan women over the age of 50.

To accomplish the aims of the dissertation, focused ethnography was the methodology applied to explore preventive health and cancer screening, through semi-structured, open-ended interviews with Afghan refugee women, family members and key informants in San Diego County. This study's sample (n = 27) consisted of 14 Afghan women over the age of 50, 5 family members who the women identified as having an influence over their health decisions, and 8 key informants who work with refugees or refugee patients. This study expands the body of knowledge about the preventive health beliefs and behaviors of resettled refugee women from Afghanistan, years beyond initial resettlement.

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Chapter I

An Integrative Review of Resettled Refugee Women's Preventive Cancer Screening Behaviors: A Socioecological Perspective

There is a paucity of research regarding the preventive screening behaviors of refugee women, even after long-term resettlement. The purpose of this study is to review all quantitative, qualitative, and mixed-method studies examining (1) cancer screening rates, and (2) the socioecological factors influencing breast, cervical and colorectal cancer screening among resettled Afghan, Iraqi and Somali refugee women residing in high-income countries. This study utilized a framework synthesis approach to integrate quantitative and qualitative studies, using the Social Ecological Model (SEM). Articles published from 1980 to 2017 were located using PubMed, CINAHL, and Web of Science and a total of 29 articles met study inclusion criteria. This study revealed that preventive cancer screening rates among refugee women are lower when compared to rates among their female US-born counterparts. Commonly reported factors influencing screening were identified as (1) language barriers, (2) low knowledge and awareness of cancer and availability of screening services, (3) provider gender and screening recommendation, (4) family support, (5) delivery of healthcare and health system navigators, (6) community-based collaborations, and (7) religion-informed health beliefs. These findings suggest that resettled refugees experience multiple levels of factors and barriers to screening, and are understudied and underrepresented in preventive cancer screening interventions. We further propose recommendations that may further guide healthcare providers and policymakers in developing evidence-based interventions and improving the delivery of preventive health services for this population.

Keywords: Afghan, Iraqi, Somali, refugee women, cancer screening

Introduction

Despite advances with increased uptake of cancer screening across native populations in the United States (US), disproportionately low mammography, Pap smear and colonoscopy rates among US immigrants and ethnic minorities persist (Gray et al., 2017; Gornick et al., 2004). Since 1980, more than 3 million refugees, or individuals fleeing their homelands from persecution, resettled in the US (US Department of State, 2018). Afghan, Iraqi and Somali refugees represent over half of the entire world's population of refugees (United Nations High Commissioner for Refugees [UNHCR], 2016), whose health beliefs and behaviors are largely misunderstood and underrepresented in health promotion interventions (Padela & Raza, 2015). Previous research has found that resettled refugees underutilize preventive health services, particularly with regards to cancer screening (Morris et al., 2009). This has been attributed to a lack of knowledge about preventive health care services, language barriers, health literacy, socio-economic problems and cultural barriers to healthcare (McKeary & Newbold, 2010; Morris et al., 2009). As refugee populations continue to resettle and age in the US, there is a need to better understand how the social and cultural context influences their health behaviors. This knowledge helps to improve the delivery of culturally relevant health care for this underserved population.

Breast cancer (BC), cervical cancer (CC) and colorectal cancers (CRC) are among the most common and preventable chronic diseases among women, regardless of race or ethnicity, in the US and globally (American Cancer Society [ACS], 2018). Early detection through screening and timely treatment of BC, CC, and CRC could substantially decrease cancer-related mortality (ACS, 2018). Consequently, expert medical groups, including the US Preventive Services Task Force (USPSTF), National Cancer Institute (NCI) and American Cancer Society (ACS), strongly recommend regular screening for BC, CC and CRC for women, especially over the age of 50

(ACS, 2018; NCI, 2018; USPSTF, 2018). Despite the evidence that reductions in cancer morbidity and mortality can be achieved through early detection and screening, immigrant and refugee women continue to present with advanced disease (Cho et al., 2011).

Although the general impression is that migrant populations have lower cancer incidences when compared to native-born populations (McDermott et al., 2011), migrant studies have shown that risk for developing cancer increases in women who move from countries with low incidence rates to countries with high rates (John et al., 2005; Nasseri et al., 2009). Such trends are consistent with research establishing the declining health status of immigrants the longer they reside in the United States (Lee et al., 2014). A study in California shows a sample of Middle Eastern (ME) populations (which included Afghan and Iraqi samples) experience a 2.4 times increase in BC, CC, and CRC cancer rates when compared to the rates in their countries of origin (Nasseri et al., 2013). This study also reported cancer incidence and prevalence of ME populations in the US are lower compared to non-Hispanic Whites (NHW) but are higher than Hispanic and Asian populations in the US (Nasseri et al, 2008). Published reports of cancer incidence and prevalence in refugee populations are extremely limited, due to the inability to capture distinct ethnic affiliations or country of birth in cancer databases (Nasseri et al., 2009).

Research among ethnic minority women residing in high-income countries reports that they are also more likely to be diagnosed with advanced-stage cancer and poorer survival rates when compared to the host country's general population (Esnaola & Ford, 2014). In a recent study that compared overall survival rates between the foreign-born and native-born cancer patients in Sweden, the survival rate was lower in foreign-born cancer patients, who were on average 4 years younger at the time of diagnosis, compared to their counterparts (Abdoli, 2017). Other findings show cancer incidence in refugees (2.6%) and migrants (1.89%) was higher than the general population in Slovakia (0.97%), with mortality rates among the refugees and migrants at 0.839% and 0.681%, respectively, compared with 0.437% in the general population study group (Suvada et al., 2015). In another study, research indicates no difference in higher mortality between refugee status and immigration status (Norredam et al., 2012). These findings support emerging research that refugees may experience higher cancer-related mortality than immigrants, but less than native-born populations (Abdoli, 2017).

Relatively little research has examined the possible multiple disadvantages of Muslim refugee women. Refugee women deal with the loss of family members and status, plus must face cultural, familial and intergenerational conflict in adapting from a traditional patriarchal society to a more egalitarian society (Lipson et al., 1995). Afghan, Iraqi and Somali refugee women represent socioeconomically and culturally diverse populations, and have unique gendered and cultural influences on health-related behaviors. Despite this heterogeneity, there are commonalities in the expatriate experience and religious background of Muslim refugee women, particularly with regards to religion-informed health beliefs. In a systematic review of the literature, researchers have found that general healthcare disparities among Muslims in the US are understudied (Padela et al., 2018). The present study seeks to fill this research gap by synthesizing peer-reviewed literature of preventive screening behaviors among resettled Afghan, Iraqi and Somali refugee women residing in high-income countries.

Theoretical Framework

The ecological perspective could be useful in understanding factors that inhibit or promote cancer screening among diverse populations. The key concepts of the ecological perspective consider multiple levels of influence on health-related behaviors. The Social Ecological Model (SEM) developed by Bronfenbrenner (1992) identifies five levels of influence for health behaviors and conditions (Kilanowski, 2017). This framework emphasizes the multiple contexts that influence behavior. One critical assumption of the ecological approach is that factors across and within each context are interrelated and mutually influential (Moran et al., 2016). For the purpose of this review, we examined commonly reported factors at the: (1) *microsystem* level (factors include individual characteristics of knowledge, attitudes, behavior); (2) *mesosystem* (factors include social networks and support systems); (3) *exosystem* level (institutions, neighborhood); and the (4) *macro-system* level (the social and cultural values). Thus, the health behavior outcome, the woman's cancer screening behaviors, are influenced within these contexts.

Purpose

This study focused on systematically reporting the social-ecological influences on refugee women's cancer screening behaviors. Our aims are to: (1) summarize BC, CC, and CRC screening rates among Afghan, Iraqi and Somali refugee women resettled in high-income countries, and (2) synthesize social-ecological influences of BC, CC, and CRC screening among these three groups.

Methods

To address the first aim, BC, CC, and CRC screening rates were reviewed descriptively across quantitative and qualitative studies. To address the second aim, a framework synthesis of quantitative and qualitative results of peer-reviewed journal articles was conducted (Brannen et al., 2007; Dixon-Woods, 2011). Utilization of a framework analysis to examine factors to the uptake of cancer screening among refugee women, guided by the SEM, is an appropriate analytic strategy because comparing factors across different levels of influence is a part of our second aim. The SEM was chosen for its broad applicability to the research aim. This framework is then modified in response to the evidence reported in the studies in the review, so that the final product is a revised framework that may include both modified factors and new factors specific to the population that may be useful in developing future multi-level interventions addressing screening disparities in this population (Dixon-Woods, 2011).

Inclusion Criteria

Inclusion criteria for this study consisted of peer-reviewed articles that were published starting in 1980 when the annual ceiling for refugee admissions in the US substantially increased (UNHCR, 1981). We define uptake of preventive cancer screening services as services recommended according to the USPSTF (2018) for women over the age of 50: mammography every two years, Pap smear every three years, Fecal Occult Blood Test (FOBT) every year and colonoscopy every 10 years. For detailed screening recommendations, see Table 1. We limited our sample to studies with Afghans, Iraqi and Somali populations residing in high-income countries, defined as high or upper middle-income countries according to the World Bank (2018).

Search Strategy

Relevant peer-reviewed studies were identified through electronic sources including PubMed, CINAHL, PsychInfo, and Web of Science. We applied a string combination of keywords using search terms "cancer screening" OR "breast cancer" OR "colorectal cancer" OR "cervical cancer" OR "breast cancer screening" OR "cervical cancer screening" OR "colorectal cancer screening" OR "pap smear" OR "colonoscopy" OR "mammography" OR "FOBT" for four separate groups “AND Somali”, “AND Iraqi”, “AND Afghan”, and “AND refugee”. Reference lists of literature reviews were also scanned for potentially relevant articles.

Study Selection Process

The three search engines yielded a total of 332 potentially relevant articles. After deleting duplicates, 33 articles were screened for eligibility. After screening titles and abstracts, a total of 26 articles met the inclusion criteria. Figure 1, adapted from the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) (Moher et al., 2009), provides the outlay for our study selection process which included studies relevant to the research questions. Further review of the full text of 34 studies resulted in the exclusion of 7 articles: one study focused on men (Abakporo et al., 2017), one study focused on immigrant women's response to mammography controversy (Nagler et al., 2017) and five studies that did not include the populations of interest (Anaman et al., 2017; Ornelas et al., 2017; Vahabi et al., 2016; Wiedmeyer et al., 2012; Wallace et al., 2014; Zhang et al., 2017).

Data Extraction and Synthesis

A total of 29 articles are detailed by study setting, type of cancer, recruitment strategy and sampling, sample characteristics (sample size, ranges of age/education, types of insurance, etc.), study design, outcome measures, main findings and SEM level of influence to screening addressed (Table 2). Proxy measures of acculturation (migration status, years in the country, language preference, etc.) were also examined if the information was reported. Appraisal of quantitative studies are outlined in Table 3, and appraisal of qualitative studies are outlined in Table 4. Cancer screening rates are summarized separately in Table 5.

Quality Appraisal

Methodological quality of studies was appraised to identify strengths and weaknesses of each article and whether any risk of bias or alternative confounding factors may have influenced results in study findings. Qualitative studies were assessed using the Critical Appraisal Skills

Program [CASP] (2018) checklist, whereas quantitative studies were assessed using a tool developed by Fowkes & Fulton (1991), both of which ensure consideration of several fundamental areas ideally reported in qualitative and quantitative reports ranging from appropriateness of the research design to rigor in data analysis and ethical issues.

Results

Sample Characteristics

The majority of studies (*n* = 21) were conducted in the US, within large refugee-resettlement hubs, specifically in the San Francisco Bay Area, San Diego, Seattle, Rochester, Minnesota, Massachusetts, Philadelphia, Maine, Buffalo and Washington D.C. Several studies were conducted in Canada (*n*=2), United Kingdom (*n*=2), Finland (*n*=1), Norway (n=1) and Netherlands (*n*=1). Study participants from Afghanistan, Iraq, and Somalia were referred to as either refugees or immigrants and ranged in age from 18 to 86 years, dependent on the type of screening being studied. Most studies included participants starting at age 40 for mammography screening, 18 for Pap smear and 50 for colonoscopy screening.

Detailed sociodemographic findings are summarized in Table 2. Most studies included Somali participants (*n* = 21) while Afghans were the least studied (*n* = 6). Two studies interviewed key informants regarding Somali refugee populations (Ghebre et al., 2015; Zhang et al., 2017). Ten studies identified broad racial categories according to Middle Eastern (which identified participants from Iran, Iraq, Afghanistan, Lebanon & Yemen) and African immigrants (which identified participants from Somalia, Angola, Congo, Ethiopia, and Eritrea). From the studies that reported sociodemographic information, refugee women were mostly married, had generally low levels of education, high levels of unemployment, and living in poverty (Carroll et al., 2007; Gele et al., 2017; Gondek et al., 2015; Jillson et al., 2015; Piwowarczyk et al., 2013;

Pratt et al., 2017; Shirazi et al., 2013). Studies that reported insurance status for women reveal that majority of participants had either no insurance or relied on government insurance (Jillson et al., 2015; Percac-Lima et al., 2009). Thirteen studies reported participants as residing in the host country between less than a year to up to 35 years, with majority of studies reporting participants residing in the US for less than 5 years (Adbullahi et al., 2009; Carroll et al., 2007; Gondek et al., 2015; Howard et al., 2009; Redwood-Campbell et al., 2011; Saadi et al., 2012; Samuel et al., 2009). Five studies reported participants residing in their host country for less than10 years (Piwowarczyk et al., 2013; Pratt et al., 2017; Raymond et al., 2014; Salad et al., 2015; Sewali et al., 2015) and only three studies reporting on participants that have primarily resided in the host country for over ten years (Gele et al., 2017; Idehen et al., 2016; Shirazi et al., 2013).

Most studies focused on a single type of cancer (*n* = 20) and the rest focused on a combination of two or more preventable cancers (*n* = 8). Specifically, the majority of studies focused on BC (*n* = 8) and CC (*n* = 11) screening, particularly in Somali populations. Fourteen articles used quantitative methods which included two mixed methods studies, one randomized and six non-randomized intervention studies. Fifteen articles used qualitative research methods (51.7%). Qualitative data was generally collected through in-person interviews (*n* = 6), focus groups (*n* = 6), a combination (*n* = 2) and key informant interviews (*n* = 2). Quantitative studies used a retrospective examination of electronic data or medical records (*n* = 3). Intervention studies employed a quasi-experimental design (*n* = 6) and randomized controlled trials (*n* = 2). Intervention studies (*n* = 8) primarily used an educational component to increase women's health literacy of cancer and cancer screening (Gondek et al., 2015; Jillson et al., 2015; Piwowarczyk et al., 2013; Percac-Lima et al., 2012; Sewali et al., 2015). Mixed methods studies primarily used a combination of retrospective evaluation of medical records with in-person interviews (Idehen et al., 2016; Samuel et al., 2009).

Quality Appraisal of Quantitative and Qualitative Studies

Fowkes and Fulton's appraisal tool for quantitative studies supported the use of cross-sectional studies and intervention studies designed to assess screening rates and factors for screening. Most studies in the sample relied on non-random sampling methods, posing challenges to external validity. All intervention studies were evidence-informed, community-based and adapted previous research and models (Bell et al., 1999; Gondek et al., 2015; Jillson et al., 2015; Sewali et al., 2015; Shirazi et al., 2015) or were tested through previous pilot studies (Piwowarczyk et al., 2013). Only one study reported a basis of the intervention on a theoretical framework (Shirazi et al., 2015) and only two intervention studies addressed cost-effectiveness (Percac-Lima et al., 2008; Percac-Lima et al., 2012).

According to the CASP appraisal checklist (2018) for qualitative studies, all studies' methodologies were deemed appropriate for exploring the subjective perceptions and experiences of participants of this study's sample. Most studies provided sufficient rationale for the methodology and recruitment strategies. All qualitative studies reported ethical considerations through the approval by internal review boards, and most qualitative studies provided sufficiently rigorous analysis of the data.

Research Question 1: Cancer Screening among Refugee Women

To address our first research question, publications investigating cancer screening rates among samples of Afghan, Iraqi and Somali women are descriptively reported below. Table 6 summarizes all studies' cancer screening rates, by screening method and sample.

Breast cancer screening. Rates for mammography adherence, defined as having a mammogram within the previous 2 years, ranged between 15.8% to 34.1% among Afghan women between the ages of 40 and 87 (Gondek et al., 2015; Shirazi et al., 2012), 44% to 44.5% among Iraqi women over the age of 40 (Percac-Lima et al., 2013; Saadi et al., 2012) and between 23% to 46.4% among Somali women over the age of 40 (Piwowarcyk et al., 2013; Percac-Lima et al., 2013) compared to adherence rates found among Black (69%), Hispanic (61%), American Indian/Alaska Native (60%) and Asian women (59%) in the U.S. (American Cancer Society, 2017). Gondek and colleagues (2015) found that 16% of their sample including Afghan, Iraqi and Somali populations had never had a mammogram while 34.1% of a sample of Afghan women were found to never had a mammogram (Shirazi et al., 2012).

Cervical cancer screening. Pap smear adherence rates, defined as having had a Pap smear within the last three years, were identified as 51% among 310 Somali women age 18 to 65 (Morrision et al., 2013). Studies have found high rates for never having a Pap smear among Somali women ranged from 20% (Murray et al., 2013), 48.8% (Morrison et al., 2012) and 66.6% (Piwowarczyk et al., 2013) in contrast to 68% of women in the U.S. who had never received a Pap test in their lifetime (CDC, 2017). In a study comparing Somali immigrants to Russian and Kurdish immigrants, Somalis reported the lowest participation rates (Idehen et al., 2016). No studies were identified by the author, that examined Pap smear adherence rates among Iraqi and Afghan women.

Colorectal cancer screening. Screening rates for ever having had a colonoscopy, were identified as 14% among Iraqi women over the age of 50 (Jillson et al., 2015), 38.5% among Somali women age 50 to 80 (Morrison et al., 2012), while no rates have been found among Afghan women. One study found that Somali women were the least likely to have an endoscopy (colonoscopy or sigmoidoscopy) and FOBT when compared to other immigrant women (Samuel et al., 2009). Colonoscopy appears to be the colorectal cancer screening least adhered to, with no research identified to have examined rates for other recommended colorectal cancer screening procedures such as FOBT or sigmoidoscopy utilization among Afghan, Iraqi or Somali populations.

Research Question 2: Social Ecological Factors to Screening

Eight over-arching themes were found to influence BC, CC and CRC screening among refugee women, organized by level of influence of the SEM.

Language barriers and knowledge about cancer. Difficulty with the host country's language was the most reported individual level barrier to screening and accessing health services in general in qualitative studies (Abdullahi et al., 2009; Al Amoudi et al., 2015; Carroll et al., 2007; Gele et al., 2017; Ghebre et al., 2015; Murray et al., 2013; Raymond et al., 2014; Redwood-Campbell et al., 2009; Saadi et al., 2015; Salad et al., Shirazi et al., 2015; Zhang et al., 2016). It appears that language barriers also exacerbated lack of knowledge (Abdullahi et al., 2009), caused distrust in interpreters (Ghebre et al., 2015), providers (Shirazi et al., 2015), as well as distrust of the entire U.S. health care system (Raymond et al., 2014). Intervention studies emphasized the importance of information to be delivered in refugees' native language, thus all interventions delivered language-specific health education for refugee women and were a necessary component of their programs (Gondek et al., 2015; Jillson et al., 2015; Shirazi et al., 2015). Participants favored receiving health education verbally or through visual-audio or from peer educators who were members of their community (Abdullahi et al., 2009; Shirazi et al., 2015).

Majority of studies (*n* = 12) examined knowledge, beliefs, and attitudes of cancer screening and found low levels of knowledge and awareness of cancer and screening among all three groups (Abdullahi et al., 2009; Al-Amoudi et al., 2015; Carroll et al., 2007; Ghebre et al., 2015; Jillson et al., 2015; Murray et al., 2013; Pratt et al., 2017; Raymond et al., 2014; Salad et al., 2015). Knowledge deficit among Somali women was due to women not recognizing or understanding the term "cancer" or reported as rare in Somalia, and evoked shame, fear of diagnosis or associated with death (Carroll et al., 2007; Raymond et al., 2014). This 'silence' around the topic of cancer was more pronounced in studies of Somali participants, particularly with focus group discussions (Al Amoudi et al., 2015; Raymond et al., 2014; Saadi et al., 2012; Ghebre et al., 2015; Murray et al., 2013; Redwood-Campbell et al., 2011).

Mesolevel: Provider factors. Issues around modesty and embarrassment were reported as barriers to having a Pap smear or mammogram among Afghan, Iraqi and Somali women (Abdullahi et al., 2009; Howard et al., 2009; Pratt et al., 2017; Raymond et al., 2014; Saadi et al., 2015; Shirazi et al., 2013). The possibility of having a man perform the test was reported a significant barrier to screening, while having a female provider increased women's likelihood to have mammography and Pap smear screening (Abdullahi et al., 2009; Gele et al., 2017; Redwood-Campbell et al., 2011; Saadi et al., 2015; Salad et al., 2015). On the other hand, studies that reported that refugee women's preference for female providers also stated that it was negotiable (Ghebre et al., 2015; Salad et al., 2015; Shirazi et al., 2013). Study findings report that although religion itself did not prevent women from seeing a male physician, Somali women would prefer a female physician if available (Ghebre et al., 2015). Interventions addressing modesty restricted educational sessions to female only attendees (Gondek et al., 2015) and options for home-based HPV testing appear to be effective approaches to increase screening (Sewali et al., 2015).

Studies reported providers having a significant influence on the uptake of screening services in this population as a primary source of education and recommendation for cancer screening (Al Amoudi et al., 2015; Zhang et al., 2016). Similarly, having had at least one gynecological check-up within the past 5 years (Idehen et al., 2016), having had a primary care visit within the past year (Morrison et al., 2012), a post-natal check-up or advice from providers (Abdullahi et al., 2009), an endorsed letter from providers (Bell et al., 1999) as well as appointment reminders and personal contact from health providers (Saadi et al., 2015) facilitated the uptake of screening services among refugee women. On the contrary, refugees, in general, live in a situation that may make it more difficult for them to develop trust, especially with providers (Ghebre et al., 2015; Murray et al., 2015). Following physicians' advice differed for Somali refugee women. For example, Somali women in one study reported that they would not follow the doctors' instructions without asking other women in the community for advice first (Ghebre et al., 2015).

Mesolevel: Family involvement. Three studies of Somali and Afghan women found that family support was an important factor that influenced health-care decision making (Carroll et al., 2009; Raymond et al., 2014; Shirazi et al., 2015; Sewali et al., 2015). For example, 90% of the sample of Afghan women reported that they relied on their husbands for transportation, interpretation and with decision-making regarding screening and healthcare (Shirazi et al., 2015). A randomized control intervention found that women who reported having friends/family members to talk about cancer screening were approximately three times more likely to complete any screening test than those who did not (p = 0.127) (Sewali et al., 2015). In some cases, reliance on family members and lack of support may be a barrier to receive screening. For example, despite the influence of husbands over decision making among Afghan women, most Afghan husbands will not tell their wives to get examined (Shirazi et al., 2015). Similarly, Somali focus group participants reported they never talked about BC, especially with their husbands (Al-Amoudi et al., 2015). One study reported that Iraqi and Somali women cited work and childcare commitments as common barriers to getting a mammogram (Saadi et al., 2015).

Exolevel: Health system factors. Studies reported refugees' dissatisfaction with health system appointment times and availability of interpretation services, which hindered satisfaction with accessing health services in general (Abdullahi et al., 2009; Zhang et al., 2016). Practical difficulties such as inconvenient appointment times and lack of childcare were perceived as a barrier to attending a screening, especially for single mothers with young children (Abdullahi et al., 2009). Some women specifically mentioned their frustration about the inability to obtain immediate access to a physician (Saadi et al., 2015). Some studies reported women feeling hopeful and expressed gratitude for the health services they receive in the U. S. compared to their home countries (Murray et al., 2013; Saadi et al., 2012; Saadi et al., 2015).

Exolevel: Community-based approaches and collaboration. Intervention studies that focused on community-based approaches improved cancer screening among refugees (Gondek et al., 2015; Jillson et al., 2015; Percac-Lima et al., 2013; Sewali et al., 2015; Percac-Loma et al., 2012; Shirazi et al., 2015). These approaches included establishing community contacts, collaborating with community based organizations (Gondek et al., 2015) and utilizing a health navigator or peer navigator to assist participants in accessing screening services (Gondek et al., 2015; Jillson et al., 2015; Percac-Lima et al., 2012; Sewali et al., 2015). Most studies used key informants and local members of the community to assist in the recruitment of this hard-to-reach population.

Macrolevel: Religion factors. Studies have examined religious, traditional, and medical beliefs about cancer (Al Amoudi et al., 2015; Carroll et al., 2007). A majority of Afghan, Iraqi and Somali participants either identified themselves as Muslim or are from Muslim majority countries (Ghebre et al., 2015; Shirazi et al., 2015). Religion played a significant role in women's health promotion behaviors, particularly with regards to cleanliness and diet restrictions, their perception of disease; their explanation for its occurrence; and is used as a measure for coping with illness (Al Amoudi et al., 2015; Carroll et al., 2009). One study reported religious fatalism as a barrier to care (Ghebre et al., 2015), while other studies reported that women indicated God's will in health outcomes was not necessarily associated with fatalism, but that religion encouraging healthy behaviors (Raymond et al., 2014; Shirazi et al., 2015). Studies also reported that faith-based messages implemented in interventions can facilitate screening (Pratt et al., 2017; Shirazi et al., 2015). On the other hand, one study found that those who had fatalistic beliefs were less likely to access screening (Ghebre et al., 2015).

Discussion

This integrative review of the literature highlights commonly reported contextual factors that influence resettled refugee women's preventive cancer screening. The results of this synthesis suggest that resettled refugee women originating from Afghanistan, Iraq, and Somalia are not only largely understudied, but underutilize preventive cancer screening services, specifically with regards to invasive screening services such as mammography, Pap smear, and colonoscopy.

Our first aim examined reports of cancer screening rates and findings provide evidence for lower uptake of breast, cervical and colorectal cancer screening in resettled refugee women from Afghanistan, Iraq, and Somalia. There is relatively little research that evaluated screening rates in samples of refugee populations. As such, it is difficult to generalize rates of screening from non-random samples across three ethnic populations, so we summarize reported rates. We did find evidence to suggest that screening disparities persist in resettled refugee populations and that screening uptake was even lower than the rates among women when compared to other immigrant groups in the same sample. High rates of never had a mammogram among Afghan, Iraqi and Somali women contrast with 54% of U.S. born women aged 50 to 74 years who had never received a mammogram in their lifetime (Centers for Disease Control and Prevention, 2017). Low rates of Pap smear use among Somali women are in sharp contrast to the National Health Interview Survey (NHIS) data indicating that 80.7% of women 21-65 years old reported having a Pap smear within the past 3 years (Sabatino et al., 2013). Rates of ever had a colonoscopy are lower compared to 64.5% of the general US population that had ever had an FOBT or colonoscopy (ACS, 2018). Overall, our findings establish a low uptake of screening among resettled refugees and support other research determining that having a refugee status is significantly associated with not receiving appropriate preventive screening services (Vahabi et al., 2016).

Our second aim examined socioecological influences, informed by the SEM. Underutilization of preventive screening services was associated with commonly reported barriers in other immigrants of low socioeconomic status. Consistent with existing literature in immigrant and other refugee groups, language, trust and miscommunication between refugees and healthcare providers were perceived to be the most limiting barrier to health care (Morris et al., 2009). Other studies with health providers confirm that trusted relationships are appreciated by their refugee patients and promote the likelihood of getting screened (Zhang et al., 2016). According to our findings, language barriers seem to have an impact beyond the individual level and persisted through all levels of healthcare, from making appointments to accessing medications at the pharmacy. Health systems in the U.S. are mandated to provide interpreter services, however concerns regarding quality of interpreters provided, trust in the interpreter, embarrassment around disclosing private issues to the interpreter, and the gender of the interpreter were reported as major concerns of women (Abdullahi et al., 2009; Ghebre et al., 2015; Shirazi et al., 2013). These findings suggest inadequate interpretation services and have important practice implications for nursing and healthcare to address.

Other interpersonal factors that influenced the use of preventive screening services included provider recommendations, family support and support through health system navigators. Although some studies identified the importance of family support in the use of screening, family support was less utilized as an approach in interventions. Similar approaches to mammogram engagement using family and husband support to increase uptake of screening have been effective among other ethnic minority women, including Latina (Molina et al., 2015) and Korean women (Lee, 2014), and maybe a favorable intervention to promote within this population. Interventions that appear to effectively increase screening in Afghan, Iraqi and Somali populations, employed community-based approaches, appropriate use of culturally and linguistically trained interpreters, and is consistent with studies that seek to improve the healthcare delivery in other immigrant and ethnic minority populations in the US (Pottie et al., 2014).

This study identified a range of cultural and religious factors that were mostly reduced to variables of fatalism, modesty, female genital mutilation (FGM), and sensitivity around sexual health topics (Abdullahi et al., 2009; Pratt et al., 2017; Zhang et al., 2016). Modesty as a religious value influenced women's use of preventive screening services. Due to embarrassment and shyness, women preferred being examined by female providers (Carroll et al., 2007; Ghebre et al., 2015). However, preferring female providers was negotiable for other women (Saadi et al., 2009; Shirazi et al., 2012). It is possible that openness to be seen by a male provider, if needed, is associated with length of residency in the host country, as some participants, in samples were unaware that they could request female providers (Abdullahi et al., 2009) and reported having difficulty in securing a female or Muslim doctor (Al-Amoudi et al., 2015). The religious factor of fatalism was less understood. It appears that key informants report 'religious beliefs' as well as 'fatalism' as a barrier to screening (Ghebre et al., 2015). However, women reported religion as a major influence on women's health behaviors and intervention programs incorporating the use faith-based messages or religion-tailored messages, facilitated the uptake of screening (Pratt et al., 2017; Shirazi et al., 2015). These contrasting findings support the need to further conceptualize how exactly religion factors facilitate healthy behaviors (Padela & Raza, 2014).

Emerging research in immigrant women's health suggest that the migratory experience and its phases is an important determinant of health that is often minimized or overlooked in health research, and often, confused with culture (Thurston & Vissandjee, 2005). This study did not find the length of residency as a commonly reported factor in the use of screening. It was apparent within the review though, that participants' immigration status, acculturation, and integration were reduced to proxy variables of 'length of residency' or 'years residing in host country' (Abdullahi et al., 2009). Only one study found that length of residency increased the likelihood of completing CC screening (Sewali et al., 2015). A conflicting report found that length of residency was associated with increased likelihood of CRC screening, but it was not statistically significant for the uptake of mammography or Pap smear screening due to sample size constraints (Samuel et al., 2009). There is a need to further conceptualize how both migration experiences, age and years residing in the host country, all influence health-seeking behaviors.

Recommendations

Based on our findings, our first recommendations for BC, CC and CRC screening in refugee women residing in the US is to follow general guidelines for at-risk populations of women over the age of 50, with special considerations to the time of arrival and urgent needs of those recently resettled, and to establish preventive care within the first 8 months of government-sponsored care. One study reported providers' concerns that due to the stress of initial transition, newly resettled refugees may not be receptive to unfamiliar preventive screening services when more pressing issues of ongoing stressors were present (Zhang et al., 2016). However, refugees who are exposed to preventive health services, even to refuse them, have an increased opportunity to adopt preventive screening sooner than later. This way, resettled refugees are also able to utilize services before they enter a stage of non-coverage between having coverage and waiting to qualify for federally mandated health insurance. Earlier in the resettlement process is critical for cost-effective care, yet there is no national framework for providing needed health information to incoming refugee communities.

Our second recommendation is for the need for further research which addresses how refugee women's migration experiences, length of residence, the healthcare environment and structures promote or inhibit preventive health behaviors in this population. Research has established that increasing length of residence promotes convergence of developing chronic health issues, understood as the diminishing health status of migrants over time (Kearns et al., 2017). Further examination and conceptualizing of acculturation in these populations is warranted to provide a deeper understanding of the process of the adoption of preventive health services, especially among refugees who come from countries with lower cancer surveillance and less emphasis on early detection and prevention.

Our final recommendation is to utilize a multi-level approach to addressing screening disparities in this population. Effective interventions should incorporate linguistically appropriate, community-based approaches and utilize collaborations between health systems and the community-based organizations (CBOs) (Han et al., 2015). Coordinating intervention strategies between health care providers and CBOs provides a way to educate and engage communities to establish feasibility, identify challenges and peer navigators to improve recruitment and trust between women and health promotion strategies. Family members appeared to have an influence on women's health behaviors and need to be explored.

Limitations

This study found screening disparities may exist for resettled refugee women but limited data makes it difficult to systematically compare rates with and other populations. We accounted for screening rates in non-random samples that have certain limitations. Research challenges in vulnerable populations exist, therefore it is important to consider non-random samples of hard-to-reach populations. Sampling bias may influence the results of this study, as studies were selected by the primary author and lack of inter-rater reliability. Using a statistical approach to detect significance in screening disparities is warranted. Additionally, bringing quantitative, qualitative and intervention studies together using a framework synthesis approach, findings are decontextualized and cannot be measurable by the same standard (Sandelowski & Barroso, 2007). Further, a meta-analysis of interventions included in this study would be premature, as the inclusion of non-randomized studies promotes further biases that are unmeasured or uncontrolled.

Conclusion

This study contributes to the emerging literature regarding the preventive screening behaviors of understudied resettled refugees from Afghanistan, Iraq, and Somalia—vulnerable groups that are at high risk for presenting with later stages of preventable cancers. Here, the framework-based synthesis approach was especially suitable in addressing an urgent need to examine the level of knowledge about cancer screening in refugee women and to provide recommendations for future areas of research and practice. The findings of this review, suggest that resettled refugee women may underutilize preventive cancer screening services, specifically mammography, Pap smear and colonoscopy screening. The ecological perspective provides a multi-level view of factors that influence refugee women's preventive screening behaviors. We recommend effective screening interventions that incorporate culturally appropriate and community-based approaches, as an effective way of engaging refugee community members.

Table 1

2018 Recommended *Breast, Cervical and Colorectal Cancer Screening Guidelines*

Screening	**ACS**	**NCI**	**USPSTF**	**AAFP**
Mammography				
Starting age	45	40	50	50
Frequency	Annually to age 54 y, then biennially	Every 1 to 2 years 40-49, then annually	Biennially, beginning at age 50	Biennial
Stopping age	For as long as woman is in good health and life expectancy of at least 10 years.	74	75	74
Pap smear				
Starting age	21	21	21	21
Frequency	Every 3 years from age 21-29, and every 5 years after age 30 with HPV testing.	Every 3 years from 21-29, and every 5 years after the age 30 with HPV testing.	Every 3 years from 21-29, and every 5 years for age 30-65 with HPV testing.	Every 3 years
Stopping age	65	65	65	65
Colonoscopy				
Starting age	50	50	50	50
Frequency	Every 10 years	Every 10 years	Every 10 years	
Stopping age	Undefined	Undefined	75	75

Figure 1

Flow Diagram of Study Selection Process

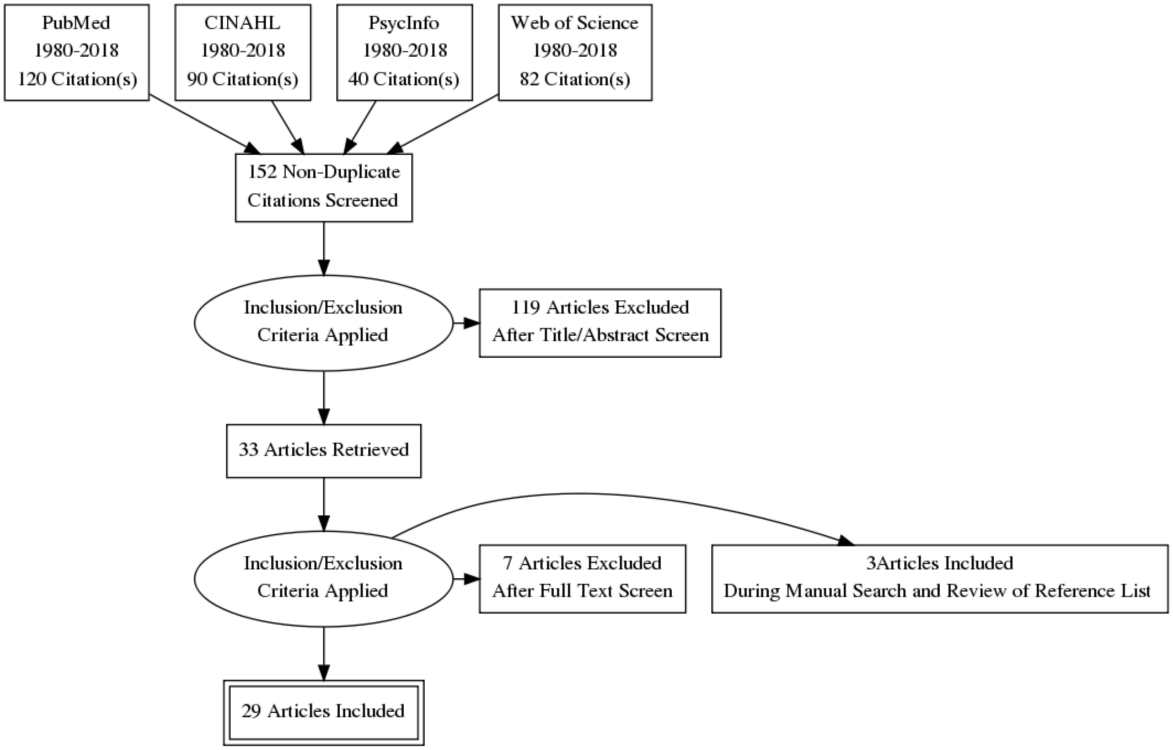


Table 3

Appraisal of Quantitative Studies Based on Checklist Developed by Fowkes and Fulton

Study No. **Criteria**	**1** **Bell** **1999**	**2** **Gon** **2015**	**3** **Ideh** **2016**	**4** **Jill** **2015**	**5** **Mor** **2012**	**6** **Mor** **2013**	**7** **Perc** **2009**	**8** **Perc** **2012**	**9** **Pick** **2014**	**10** **Piwo** **2013**	**11** **Sewa** **2015**	**12** **Samu** **2009**	**13** **Shir** **2015**
Study design													
Objective	0	0	0	0	0	0	0	0	0	0	0	0	0
Design: Cross sectional			0		0	0			0			0	
Design: Cohort study													
Design: Quasi-experimental	0	0		0				0		0			0
Design: Controlled trial							0				0		
Study sample?	0	+	0	+	+	+	0	0	+	0	+	+	+
Source of sample	0	0	0	0	+	+	0	0	+	0	+	+	0
Sampling method	0	0	0	0	0	0	0	0	0	0	0	0	0
Sample size	0	0	0	+	0	0	0	0	0	0	0	0	0
Entry criteria/exclusions	0	0	0	0	0	0	0	0	0	0	0	0	0
Non-respondents	0	++	NA	++	NA	NA	0	+	NA	NA	+	NA	+
Control group?	0	0	NA	0	0	0	0	0	0	0	0	0	+
Definition of controls	NA	NA	NA	NA	NA	NA	0	0	NA	NA	0	NA	NA
Source of controls	NA	NA	NA	NA	NA	NA	0	0	NA	NA	0	NA	NA
Matching/randomization	0	0	NA	0	0	0	0	0	0	0	0	0	+
Comparable characteristics	0	0	NA	0	0	0	0	0	0	0	0	0	0

Table 3 (continued)

Appraisal of Quantitative Studies Based on Checklist Developed by Fowkes and Fulton

Study No. **Criteria**	***1*** ***Bell*** ***1999***	***2*** ***Gon*** ***2015***	***3*** ***Ideh*** ***2016***	***4*** ***Jill*** ***2015***	***5*** ***Mor*** ***2012***	***6*** ***Mor*** ***2013***	***7*** ***Perc*** ***2009***	***8*** ***Perc*** ***2012***	***9*** ***Pick*** ***2014***	***10*** ***Piwo*** ***2013***	***11*** ***Sewa*** ***2015***	***12*** ***Samu*** ***2009***	***13*** ***Shir*** ***2015***
Quality of measurements	0	0	0	0	0	0	+	0	0	0	0	0	0
Validity	0	0	0	0	0	0	0	0	0	0	0	0	0
Reproducibility	0	0	0	0	0	0	0	0	0	0	0	0	0
Blindness	NA	NA	NA	NA	NA	NA	++	+	NA	++	0	NA	NA
Quality control	0	0	NA	0	NA	NA	0	0	NA	0	0	NA	NA
Completeness?	0	+	NA	+	NA	NA	0	0	NA	0	0	NA	++
Compliance	0	0	NA	0	NA	NA	0	0	NA	0	0	NA	++
Drop outs	0	++	NA	++	NA	NA	0	0	NA	0	0	NA	++
Deaths	NA	NA	NA	NA	NA	NA	0	0	NA	NA	0	NA	NA
Missing data	NA	NA	NA	NA	NA	NA	0	0	NA	0	0	NA	NA
Distorting influences?	+	+	0	+	+	+	0	0	+	0	+	+	+
Extraneous treatments	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
Contamination	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
Changes over time	+	+	0	+	++	++	0	0	++	0	0	+	+
Confounding factors	+	+	0	+	+	+	0	0	0	0	+	+	+
Distortion reduced by analysis	+	+	0	+	+	+	0	0	0	0	0	+	+

Table 4

Appraisal of Qualitative Studies Based on CASP Qualitative Checklist

Study No. **Criteria**	**1 Abdull [2009]**	**2 AlAmou [2015]**	**3 Carroll [2007]**	**4 Gele [2017]**	**5 Ghebre [2015]**	**6 Howard [2009]**	**7 Murray [2013]**	**8 Pratt [2012]**
Are the results valid?								
Was there a clear statement of aims?	+	+	+	+	+	+	+	+
Is methodology appropriate?	+	+	+	+	+	+	+	+
Research design appropriate?	+	+	+	+	+	+	+	+
Recruitment appropriate?	+	+	+	+	+	+	+	+
Data collection addressed issue?	+	+	+	+	+	+	+	+
Relationship of researcher?	0	0	0	0	0	+	0	+
What are the results?								
Have ethical issues considered?	+	+	+	+	+	+	+	+
Rigorous analysis of data?	+	+	+	+	+	+	+	-
Clear statement of findings?	+	+	+	+	+	+	+	+
Results helpful?								
How valuable is the research?	+	+	+	+	+	+	+	+

Table 4 (continued)

Appraisal of Qualitative Studies Based on CASP Qualitative Checklist

Study No. **Criteria**	**9** **Raymond** **[2014]**	**10** **Redwood-Campbell** **[2011]**	**11** **Reed** **[2002]**	**12** **Saadi** **[2012]**	**13** **Saadi** **[2012]**	**14** **Salad** **[2015]**	**15** **Shirazi** **[2013]**
Are the results valid?							
Clear statement of aims?	+	+	+	+	+	+	+
Is methodology appropriate?	+	+	+	+	+	+	+
Research design appropriate?	+	+	+	+	+	+	+
Recruitment appropriate?	+	+	+	+	+	+	+
Data collection addressed issue?	+	+	+	+	+	+	+
Relationship of researcher?	0	0	-	+	+	0	0
What are the results?							
Have ethical issues considered?	+	+	+	+	+	+	+
Rigorous analysis of data?	0	+	-	-	+	+	+
Clear statement of findings?	+	+	+	+	+	+	+
Results helpful?							
How valuable is the research?	+	+	+	+	+	+	+

Table 5

Table of Evidence and Description of Cancer Screening Studies that include Afghan, Iraqi and Somali Populations

Author / year	**Setting**	**Purpose/ Aims**	**Type of cancer**	**Study design and data Sources**	**Sampling method**	**Sample size and characteristics**	**Results**
Abdullahi et al., 2009	Camden, London	Knowledge and barriers to screening	Cervical	Qualitative study (focus groups and interviews)	Purposive/ Snowball by Somali outreach workers.	Total N=50 Somali = 50 (100%) Gender: women Age: 25-64	Limited knowledge of cancer screening and risk factors. Barriers to screening included fatalism, embarrassment due to female circumcision, fear of the test, language. Facilitators: Postnatal check-up or advice from GP.
Al-Amoudi et al., 2015	Seattle, Washington	Knowledge and barriers to screening	Breast	Qualitative study (focus group translated by Somali nurse)	Purposive/ snowball by Somali community leader.	Total N=14 Somali=14 (100%) Gender: women Age: 30-69 years Religion: Muslim Education: not reported Insurance: not reported	Major themes: “silence”, knowledge, barriers to screening reported as fear of pain, transportation and lack of knowledge, traditional beliefs, and religion as a coping mechanism.
Bell, 1999	Wales, UK	Screening uptake	Breast	Intervention (no control)	Non-random sample	Total N=187 Somali=32 (17%) Gender: women	Findings show translated literature, GP endorsement letter and language specific

					invitation of screening	Age: not reported Education: not reported Insurance: not reported	education increased uptake from 35.2% to 50.7%. Uptake was lowest for Somali speaking women (only 1 out of 32 attended). Transportation was free but underutilized.
Carroll et al., 2007	Rochester, New York	Knowledge and beliefs	Cervical and breast	Qualitative grounded theory approach (interviews and focus group through female lay interpreters)	Purposive/ snowball sampling through key informants and primary care provider referrals.	Total N=34 Somali=34 (100%) Bantu=16 (47%) Non-Bantu=18 (53%) Gender: women Age: 18-53 years Education: 17 (50%) no schooling, 10 (29%) grade school Insurance: not reported	Health promotion and preventive beliefs related to access to food and water, spirituality and functioning well at home. Low levels of knowledge of cancer (not recognized as a term or heard of in Africa).
Gele et al., 2017	Oslo, Norway	Participation in cervical cancer screening	Cervical	Qualitative data analysis based on Focus Group Discussion (FGD) while using Ecological Model	Convenient sample	Total N=35 N=17 Somali N=18 Pakistani	Barriers to cancer screening were language, sociocultural beliefs and system-related factors. Increasing awareness of cancer prevention through direct communication, increased use of female doctors and recall system can increase rates of cervical cancer rates among Somali and Pakistani women.

Ghebre et al., 2015	Minnesota	Barriers and facilitators to screening	Cervical	Qualitative based on Socioecological Framework (semi-structured interviews)	Purposive sample with Somali community workers.	Total N=23 Sample=Key informants	Barriers were lack of knowledge, religious beliefs, fatalism, embarrassment and fear and distrust in interpreters.
Gondek et al., 2015	Buffalo, New York	Breast cancer knowledge and uptake of mammography	Breast	Intervention based on Social Cognitive Theory (pre-post test of education program with interpreters).	Purposive sampling recruited through community based ESL venues.	N=348 Middle Eastern (Iraq/Afghanistan) = 29.5% African (Somalia)=16.8% Age: 40-49 (26%.9%), 50-59 (14%), 60-64 (4.2%), >65 (5.7%). Education: 48% (less than 6 years of formal education) Insurance: not reported	Findings suggest health education delivered in native language enhances BC knowledge and in mammography completion. 33% (58/177) of women over 40 completed mammograms.
Howard et al., 2009	Canada	Attitudes and beliefs regarding self-sampling for HPV	Cervical	Qualitative grounded theory approach (focus groups)	Purposive sampling through focus groups. Researchers identified	N=11 groups (5-7 each group N=77) Arab: N=13 (16%) Somali: N=15 (19%) Afghan: N=16 (20%)	Women generally perceived the benefits of self-sampling because issues of modesty or negative experiences with pelvic exams but overall preferred testing by a health care professional because they're accustomed to pelvic

					diverse views.	Age: 22-61 years Gender: women Education: not reported Insurance: not reported	exams, convenient and trusted results.
Idehen et al., 2016	Finland	Factors to screening; dependent variable self-reported participation in screening in the previous five years	Cervical	Mixed methods (survey data and structured in-person interviews)	Data from the Migrant Health and Well-being Survey, 2010-2012 of immigrants from Russia, Somalia or Kurds/Iraq/ Iran	N=620 Somali=132 (21%) Age: 25-60 years (mean 39.3) Gender: women Education: not reported Insurance: not reported	The age-adjusted screening participation rates were as follows: Somalis 34.7% (95% CI 26.4-43.0). Multiple logistic regressions showed the most significant factor increasing screening uptake among all groups was having had at least one gynecological check-up in the previous five years. Other factors were higher education, being employed and literacy in Finnish/Swedish.
Jillson et al., 2015	Washington, DC	Knowledge, uptake of screening and future adherence	Colorectal	Intervention (educational program using language and culturally specific materials) with follow up after 1 month.	Purposive and snowball sampling methods through local organizations serving Iraqi women.	N=32 Iraqi=32 (100%) Age: 21-59 (N=7 over 50 years) Gender: women Education: 46.9% completed college Insurance: 31% had no insurance, 31% government insurance	Generally low levels of knowledge of CRC screening. Only N=9 participants knew that screening begins at 50, 1 of the 7 (14%) of participants over the age of 50 had undergone screening. 5 of the 7 participants (71%) stated that failure to regularly screen is due to health care provider not advising it. Pre-

							and post assessment after health education showed an increase in knowledge and intent to screen.
Murray et al., 2013	San Diego, California	Knowledge of cervical cancer, perceptions of preventive care and barriers to use preventive services	Breast and cervical	Qualitative based on community based participatory research framework (focus groups)	Purposive sampling through community-based organizations serving East African communities.	N=40 Somali= not reported Sudan=not reported Age: over 18 Gender: women Education: not reported Insurance: not reported	64% of women reporting they did not know what cervical cancer was, 20% were positive that their healthcare providers had screened them for cervical cancer, approximately one-third were positive they had been screened for breast cancer.
Morrison et al., 2012	Rochester, New York	Screening uptake and factors to completion of preventive services	Breast, cervical and colorectal	Quantitative (retrospective data analysis of medical records)	Participants identified through electronic search for self-reported race/ethnicity for Somali.	N=810 Somali=810 (100%) Gender: women N=499 (61%)	Somali patients had significantly lower completion rates of colorectal cancer screening, mammography and pap smears than non-Somali patients. Use of medical interpreters and primary care services were generally associated with higher completion rates of preventive services.
Morrison et al., 2013	Minnesota	Screening rates and factors	Cervical	Quantitative (retrospective clinical data from	Participants identified through electronic	N=310 Somali=310 (100%) Gender: women	Somali patients have lower rates of completion than non-Somali. 51% of 310 women adhered to CC screening.

				medical office)	search for self-reported race/ethnicity for Somali.	Age: 18-65 years Education: not reported Insurance: not reported	Somali women more likely to undergo screening when seeing female physicians.
Percac-Lima et al., 2009	Massachusetts	Screening uptake	Colorectal	Intervention randomized controlled trial (NP program for uptake of CRC screening)	Participants identified through primary care data base, Eligible patients were randomized into intervention and control groups in a 1:2 ratio.	N=1,223 Ethnicities are unspecified for Arab, Afghan and Somali (all as “other”) Other intervention group: N=21 (5%), control group: N=56 (6.9%) Age: 52-79 years	Intervention patients were more likely to undergo CRC screening than control patients (27% vs. 12% for any CRC screening, p < 0.001; 21% vs. 10% for colonoscopy completion, p < 0.001). The higher screening rate resulted in the identification of 10.5 polyps per 100 patients in the intervention group vs. 6.8 in the control group (p=0.04).
Percac-Lima et al., 2012	Massachusetts	Screening uptake	Breast	Intervention (PN program for uptake of mammography screening)	Eligible participants contacted through health organization.	N=188 Somali= 36 (19%) Arab=48 (25%) Education: not reported Insurance: 53.7% had private insurance, 34.6	Adjusted mammography rates were lower among refugee women (64.1 %, 95 % CI: 49–77 %) compared to English-speaking (76.5 %, 95 % CI: 69 %– 83 %) and Spanish-speaking (85.2 %, 95 % CI: 79 %– 90 %) women. By the end of 2011, screening rates increased in

						had Medicaid and 8% had Medicare.	refugee women (81.2 %, 95 % CI: 72 %– 88 %), and were similar to the rates in English-speaking (80.0 %, 95 % CI: 73 %–86 %) and Spanish-speaking (87.6 %, 95 % CI: 82 %–91 %) women. PN increased uptake of mammography screening.
Pickle et al., 2014	Philadelphia, Pennsylvania	Screening uptake and abnormal pap tests	Cervical	Quantitative retrospective data analysis of medical records	Data analyzed medical records at a medical institution.	N=204 Iraqi: N=60 (29%) Afghan: N=1 (.4%) Gender: women Age: 21-65	Pap tests were performed on 129 or the 203 eligible refugee women (64%). The approximate average length of time from date of initial screening at CRH to Pap testing was 6 months. Of the 115 Pap tests reviewed, abnormal Pap tests were seen among women from Iraq, Myanmar, and Bhutan. Mean age at the time of abnormal Pap test was 36 years. The prevalence of abnormal Pap tests in the Iraqi was 9% (3 of 32 results). Prevalence of high-risk HPV in Iraqi women was 6%.

Piwowarczyk et al., 2013		Knowledge and intent to uptake screening	Breast and cervical	Intervention (UJAMBO program DVD workshop)	Purposive sampling through community organizations where workshops were conducted.	N=120 Somali: N=61 (50.8%) Gender: women Age: 25-60 years Education: 45.9% never attended school, with 18% up to high school education	Somali women were less likely than Congolese women to have received an education, be employed, and speak English, but more likely to be married, reside with children and be living in poverty.
Pratt et al., 2017	Minnesota	Perceptions of faith-based messages and breast and cervical cancer screening	Breast and cervical	Qualitative (focus groups)	Convenience sample	N=34 Somali women N=20 Somali men Age: 18- over 60 Education: None=32% Middle or high school=50% College=18% Insurance=Not reported	Barriers to screening included health literacy, a general lack of knowledge about cancer and concerns about modesty and female circumcision. Participants stated that faith-based messages had influenced their views, which indicates that faith-based messages implemented in interventions can facilitate individual behavior change.
Raymond et al., 2014	Minnesota	Knowledge, attitudes, barriers and facilitative factors screening	Breast and cervical	Qualitative based on CBPR (focus groups)	Purposive sampling through partnerships with community-based organizations	N=29 (4 focus groups) Age: 20-35 group and 36-65 group	Cancer was not only described as being rare, but also as stigmatized. Younger women remarked that cancer evoked secrecy and shame; All women agreed that issues around modesty and shyness were significant barriers to mammography screening.

							One of the older women expressed this sentiment with a reference to religion requiring modesty about the body.
Redwood-Campbell et al., 2011	Hamilton, Canada	Barriers and enablers to screening	Cervical	Qualitative study based on (focus groups)	Purposive and snowball sampling through resettlement agencies.	N=11 (focus groups) Gender: women Age: 35-69 years Education: not reported Insurance: not reported	All groups indicated a strong need for information on necessity of screening and on how the procedure is done. Use of a video and a group discussion format were desired strategies. Women had positive feelings about health prevention. Preference for female providers and language. Only Chinese and Arabic groups discussed embarrassment and modesty as barriers.
Reed et al., 2002	Seattle, Washington	Knowledge and perceptions of screening and prevention.	Breast and cervical	Qualitative (focus groups)	Purposive sampling through medical institution.	N=26 Somali, Vietnamese and Latina women.	Majority of women showed inconsistent understanding that mammogram and Pap smear screening is done to detect cervical and breast cancer that can be cured. Cultural beliefs related to reproductive behavior and women's social and family roles influenced knowledge towards health screening.

Saadi et al., 2012	US	Preventive health beliefs and perspectives, and barriers to screening	Breast	Qualitative (interviews)	Convenience sample identified through patient registry data.	N=20 Iraqi=20 (100%)	Psychosocial barriers, culturally mediated beliefs, and health consequences of war were identified as major themes, ultimately showing what factors, alone and collectively, have impeded Iraqi refugee women's ability and motivation to obtain breast cancer screening.
Saadi et al., 2015	US	Preventive health beliefs and BC screening	Breast	Qualitative (semi-structured interviews)	Convenience sample identified through patient registry data.	N=57 Bosnian, Iraqi and Somali	Barriers to care such as fear of pain and diagnosis, modesty and work and childcare commitments; facilitative factors include outreach efforts, appointment reminders, and personal contact from health providers; perceptions of US medical infrastructure compared to home countries and varying degrees of exposure to preventive care in home countries; impact of war on health systems.
Salad et al., 2015	Netherlands	Perceptions of cervical cancer screening	Cervical	Qualitative study based on Health Belief Model (interviews)	Purposive sampling through Somali-serving organizatio	N=20 Somali= Gender: women Age: 17-21 years (N=14) and mothers 30-46	Perceived barriers to the use of preventive measures across three major themes: (1) Somali women and preventive healthcare; (2) Language, knowledge, and

					ns through gatekeepers.	years (N=6)	negotiating decisions; and (3) Sexual standards, culture, and religion.
Sewali et al., 2015	Minnesota	Screening test completion and factors to screening	Cervical	Intervention using CBPR (randomized control intervention)	Purposive and snowball sampling by word of mouth and flyers.	N=63 Somali=63 (100%) Gender: women Age: 30-70 years	Participants in the HPV test group were 14 times more likely to complete the test compared to those in the Pap test group (P = 0.0002). Women who reported having friends/family members to talk about cancer screening were approximately three times more likely to complete any screening test than those who did not (P = 0.127) and participants who reported residing in the US longer were more likely to complete a screening test (P = 0.011).
Samuel et al., 2009	Portland, Maine, US	Screening rates	Breast, cervical and colorectal	Mixed Methods (retrospective data analysis of medical charts and in-person interviews)	Reviewed patient charts and random sampling for interviews.	N=100 Somali=37 (37%) Age: 50-73	Somali women were at higher risk of being unscreened for breast, cervical, and colorectal cancer compared with Cambodian and Vietnamese women. A longer period of US residency was associated with being screened for colorectal cancer.

Shirazi et al., 2013	San Francisco Bay Area	Knowledge and barriers to screening	Breast	Qualitative (semi-structured interviews)	Purposive sampling for maximum variation.	N=53 Afghan=53 (100%) Age: 40 and older Education: >12 years: 12% No formal education: 40% Has health insurance: 77%	Barriers described as 1. Afghan culture and family structure gender roles and conservative patriarchal tribal practices / men had influence on women's screening decisions. 90% of women relied on husband to translate, provide transportation, etc. 2. Access barriers related to limited English, low health literacy, transportation and communication. 3. Concerns with healthcare providers to communicate and upholding modesty.
Shirazi et al., 2015	San Francisco Bay Area	Targeting practices used in interventions within URM groups	Breast	Intervention using CBPR (randomized control trial)	Convenience based and quasi-population based sampling	N=230 Sample=Afghan, American Indian, Latina and Urban African American women Gender: Women Age: 40 or older (Afghan) African American: 50-74	3 CNPs focused on breast cancer interventions using groups of Afghans, Latina, American Indian and African American women. Findings displayed the importance of implementing open communication and tailored interventions in order to design interventions that correctly target the population at risk.

Table 6

Summary of Refugee Women's Cancer Screening Rates

Group	**Preventive Screening**	**Rates**	**Sample**	**Study**
Afghan	Never had a mammogram	16% 34.1% 50%	N=348* (over age 40) N=53 (age 40-87) N=230 (age)	Gondek et al., 2015 Shirazi et al., 2012 Shirazi et al., 2015
	Ever had a mammogram	33% 65.9% 50%	N=348* (over age 40) N=53 (age 40-87) N=230 (over age 40)	Gondek et al., 2015 Shirazi et al., 2012 Shirazi et al., 2015
	Mammogram < 2 years	15.8%	N=53 (age 40-87)	Shirazi et al., 2012
	Never had a colonoscopy	-	-	-
	Ever had a colonoscopy	-	-	-
	Colonoscopy < 10 years	-	-	-
	Never had a pap smear	-	-	-
	Ever had a pap smear	-	-	-
	Pap smear < 2-3 years	-	-	-
Iraqi	Never had a mammogram	16%	N=348* (age 40-49)	Gondek et al., 2015
	Ever had a mammogram	33%	N=348* (over age 40)	Gondek et al., 2015
	Mammogram < 2 years	44% 44.4%	Medical center statistic N=48 (over age of 40)	Saadi et al., 2012 Percac-Lima et al., 2013
	Ever had a colonoscopy	14%	N=7 (over age 50)	Jillson et al., 2015
	Colonoscopy < 10 years	14%	N=7 (over age 50)	Jillson et al., 2015
	Never had a pap smear	36%	N=204* (age 21-65)	Picke et al., 2014
	Ever had a pap smear	64%	N=204* (age 21-65)	Picke et al., 2014
	Pap smear < 2-3 years	-	-	-

Somali	Never had a mammogram	16% 15.4% 56%	N=348* (age 40-49) N=499 (age 18-55) N=34 (age)	Gondek et al., 2015 Morrison et al., 2012 Pratt et al., 2017
	Ever had a mammogram	33% 75% 41%	N=40* (age N=40 (over age 40) N=34 (age 18-60)	Murray et al., 2013; Piwowarczyk et al., 2013 Pratt et al., 2017
	Mammogram < 2 years	23% 46.4%	N=40 (over age 40) N=36 (over age 40)	Piwowarczyk et al., 2013 Percac-Lima et al., 2013
	Never had a colonoscopy	-	-	-
	Ever had a colonoscopy	38.5%	N=499	Morrison et al., 2012
	Colonoscopy < 10 years	-	-	-
	Never had a pap smear	20% 48.8% 66.6% 100% 38%	N=40* (age N=499 N=61 (age 25-60) N=35 (age 25-70) N=34 (age)	Murray et al., 2013; Morrison et al., 2012 Piwowarczyk et al., 2013 Gele et al., 2017 Pratt et al., 2017
	Ever had a pap smear	34.7% 62% 59%	N=132 (age 25-60) N=50 (age 25-64) N=34 (age 18-60)	Idehen et al., 2016 Abdullahi et al., 200. Pratt et al., 2017
	Pap smear < 2-3 years	51%	N=310 (age 18-65)	Morrison et al., 2013

**heterogeneous sample of different ethnicities but includes Afghan, Iraqi or Somali participants*

Table 7

Sample Characteristics of Cancer Screening Studies (n = 29)

Characteristics	N = 29 (%)	References
Country of Origin		
Afghanistan	5	Gondek et al., 2015; Howard et al., 2009; Pickle et al., 2014; Shirazi et al., 2013; Redwood-Campbell et al., 2011;
Iraq	9	Bell, 1999; Gondek et al., 2015; Howard et al., 2009; Jillson et al., 2015; Percac-Lima et al., 2012; Percac-Lima et al., 2013; Pickle et al., 2014; Saadi et al., 2015; Saadi et al., 2012;
Somalia	21	Abdullahi et al., 2009; Al-Amoudi et al., 2015; Bell, 1999; Carroll et al., 2007; Gele et al., 2017; Gondek et al., 2015; Howard et al., 2009; Idehen et al., 2016; Murray et al., 2013; Morrison et al., 2013; Morrison et al., 2012; Percac-Lima et al., 2012; Percac-Lima et al., 2013; Piwowarczyk et al., 2013; Pratt et al., 2017; Raymond et al., 2014; Reed et al., 2002; Saadi et al., 2015; Salad et al., 2015; Sewali et al., 2015; Samuel et al., 2009;
Key informants	2	Ghebre et al., 2015; Zhang et al., 2017
Mixed samples	11	Gele et al., 2017; Gondek et al., 2015; Howard et al., 2009; Idehen et al., 2016; Murray et al., 2013; Percac-Lima et al., 2009; Percac-Lima et al., 2012; Pickle et al., 2014; Piwowarczyk et al., 2013; Reed et al., 2002; Saadi et al., 2015
Study Location		
US	21	Al-Amoudi et al., 2015; Carroll et al., 2007; Ghebre et al., 2015; Gondek et al., 2015; Jillson et al., 2015; Murray et al., 2013; Morrison et al., 2013; Morrison et al., 2012; Percac-Lima et al., 2012; Percac-Lima et al., 2013; Pickle et al., 2014; Piwowarczyk et al., 2013; Pratt et al., 2017; Raymond et al., 2014; Reed et al., 2002; Saadi et al., 2015; Saadi et al., 2012; Sewali et al., 2015; Samuel et al., 2009; Shirazi et al., 2013; Zhang et al., 2016;
UK	2	Abdullahi et al., 2009; Bell; 1999;

Table 7 (continued)

Sample Characteristics of Cancer Screening Studies (n = 29)

Characteristics	**N = 29 (%)**	**References**
Canada	2	Howard et al., 2009; Redwood-Campbell et al., 2011;
Finland	1	Idehen et al., 2016;
Netherlands	1	Salad et al., 2015;
Norway	1	Gele et al., 2017
Sample/Gender		
Women only	23	Abdullahi et al., 2009; Al-Amoudi et al., 2015; Bell; 1999; Carroll et al., 2007; Gele et al., 2017; Gondek et al., 2015; Howard et al., 2009; Idehen et al., 2016; Jillson et al., 2015; Murray et al., 2013; Percac-Lima et al., 2012; Percac-Lima et al., 2013; Pickle et al., 2014; Piwowarczyk et al., 2013; Raymond et al., 2014; Reed et al., 2002; Saadi et al., 2015; Saadi et al., 2012; Salad et al., 2015; Sewali et al., 2015; Samuel et al., 2009; Shirazi et al., 2013; Redwood-Campbell et al., 2011;
Women + Men	3	Morrison et al., 2013; Morrison et al., 2012; Pratt et al., 2017;
Unspecified or Key informants	2	Ghebre et al., 2015; Zhang et al., 2016
Type of Cancer		
Breast Only	8	Al-Amoudi et al., 2015; Bell; 1999; Gondek et al., 2015; Percac-Lima et al., 2012; Percac-Lima et al., 2013; Saadi et al., 2015; Saadi et al., 2012; Shirazi et al., 2013;
Cervical Only	11	Abdullahi et al., 2009; Gele et al., 2017; Ghebre et al., 2015; Howard et al., 2009; Idehen et al., 2016; Morrison et al., 2013; Pickle et al., 2014; Salad et al., 2015; Sewali et al., 2015; Redwood-Campbell et al., 2011; Zhang et al., 2016
Colorectal Only	1	Jillson et al., 2015;

Table 7 (continued)

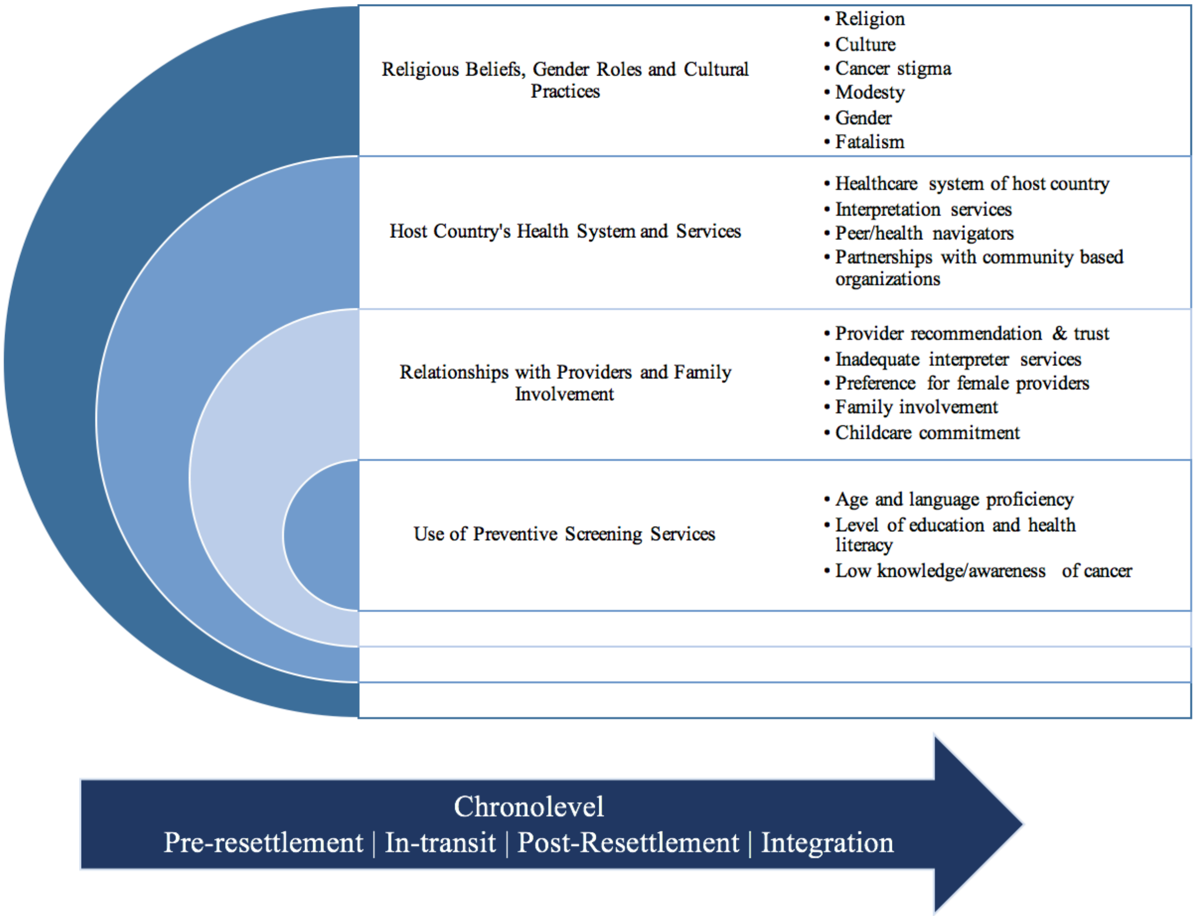
Sample Characteristics of Cancer Screening Studies (n = 29)

Characteristics	**N = 29 (%)**	**References**
Multiple: breast, cervical, colorectal	8	Carroll et al., 2007; Morrison et al., 2012; Murray et al., 2013; Piwowarczyk et al., 2013; Pratt et al., 2017; Raymond et al., 2014; Reed et al., 2002; Samuel et al., 2009;
Design		
Qualitative	15	Abdullahi et al., 2009; Al-Amoudi et al., 2015; Carroll et al., 2007; Gele et al., 2017; Ghebre et al., 2015; Howard et al., 2009; Murray et al., 2013; Pratt et al., 2017; Raymond et al., 2014; Reed et al., 2002; Saadi et al., 2015; Saadi et al., 2012; Salad et al., 2015; Shirazi et al., 2013; Redwood-Campbell et al., 2011; Zhang et al., 2016;
Quantitative	3	Morrison et al., 2013; Morrison et al., 2012; Pickle et al., 2014;
Mixed Methods	2	Samuel et al., 2009; Idehen et al., 2016
Intervention	9	Bell; 1999; Gondek et al., 2015; Jillson et al., 2015; Percac-Lima et al., 2012; Percac-Lima et al., 2013; Piwowarczyk et al., 2013; Sewali et al., 2015; Shirazi et al, 2015
Types of Outcomes		
Screening rates	4	Morrison et al., 2013; Morrison et al., 2012; Pickle et al., 2014; Samuel et al., 2009;
Beliefs, knowledge, attitudes & experiences	12	Al-Amoudi et al., 2015; Carroll et al., 2007; Gele et al., 2017; Howard et al., 2009; Murray et al., 2013; Raymond et al., 2014; Reed et al., 2002; Saadi et al., 2015; Saadi et al., 2012; Salad et al., 2015; Shirazi et al., 2013; Redwood-Campbell et al., 2011;
Behavioral factors	3	Ghebre et al., 2015; Idehen et al., 2016; Morrison et al., 2012;
Barriers to uptake	9	Abdullahi et al., 2009; Al-Amoudi et al., 2015; Ghebre et al., 2015; Saadi et al., 2015; Saadi et al., 2012; Salad et al., 2015; Shirazi et al., 2013; Redwood-Campbell et al., 2011; Zhang et al., 2016
Intervention outcomes	8	Bell; 1999; Gondek et al., 2015; Jillson et al., 2015; Percac-Lima et al., 2013; Piwowarczyk et al., 2013; Sewali et al., 2015; Percac-Lima et al., 2012; Pratt et al., 2017;

Figure 2

Modified Social Ecological Framework of Refugee Women's Preventive Screening Behaviors

Bronfenbrenner (1992)



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Chapter II

Sociocultural Factors to Health and Healthcare Experiences among Afghan Refugee Women

Decades of war in Afghanistan have resulted in massive displacement and the largest diaspora of Afghan refugees in the United States currently reside in California. This qualitative study explores the perceptions of health and healthcare experiences among middle-aged and older Afghan refugee women who are now aging in the US. We conducted semi-structured interviews with a purposeful sample of Afghan refugee women (*n* = 14) residing in San Diego County, and triangulated this data source by interviewing their family members (*n* = 5) as well as Afghan health professionals and key informants (*n* = 8). Interview transcripts were inductively coded using Atlas.ti software, where focused codes were sorted and reduced into categories and we extracted meaning around groups of categories. This study revealed four overarching themes: 1) Women's health beliefs were viewed holistically as a state of wellbeing and prevention was viewed in the form of diet and cleanliness; 2) Even after living in the US for over 10 years, women reported on going "worries", health concerns and prioritizing family that negatively influenced women's satisfaction with their health; 3) Unmet treatment expectations and preferences with providers diminished women's perceived quality of care; and 4) Women reported needing support but finding it difficult to navigate the health care system. Women emphasized the importance of family, religion and the cultural emphasis of modesty as having an influence on their health and health behaviors. Communication between healthcare professionals and refugees continue to be a barrier to quality healthcare, even decades after resettlement.

Key words: Afghan, aging, health behaviors, perceived health, refugee, women

Introduction

Afghan refugee women who have been resettling in the United States (US) since the 1980's are now aging and may face multiple layers of disadvantage, experience increased burden of disease, and face challenges to equitable access to preventive health screening (Morris et al., 2009; Nelson-Peterman et al., 2015). While there is significant research on health outcomes of newly resettled refugees and long-term mental health experiences of established refugees, there is currently little information about how sociocultural factors influence refugee women's health and health behaviors decades after the initial resettlement period. Information on factors to refugee health post-resettlement provides researchers with targeted ways to improve refugee health and may help refugee agencies, policymakers, educators, and service providers identify health promoters and stressors to improve community health (Krieger et al., 2002).

Majority of Afghan refugees are Muslim and may have unique social, cultural and religious influences on health and health-related behaviors. Previous research of Muslim ethnic minority women indicate religion-informed beliefs that influence their health beliefs and practices and have cultural explanatory models that often differ from health providers (Alemi et al., 2016; Pavlish et al., 2010). According to Kleinman (1980), women's health beliefs are a product of their social and cultural context: cultural beliefs (resulting from desirable or undesirable life experiences, experience with the medical system, modesty issues and past illness experience); socioeconomic factors; and impact of community social networks. Research has established that a lack of congruence between practitioners' and patients' explanatory models has an adverse impact on patient outcome variables, such as the use of health services or adherence to treatment recommendations (Schinkel et al., 2016). Understanding the social and cultural factors to health and healthcare experiences of refugees is important in improving health outcomes and quality of healthcare in underserved populations (Campbell et al., 2014).

For Afghans, religion and family values may influence health behaviors. Afghanistan is a traditionally patriarchal culture and women rely on men as gatekeepers of the family for input on decision making (Lipson & Omidian, 1997; Morioka-Douglas et al., 2004). Modesty as a religious value has been identified to affect health care practices of Muslim women and influences their preference for female providers (Morioka- Douglas et al., 2004; Shirazi et al., 2013; Smith, 2009). Family, are also likely to have an important influence on Muslim women's health behaviors and is particularly relevant to Afghan women. The influence of husbands on Afghan women's health has been documented in limited studies (Lipson et al., 1992; Rintoul, 2010; Shirazi et al., 2013), while the influence of other family members on health in general, have not been widely studied.

Aim

Muslim refugees in general, remain relatively understudied and underrepresented in health promotion interventions (Padela et al., 2015; Walton et al., 2014). This study attempts to expand on emerging research of resettled refugee women by examining middle-age and older Afghan refugee women's perceptions of health and sociocultural factors that influence their health-related behaviors. This study was part of a larger investigation of sociocultural factors associated with preventive cancer screening among Afghan refugee women (Shabaik, 2018). The research questions that guided this study included:

1. What are Afghan women's perceptions of health?
2. What are factors that influence Afghan women's healthcare experiences?

Theoretical Perspectives

This study uses a focused ethnographic inquiry informed by the social-ecological perspective (Bronfenbrenner, 1994) as a theoretical and methodological approach examining social and cultural factors to Afghan refugee women's health and health-related behaviors beyond initial resettlement. The ecological model posits that factors influencing health behaviors occur at multiple levels of influence, at the *micro-level* (individual), *meso-level* (interpersonal), *exo-level* (institutional) and *macro-level* (social and cultural) (Bronfenbrenner, 1994). Another level of influence that may be significant to immigrant and refugee health, is the dimension of *chrono-level* (time) (Bronfenbrenner et al., 2006). Researchers have hypothesized that the migratory experience has a life cycle that is significant to health and needs to be understood in three general phases: 1) pre-migration (experiences from decision to emigrate), 2) settlement (arrival in host country up to five years after migration), 3) post-migration (referring to six to ten years after migration) (Thurston & Vissandjee, 2005). This perspective allows researchers to consider the influence of length of time in the host country on resettled refugee women's' health.

Intersectionality perspective provides the lens for researchers to acknowledge the ways that social status, health status, and cultural contexts intersect with women's lives and impact their health (Crenshaw, 1989). The combination of intersectionality and social-ecological perspective brings an innovative theoretical approach to the study of Afghan women's experiences that have not been widely used in similar studies in feminist and critical ethnographies. Finally, community-based approaches have been considered throughout this project. This included a preliminary pilot study in the community that informed the topic of interest of the present study and through inquiries with Afghan key informants.

Methods

Study Design

Using a focused ethnography study design (Creswell, 2006), we examined shared values, behaviors and beliefs about health and wellness through semi-structured, open-ended interviews with aging Afghan refugee women, their family members and community key informants residing in San Diego and nearby regions. Focused ethnography may enable researchers to understand the interrelationship between people and their environments in the society in which they live. Data collection took place between July 2017 and April 2018. Verbal consent with a study information sheet was used in place of signed consent forms (Smith, 2009). Participants were provided a $20 local store gift card for participation after the interview was completed. By design, this study identifies nuanced themes from interviews mainly with Afghan women over the age of 50, when analyzed as a group.

We also interviewed family members and key informants to triangulate data sources that enrich women's descriptions of their social and structural context. Previous research reporting ethical and effective ethnographic research with Afghan refugees identifies Afghan women as a group at risk for being marginalized, especially those who were recently resettled from rural areas, where they had little or no formal education, did not speak English and were sometimes widowed. Access to this "hard to reach" population can be difficult, therefore, interviews with key informants may provide valuable insights into this community (Smith, 2009). This study was approved by the University of California, Los Angeles (UCLA) Institutional Review Board.

Entry into the Field

The primary researcher who developed the research questions, study design, data collection and analysis of the present study, is of Afghan heritage and had developed years of entry within the field as a member of the San Diego Muslim community and as a health advocate. The primary researcher's assumptions, positionality, and analytic decisions were tracked in reflexive memos throughout the study process. Prior to the present study, a separate IRB approval was obtained for a preliminary pilot study exploring Afghan women's health concerns was conducted to inform the development of the present study, specifically appraising the appropriateness of the interview guide, consent form, recruitment strategy and entry into the field. The accuracy and cultural appropriateness of interview guides and questionnaire were assessed by enquiring native-language speakers to review them and provide feedback. Preliminary pilot study data revealed topics for further inquiry for the present study.

Sample

Inclusion criteria for this study included Afghan women over the age of 50 who was born in Afghanistan. Selection of participants was a combination of purposeful, snowball sampling, which identified participants of interest (Creswell, 1998). Afghan women were mainly recruited by word of mouth, flyers at local mosques and a local Afghan restaurant in San Diego. Inclusion criteria for family members were defined as any member of the household that the woman identifies as having the most influence on their health-related decisions. After interviewing the first few participants, we identified and recruited key informants that could elaborate on concepts discussed by participants. Inclusion criteria for key informants were that they had worked in the Afghan or refugee community for at least two years. The primary investigator and research assistant recruited community key informants through a refugee-serving organization, resettlement agency and Afghan social media networks. Additional referrals for participants through key informants were effective. A target total of 20 total participants was planned as it is the range of participants which allows for thematic saturation (Saldana, 2009) and standard for ethnographic inquiries (Creswell, 2009).

Data Collection

The first author conducted semi-structured interviews lasting approximately one hour with 14 Afghan women in participants' home or preferred locations. Most women (*n* = 9) requested an interpreter during interviews, in which a trained Farsi-speaking research assistant conducted the interview with the presence of the first author. Follow up interviews with five Afghan women's family members were conducted in English also conducted in person. At the end of interviews, women and their family members completed a demographic questionnaire, offered in both English, in Farsi or were read out loud by the interpreter as they answered them. A total of eight key informants were interviewed in English by the primary author. Most of the key informants (*n* = 6) were interviewed over the phone, as they were eager to participate, but preferred the convenience of a phone interview. To maintain confidentiality, the participants were given a unique study ID. A recording device, as well as a password-protected smartphone recorder, was turned on, and notes were taken during the interview for data collection purposes.

Data Analysis

Interviews conducted in Dari (Farsi) were translated by an Afghan research assistant, who was a trained medical interpreter and trained to conduct interviews by the primary author. To improve rigor of interviews and address the impact of translation on the depth and richness of data, co-authors who were experienced qualitative researchers assisted with reviewing initial interviews. Recorded interviews were then transcribed by the primary author and a research assistant. After transcription, random selections of interview recordings were also assessed by a native speaker (an English-Farsi educator) for transcription accuracy to consider alternative translations of the data. Slight translation discrepancies did not influence major changes in the interpretation of the data. Transcripts were imported into the Atlas.ti software to facilitate data coding and analysis. Interacting

First cycle coding was employed descriptively, resulting in a total of 165 initial codes (Saldana, 2013). Various code clustering techniques such as creating tables to group similar codes and creating 'messy maps', which is a "preliminary map that roughly lays out all the elements the researcher think may be in that situation" (Clarke, 2005, p. 267). Messy maps were later ordered into a situational map that was used to explore meaningful processes, tensions, explanations, causes, and consequences (Corbin & Strauss, 2008; Saldana, 2009). Redundant and extraneous codes were eliminated; 53 codes resulted. Second cycle coding was employed to elicit relations among the 53 codes which developed into 10 categories. Themes that illustrate meaning were then extracted from categories. Constant comparison, where each new finding that emerged during data analysis was compared to existing findings, was used throughout the process (Lewis-Beck et al., 2004). Refer to Table 1 for a detailed coding scheme of emergent themes. The researcher used the process of member checks as a method to validate participants' responses. Triangulation of data results was also achieved through key informant interviews (Carter et al., 2014). Communicating with a cultural informant during data analysis provided an increased understanding of interpretations.

Results

Sample Characteristics

Detailed sociodemographic information about the women, family and key informants can be found in Table 1. The mean age of 14 Afghan women was 61.14 years (range: 50-82, SD =

9.75). Most women were married (71%), and the rest were widowed (7%), single (7%) or divorced (14%). More than half of participants (57%) reported less than high school or no formal education. Most (71%) reported no employment outside the home. Most women had Medi-Cal or Medicare (71%). Although income level was not inquired, having government-sponsored insurance indicated lower household income for most women. The average number of years resided in the U.S. was 26 years (range: 14-36, SD = 9.13). An inquiry into women's health history revealed that more than half of women (71%) reporting having one or more chronic health issues. Demographics among family members and key informants are also detailed in Table 2.

Theme 1: Seeking Wellness Holistically

Holistic health beliefs. Afghan women emphasized the importance of having good health, as illustrated by one participant "when a person is healthy, think that you are the wealthiest person in the world". Participants described health holistically, as described by another participant, "the thing about health comes to mind is that overall if you're good, mentally or physically". Women not only identified health in terms of physical function or lack of symptoms but also specifically identified wellness features such as a positive emotional state, ability to socialize, having a spiritual connection with God and having a good relationship with family. "Being healthy is also emotional. A person should always try to have positive ideas about their health, not negative" one participant explained. Another participant illustrated, "A healthy person has sound mind, can work and is self-reliant and do not depend on others. He/she enjoys life and has hopes." Women described 'being unhealthy' in the opposite sense, using specific examples of physical symptoms or function, spiritual disconnection, and having negative thoughts. For example, one woman stated, “when a person is not healthy and sick, he/she is depressed, lives in isolation and does not know the meaning of life”.

Preventing illness. Some women described the concept of prevention in the form of diet and cleanliness, mainly influenced by religious practices. One participant stated:

> I think my religion has a big influence on my eating and lifestyle behavior. Alhamdulillah [Thank God] that I am Muslim, and I say it proudly. I am a Muslim woman, and when it comes to my religion, everything comes first. My religion is so important to me that I don’t drink things that are not permissible for me like alcohol or doing drugs or anything that’s toxic.

Another participant explains the prevention in Afghan culture is based on cleanliness, according to religion. “One of the part of our religion, is the focus on cleanliness, to be pure, like for praying, but they don’t do that.” Another participant stated, “When you making whudhu (cleansing ablution), five times a day, all your body is clean, it prevents infection too.” Preventing future diseases were also viewed by some women in terms of diet. For example, one woman stated:

> First, the food that we eat affects our body, being happy and having no worries and we always need to do regular checkups to make sure we are healthy and we do not have any problem.

Less reported, was the concept of physical activity and screening for future diseases. For some Afghan women, taking walks was the preferred way to exercise, as stated by a participant, “Now that the kids are older… My husband and I, we like to take walks together.” A family member describes her perceptions of why Afghan women, may not necessarily be involved in exercising:

> Like for my mom and her friends, they can't just go to the gym. It's also cultural, in terms of what clothing they will wear, or are they OK being around men, doing exercises, you know things like that.

Theme 2: Having Many 'Worries' and Putting Family First

Ongoing stressors. Women described many ongoing 'worries' and stressors that negatively influenced women's satisfaction with their health. "When Afghan women come here, they come with a lot of stress. They come here with a different culture, different society, after the kids grow up, you worry a lot", stated one participant. Another participant illustrated:

> Yes, my family, the separation of the culture, and I was worried about my children, how they will grow up in this new culture, and how I will be able to manage it. Will I be able to do anything? [Interviewer: Did anything change since then in terms of your worries?] In my worries no, the children grew up and now I have grandchildren. So, I don't think my worries ends. There is no end to my worries. I always think, it's much better now, because the whole family came. In the beginning, I was the only one that came. Just me and my children.

Health concerns. More than half of women had history of at least one chronic health issue, and majority reported dissatisfaction with their quality of health. Women revealed health concerns, specifically identifying physical symptoms and pain. For example, one participant illustrates, "diabetes and rheumatism bothers me too much. Sometimes, I cannot handle it at all and it makes me very weak and I cannot take the pain anymore". Women without history of chronic health issues were particularly worried about developing health issues with older age. Two women without any history of prior health issues discussed being worried about future disease, as narrated by one participant:

> “Yea of course, I am concerned about my health, because right now I’m getting old, and it comes with a lot of unhealthy – my body is getting old, with it – the arthritis, high blood pressure, that is the kind of stuff that old people catch”.

Mental health issues were a concern for few women, as one participant stated, “I feel 99 % of Afghan women have depression due to family issues. The reason why they are not healthy is due to the fact that they have family issues. Because for the majority of Afghans, it is hard to accept other culture.” Other participants were not so explicit about the topic of mental health concerns, but were further corroborated through interviews with family members as well as key informants. A health provider, who primarily works with newly resettled refugees with medically complex cases, described health concerns for newly resettled refugees:

> Some of the patients that I see, they usually don’t notice but I see that they tend to struggle with anxiety, depression, or PTSD from their experience of being displaced from home and placed in refugee camps and realizing that life here is going to be just as difficult or maybe even more difficult than life back home. In terms of specific health concerns, they talk about things that they immediately worry about.

Managing symptoms. Most women reported seeking care through doctors when ill, as stated by one participant, “Of course, going to the doctor helps”. However, for some women, symptom severity prompted both women with and without chronic health issues to visit the doctor for treatment, as stated by a participant, “when I am I sick, 99% of the time I help myself… I do not go to the doctor until my sickness gets serious.” Another participant stated, “as long as it’s not severe… but if I feel like I’m going to vomit, then I would go to a doctor or urgent care”. Few women described concerns over unmanaged symptoms that influenced their ability to function, care for family, socialize with family and perform the religious actions such as ablution, fasting and prayer. For example, one participant stated, “With my situation [diabetes and cancer], unfortunately, I cannot fast this year but I do everything else… I always have a connection with Allah [God]. Always, always. That’s very, very important.”

A family member also described the debilitating consequences of her mother’s back pain and other symptoms on her physical ability to pray and to socialize with family:

> One of the things she’s mentioned to me, was that she misses praying and putting her forehead on the ground. That’s what she misses the most. She wasn’t able to because of the vertigo. And they were giving her some medications that was suppose to help with vertigo but it was making her tremors worse. She wouldn’t be able to get a lot of things – it was emotionally affecting her to the point where when she was invited somewhere, she wouldn’t go. Of course, that made her even more depressed, she would lose sleep at night.

Prioritizing family. Most women emphasized the primary consequence of having an illness would be their inability to fulfill their role within the family, as described by one participant, “I want to be healthy to live and support my children”. Another participant stated, “If you’re sick, you are in bed all the time, you can’t take care of your husband, you can’t take care of your family, your house, kids, grandkids, or if someone needs you in the family”.

One participant explained Afghan women’s role within the home:

> …Both [men and women] have a status. It’s the Afghan culture that says, man and woman are both responsible for something. The man has to go to work. But that’s their only job. And the woman takes care of the family. There’s more

> pressure for Afghan women because they are doing everything in the home and sometimes they [women] even do more than the husband.

Some women described both positive and negative consequences of prioritizing their family has on their health. For example, few women identified feeling a sense of fulfillment and love from their dedication to their family, as stated by a participant, “Family is a huge influence on my life because I’m so blessed to have such a wonderful husband and wonderful children, they always support me and they are my life”. Some women identified the negative consequence of prioritizing family had on their health. “Before I was so busy with working, with three daughters, I was so involved with their lives and working, I didn’t pay attention to my health. And I was never not a bad eater, nor had a heavy weight… Later, I got diagnosed with diabetes.” Another participant described:

> When I see all Afghan woman, I see they are sick… Because they are hardworking at home. Because our culture, it’s very hard to do something, for a woman. Women work at home… It doesn’t matter if she’s sick, or tired, or working too.

An Afghan health professional expanded on this concept and stated,

> Especially with our culture, the men are the ones to go make the money and the women are the ones at home, so there’s a lot that they’re [women] responsible for that overrides their ability to have time to do those things and to focus on themselves and to focus on their health. It’s really about their children, their husbands, about everybody else.

Theme 3: Communicating Health Concerns, Preferences and Needs to Providers

Treatment expectations. Receiving medications for side effects and other health issues that wasn't their initial complaint, or when the doctor couldn't identify the exact cause of their complaint, appeared to negatively influence women's perceived quality of care. One participant stated, "I use cream to rub over my body and eat some herbal medicines if someone asks me to eat. At least it does not have a side effect. The medicine that the doctor gives me does not work on me… Sometimes, I do not take medicine at all because it affects my stomach and I have trouble in my stomach." Another participant stated, "Those surgeries took place partly, because of misdiagnosis or the doctors did not understand the issue properly. For example, I had rotator cuff tear, but the doctors were giving me medicine for arthritis. Some of them medicines with so many side effects."

Another participant described:

> If you go to the doctor, they create stress for you. For example, if I would've gone to a doctor, they tell me if you take this medicine and don't feel better, come back, then why are you so lost and confused if you can't give me a good medicine. After that they give you some antibiotics and your stomach starts hurting, and tell you to drink lots of water. I don't have time for that. Why are you giving me medicine that's not good for me or causing me upset stomach or heart attack? Why are they giving me this in the beginning? That's what worries me and stresses me.

Female providers. Women described how unmet expectations in the healthcare setting with regards to accommodating their requests for female providers, also diminished women's perceived quality of care. One participant explained, "Well, if the provider is going to be female, it will be good it will make us more comfortable, if it's a man, then we won't feel comfortable."

Most women also emphasized that this preference is may be compromised in cases of emergency, as their religion allows them to do so. Another participant stated,

> When a lot of Afghan women go to the hospital, they complain about the way they take care of the woman… If she [Afghan woman] doesn't care, then that's OK. Some people don't care, but some people are very strict with that. If she wants to have a woman doctor, that should be important.

Other participants had no issues in having access to female providers.

> Maybe, some Afghans might have problem going to a male doctor. I prefer a woman doctor or nurse. My family doctor is a woman and if I need nurses, I advise or ask for female nurses. No religion and culture prevents you from getting health treatment.

Female providers in Afghanistan were not common, but with the availability of female providers in the US, women expected their requests to be accommodated, as stated by a participant, "I want a woman doctor. It's more comfortable for me, that's my own preference. Of course, in emergency, I am not going to not see the doctor. We are allowed to see a man doctor. But there's no reason not to see a woman doctor because they are everywhere."

Women also described embarrassment with talking about sexual health topics or women-specific health issues with the opposite sex, as stated by one participant: "We don't want to go to the man doctor and talk about women's things and illnesses and anything genital, it's shameful and that's what we don't want to talk about it". Another participant illustrates the extent of her embarrassment even with family members of the same sex, "I was always modest and I would hide my period from my mom, I was a very, very modest person, to me everything was shame… I am uncomfortable about talking about that stuff, even to my husband".

In contrast, adult family members who were interviewed in this study explained a more open perspective of second-generation Afghans:

> The younger generation among our families, we are very open. Every disease we talk about it. But my mom's generation are embarrassed and try to avoid talking about some diseases like it was a shame. It was just the culture and time they grew up. But we are very open and talk about anything… Also, sexually transmitted diseases. They don't talk about those things and consider it to be something that's not talked about. They won't even talk to their doctor about it. But this generation is very open.

Language barriers. Difficulty with the English language and transportation were the most commonly reported barriers to receiving appropriate and quality care among participants. "The religion and culture is not the problem, it's the language," stated a participant. Language barriers were particularly difficult in women's initial period of resettlement, but continue to be a problem for women, even years after resettlement. Another participant illustrated, "Yes, we had a lot of problems like; we did not know the language and needed someone to translate. We needed a ride to go to the doctor and did not know about medicine and how to use it. It was very difficult".

Participants described how language affected their ability to fully explain to providers what was wrong with them and how important communication is to the patient-provider relationship. "Except the language… I couldn't explain very well what I wanted." Some women described having interpreters during visits helped alleviate this issue, but for most women who reported the need for interpreters, preferred their family members, as stated by one participant, "I do not drive and when needed, my nephew and my niece help me to interpret to my doctor". A participant who rated her English as ‘fair’, described how she translated for individuals within her family and close friends and stated:

> They were more comfortable with me, to tell me what was going on, because I was a family and also I knew what was going on with them, at the same time, I could explain that to the doctors or to the nurses. And I could explain it to them better.

An Afghan health professional, illustrated how language barriers influences the quality of care refugees will receive:

> They [doctors] couldn’t get to the exact cause of his pain. He has issues with his hips too, and they’re recommending hip surgery, but he has no idea if he should or shouldn’t, and it causes a lot of conflict and confusion. It’s very hard to give this type of information to him when there’s no one to translate for him and there’s no one to be there to help with that. So, I know language is a big barrier, when it comes to health, because of course, you [the patient] want to know what’s going on, and you care about your health, and you’re just barely surviving.

Needing Support and Navigating the Healthcare System

Family support. All participants described the importance of family members’ involvement in their health and decision-making process. Women generally endorsed to an extended family perspective, defined by kinship through the extended family, siblings and in-laws through marriage. For women with higher dependency needs, family members were essential to accessing health care and overcome language and transportation barriers. “I seek help from my husband and family. I do not drive and when needed, my nephew and my niece help me to interpret to my doctor”. Women identified a range of close family members as having a significant influence on their health for specific types of support through different family members. For example, women who identified their husbands as having an influence on their health, turned to them for practical support and advice on health-care decisions. Some women identified adult female daughters for information and emotional support, and other extended female family members with regards to women-sensitive topics. Women also turned to family members who were more fluent in English, had access to transportation and helped to advocate for their health and information needs.

> Now the children are a very big help. They know everything, they search in the internet, and they teach their parents. At least what to do and what not to do. That helps nowadays. But the ones who come straight from there, with little children, they don't have that same information. If the husband knows, they're also not that helpful, they're busy. They're working and taking care of stuff outside, you know. They come home tired and just want to eat and go to sleep.

An Afghan health provider illustrated the need for family support among resettled refugees:

> I think older people who are isolated end up being depressed, and also people who have family members that come to their appointments tend to be less isolated because they have a support group, and it goes not only for Afghan patients but for all refugee patients, there are definitely families who support their ill family members, like driving them to their appointments, making sure they take their medications and go to their follow-ups, is helping them navigate the system, whether or not that person actually speaks English. And there are people who come by their selves who clearly need help but they don't have that help either

> because their family members have to work or because emotionally their family is not structured to give them that kind of support.

On the other hand, some women also described situations where the war in Afghanistan and the process of fleeing their home country, resulted in the death of certain family members and separation of families. Women described being separated from their parents, siblings and husbands that caused their extreme distress upon the memory of it. A participant stated:

> I started working with American people, and after that the situation in Afghanistan was not so good, it was very bad. They put my husband in the jail, and I was alone in my big house, so I took my three young daughters and escaped to Pakistan. It was a very bad time… I was alone living with my three daughters, the bombs destroyed things around my house, and I was really afraid. Being alone was the hardest part.

Another participant stated:

> In the beginning, I was the only one that came. Just me and my children. My mother and father, brother and sister and everyone was far from me, and I was worried about each one of them, everywhere… Until they came, I was - every night before they came, I was crying every night for them, worried about them, wondering what would happen to them. Until each one of them got here and got settled and everything, what do you say - they found their ways, they were settled, and I got better. Little by little, day by day.

Some women described how their family structures in the US differed significantly than what they were used to back home. For example, a family member stated, “being a woman in Afghanistan meant that you were cared for by your family, it didn’t matter if you had three or four or even more than six children, your extended family would help care for them but here, you have to find work and have the stress of paying bills, to help your husband and no one to help you."

Community support. Some women emphasized the need to seek community resources for assistance with language, job placement, education, and health information, especially during the initial resettlement. For some women, initially resettling within an established Afghan community was a beneficial part of integrating to life in the US. For instance, one woman described, "I think being with other Afghans can have a very much positive effect on you. When we came here, they helped a lot, especially they help Afghan women and kids". However, not all women had access to a supportive community. For example, one participant illustrated the hardships of not having community resources:

> Starting out our life here, in a new country, I didn't know any English, but we worked hard to learn it. It was very hard... We started from zero, we didn't get any help from government or anything. We didn't even know anything about government help or health or anything. But when we moved to San Diego, we met Afghan friends, we would talk about jobs, and education, things like that, and then we started to learn about it.

An Afghan key informant who previously worked with coordinating services for resettled refugees supported this concept with an example: "He [an Afghan refugee] wasn't able to do it [get a license and job] until he got connected with people. Because they feel like they're a part of the fabric of the community". Upon resettlement in the US, women relied on community resources that enabled them to find jobs on the condition that one learns the language and receives an education.

Women also described the importance of the need for established Afghans assisting newly resettled refugees that may help them positively adjust to the US, as stated by a participant, “I help my friends, if there are any issues with health, if I have information for it I will tell them, to go to the hospital, to do this, or any Muslim or American woman, any human. Thanks God I have kids and husband that help me, so I try to help others.” Another participant emphasized the need to educate with reading in English and the computer, she stated, “Over 2,000 refugees are coming here. Anyway, they don’t know English and this is very important and this is the first thing they should [learn]. Some people who came a long time ago, should help them (the newcomers).”

At the center of the community, key informants talk about the mosque as a place where the community gets together through both worship and community programs. One woman describes the mosque as an appropriate place to receive health information, “Well, yea especially for religion, somebody could go to the mosque, someone could go in there, educate them, answer their questions, and when somebody answers their questions”. On the other hand, one participant stated that “No I cannot imagine the Imam [religious leader] talking about that stuff [women’s health]”. Additionally, some women with high dependency needs, do not seek out activities in the community setting due to frailty. “No, I do not go to any of those places. I cannot go because I have a problem in my bones; I do not go because I will fall. I am sick and I cannot walk”.

Navigating health systems. All women in this study reported having had some form of insurance, with majority of them having Medical or Medicare and needing support in navigating the healthcare system. Women who were assisted by health navigators, nurses or doctors following up by phone call increased women’s perceived quality of care. For example, some women emphasized the importance of provider recommendation for services and scheduling appointments: “The doctor himself/herself makes appointment for me, they call me every once or three months, they make an appointment for me”. Another participant stated:

> The healthcare system was absolutely different… at first when we came, they [social workers] sent us to immigration, they ask us to go and get a checkup at the hospital or clinic… Yes, we went through that, and after that, the doctors were asking us to do this, and such and such tests, and when to do it and why you should do it. So, they were actually teaching us, what to do. And then we learned from our surroundings – the people and what everyone was saying about that [health screening].

However, some women reported coverage changes contributed to lack of needed services such as transportation, urgent care hours and one participant reported specific medications that were uncovered, as stated by one participant, “With the insurance that I had, I couldn’t go to a lot of doctors and specialists and they did not give me a lot of medicines that I needed because they were outside network.”

Some participants seem to benefit from health navigation services as stated by one participant:

> It is the best clinic and the nurses call you to make sure the medicine works fine and they give you the best medicine and make the insurance company pay for it and tell them that the patient really needs it. The clinic very good and they even have walk-ins.

Navigating social services is an important ongoing issue for most women, especially with government insurance. Both Afghan participants and key informants described how navigating the health system is an ongoing struggle, particularly in the resettlement phase. A key informant explained, “Being able to help your patients manage the social services aspect can go a long way when helping refugees as a primary care physician and as a clinician”.

Lack of insurance was not perceived to be a primary barrier to health care, as most women had government-sponsored health insurance, MediCal or Medicaid. However, the period of lapses in health insurance was challenging for some women, described by one participant:

> “We had problems for a long time. I did not know the language; I had no education and I was jobless. For 8 months, I was paid $350 [per month]. After 8 months, they said you have no right to receive more. Then, I told them what should I do? They told me to bring a document from my doctor so that they [would] pay me. At that time, it was not clear who would be my doctors. For few years, I was left like that”.

Discussion

Main Findings

Similar to previous studies on healthcare topics among Afghan populations residing in the US, this focused ethnographic study found that Afghan women’s perceptions of health were not static, but a dynamic interplay of cultural and religious beliefs. Afghan women’s holistic health beliefs corroborate previous research with other Muslim groups’ beliefs regarding health and disease that incorporate spiritual, physical and psychosocial factors (Padela et al., 2018; Tirodkar et al., 2011). Women described socio-cultural factors of family involvement, religion and the cultural emphasis of modesty, were all factors participants described as having an influence on their health and health behaviors. Socio-cultural barriers included patient-physician communication and limited social capital negatively influenced women's perceived quality of care.

Health Concerns

This study builds on previous research regarding aging women's specific health concerns regarding stress and the prevalence of depression in refugee populations post-resettlement. Women's reported health concerns about on-going stress and depression, supports previous findings in research among Afghans and other Muslim refugees regarding the high prevalence of psychological distress and mental health issues in Afghan populations (Alemi et al., 2013; Sulaiman-Hill, 2012). Participants in this study also presented symptom based health concerns, which supports previous research which find Afghans' association of mental worries and bad experiences to physical health issues (Feldmann et al., 2007).

This study offers new insights of Afghan women who are aging in the US with chronic health and comorbidities and suggests that some older women may be at risk for unmanaged chronic health conditions due to isolation, higher dependency needs and experience language and transportation barriers. The need to explore the phenomena of unmanaged pain and chronic health issues in this group is supported by previous research of resettled refugees having increasing rates of chronic diseases in the decades following resettlement (Kinzie et al., 2008; Nelson-Peterman et al., 2015).

Social and Cultural Factors

Another major theme in this study describes the value placed on family and the influence of family involvement in women's healthcare, similar, to other ethnic minority women (Upadhyay et al., 2015; Story et al., 2012). This study provides new insights on the influence of family on women's health, particularly with regards to how women identified which family members they turned to for specific types of support. Women identified close family members, including husbands, adult children and extended family members as important individuals that influence their health decisions the most. Identified family members all had similar characteristics of being fluent in English, had access to transportation and were of older age. Older adult daughters appeared to be a source of information and emotional support, while husbands were primarily sources of financial support and advocate for the household. Adult daughters were married, had children or single but in the health field. These findings did not agree with some previous literature that suggests Afghan women and Muslim women solely prefer a male family member, traditionally the head of household as the gatekeeper of the family, that influences her health care making decisions (Lipson et al., 1995; Shirazi et al., 2013). Future health promotion programs may consider a family-centered approach, rather than specifically husbands, as women are aging with adult children and the high number of widowed Afghan women resettled in the US.

This study also emphasizes the importance of family reunification on refugee women's wellbeing (Rousseau et al., 2004). Family reunification in general, has been identified by refugees as crucial to effective resettlement (Choummanivong et al., 2014). Although there has been relatively little research into the relationship between family reunification and the mental health and wellbeing of resettled refugees and resettlement outcomes, these views have significant implications for future policy development in relation to improving the long-term health outcomes of resettled refugees in the US.

Religion, specifically Islam, as having an influence on Afghan women's health beliefs and practices, permeated throughout women's responses, supporting previous research in Afghan as well as other Muslim populations (Padela et al.; Morioka-Douglas et al., 2014). For example, women emphasized the influence of Islam on eating healthy, avoiding alcohol and emphasis on cleanliness as important healthy behaviors. This study offers some new insights on Afghan women with chronic health issues and their concerns regarding their inability to properly wudhu, stand to pray and fast during Ramadan, even though the religion provides leniency for Muslims with health problems. This may have important implications for clinicians who have patients with arthritis and its implications for daily prayers and patients with diabetes and fasting.

Interactions with Providers

Women in this study emphasized the importance of language rather than religion or culture, had an influence on women's access to healthcare. Women also identified unmet expectations with treatment received from providers that influenced their trust and patient-provider relationship. A previous study of Afghan refugees and their general practitioners in the Netherlands revealed negative previous experiences with providers interpreted as a sign of prejudice on the part of the healthcare professional and undermined trust (Feldmann et al., 2007). Additionally, respecting women's preference for female providers was an important factor that developed trust with providers. This finding supports research that show how access to female providers improved women's satisfaction with their overall care provider's willingness to be culturally sensitive towards the women's health needs and that Muslim women are allowed to see male providers in cases of emergency (Shirazi et al., 2013; Saadi et al., 2015). Due to the availability of female providers, preferring female providers was an act of agency, rather perceived as a barrier to accessing healthcare. On the other hand, contrasting findings show that modesty as a factor was a barrier to care (Vu et al., 2016). Based on our findings, recommendations for promoting awareness of the availability of female providers and knowledge of patient rights to request female providers may be necessary for empowering newly resettled refugee women in their health care decision-making process. When providers assess women’s expectations and address their concerns and preferences through effective communication, trust and understanding between patient and provider improves and leads to higher patient satisfaction, more fulfillment of information needs, and more understanding of information (Schinkel et al., 2016). Therefore, it is essential to understand women’s health beliefs and their sociocultural context that may help promote more effective and culturally appropriate health promotion strategies.

Health Promotion Strategies

This study provides directions for the need for the development of a future health promotion program and is a high priority for this group. Health promotion strategies should address women’s explanatory models of health and illness, their health concerns and utilize a culturally-tailored approach to health and wellness. Health promotion is achieved by proper management of diseases, and women in this interview reported high motivation to maintain health and high need of health information from trusted sources. Women also recommended appropriate and informal sources of information, in which such goals should be directed to the individual and family, the community and the health system. Previous interventions utilizing a religion-informed approach (Shirazi et al., 2015) and a community-based psychosocial approach (Omidian & Lawrence, 2007) have been conducted in Afghan communities, which suggests the need for additional intervention strategies for general health promotion in this group. Some women in this study reported difficulties with transportation and frailty as a barrier to accessing community-based resources, supporting the need of female providers in delivering chronic care services on-site in patients’ homes for this hard-to-reach population (Clarke et al., 2017).

Interviews with key informants also offered insights into emerging issues with more of the newly resettled Afghan women who are arriving in the US, specifically with the increase in Special Immigrant Visas (SIV's) that are unique to refugees from Afghanistan and Iraq, offered to those who have risked their lives to work with the US government. According to key informants, newly resettled Afghan women over the age of 50, may have different health priorities and pre-migration experiences than earlier cohorts of Afghans who arrived in the 1980's and have more memories of a stable Afghanistan than for women who have lived most of their lives in the country under three decades of instability and deteriorating infrastructure. These findings suggest the need for health providers heightened awareness of the heterogeneity of resettled refugees and the need for a distinction between the health needs and priorities of resettled refugees during the initial phase of resettlement and health needs and priorities of resettled refugees during the 'integration' phase, defined as over ten years beyond the initial resettlement phase.

Strengths and Limitations

This study explored Afghan women's perceptions of health and health concerns that focus on women over the age of 50 beyond their initial resettlement phase. The combination of interviews with Afghan women, their family members and key informants provide deeper insight into the social and cultural environment of resettled Afghan women aging in the US. However, through selection bias, the researcher sought Afghan women who have lived in the US for over 10 years and those willing to talk to the researcher were possibly less vulnerable which may have skewed findings, but interviews with key informants offered triangulation of data and provided additional insights on comparing newly resettled cohorts of Afghan women entering the US. Conducting interviews in participants' homes opened the interviews to family members sitting with the participant, and it was not possible to conduct interviews at a different location due to women’s preference. The researcher offered participants to follow up at any time by calling by phone. Reported quotes demonstrate the range of perspectives and experiences elicited from study participants and do not represent the full range of women’s experiences in this very diverse community. More studies are needed with Afghan women of all ages to gain a fuller understanding of their healthcare experiences in the US.

Implications

This study has shown that health promotion interventions targeted at improving resettled refugee women’s health, may benefit from incorporating a culturally-tailored and family-centered approaches. This study also contributes to an increased understanding of how cultural beliefs and religion play a role in health beliefs and behaviors among Afghan women. It is important for nurses and other health providers to understand that ethnic minority women faced with health adversity or illness have cultural explanatory models that often differ from health providers. Specifically, nurses within the community or primary care setting are positioned to promote the convergence of cultural explanatory models and biomedical model, encourage navigation of health services and identify a holistic approach to improve refugee and immigrant women’s health.

Conclusion

This study highlights new and emerging issues, not previously examined in earlier research with Afghan refugees, such as the perceived health of Afghan women and living with chronic health issues. Community health nurses and peer-health navigators have an important role in the management of chronic diseases and affects the patient who is the primary manager of her illness, who is a part of a community and culture, which in turn has an influence on her health outcomes. Programs targeted at the interpersonal and health systems level may benefit from utilizing culturally sensitive and family-centered approaches. These findings have broader implications on improving the health outcomes for ethnic minority women who experience on-going health disparities. Addressing health concerns through culturally informed interventions and interactions may help providers improve health outcomes for all underserved ethnic minority women.

Table 1

Qualitative Code Schema

THEME	SUBTHEMES	IN VIVO QUOTES	CATEGORIES	CODES
Holistic beliefs of health	Holistic health beliefs	"…the meaning of life" "health is wealth"	Holistic health beliefs Preventive health Health concerns Managing symptoms	Being healthy Being unhealthy Health concerns Having pain Afghan diet Avoiding the doctor Belief that health is important Cause of Illness Eating healthy Exercising Feeling good about taking care of health Getting preventive care in the US Getting rest Going to the doctor Going to the emergency Having worries Symptoms not helped by medicine Taking herbal remedies Watching health shows on TV Medicine with side effects
Family and religious duty to health			Prioritizing family Religion	Generational differences Prioritizing family Women's role Maintaining a connection to God Praying/wudhu Religion facilitates healthy behaviors Preferring a female provider "Doctor is mahram"

				Modesty with providers Shame in sexual health topics
Interactions with providers		"I am not wanting a man to be there."	Modesty Language	Communicating with provider Dissatisfaction with care Distrusting doctors Expectation of doctors Language barriers Learning about health from providers Negative interaction with provider
Needing support and the navigating health system	Family support Community support Navigating health systems	"I seek help from my husband and family." "When we came here, they helped a lot"	Family support Community support Navigating health systems	Relying on family Family encouragement Adjusting to the US Difficulty adjusting to the US Getting appointment reminders Going to community events Having long appointment times Health information online Needing transportation Learning about health from family Social isolation due to symptoms

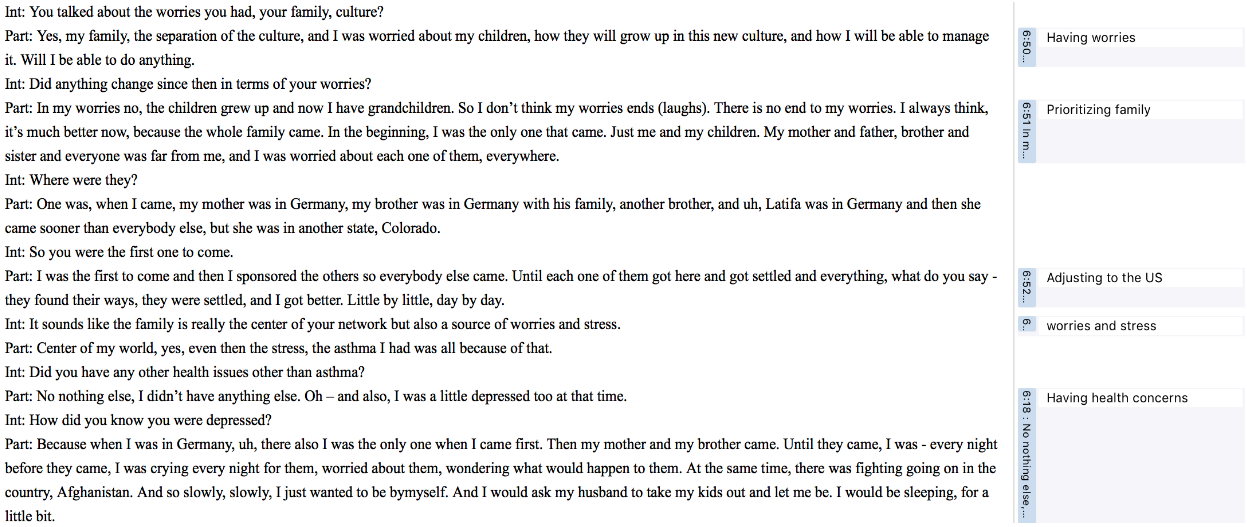
Table 2

Sample Characteristics of Afghan Women, Family Members and Key Informants (n = 27)

Afghan women (n = 14)	Age range	Mean = 62.7 (SD = 11.19)
	Married	64% (n = 9)
	Below high school	57% (n = 8)
	Medical/Medicare	71% (n = 10)
	Years in the US	Mean = 23.4 (SD = 9.4)
Family member (n = 5)	Age range	Mean = 34
	Daughter	100% (n = 5)
	College educated	100% (n = 5)
Key informant (n = 8)	Health field	50% (n = 4)
	Community worker	50% (n = 4)

Figure 1

Initial Coding on Atlas.ti Sample



Int: You talked about the worries you had, your family, culture?

Part: Yes, my family, the separation of the culture, and I was worried about my children, how they will grow up in this new culture, and how I will be able to manage it. Will I be able to do anything.

Int: Did anything change since then in terms of your worries?

Part: In my worries no, the children grew up and now I have grandchildren. So I don't think my worries ends (laughs). There is no end to my worries. I always think, it's much better now, because the whole family came. In the beginning, I was the only one that came. Just me and my children. My mother and father, brother and sister and everyone was far from me, and I was worried about each one of them, everywhere.

Int: Where were they?

Part: One was, when I came, my mother was in Germany, my brother was in Germany with his family, another brother, and uh, Latifa was in Germany and then she came sooner than everybody else, but she was in another state, Colorado.

Int: So you were the first one to come.

Part: I was the first to come and then I sponsored the others so everybody else came. Until each one of them got here and got settled and everything, what do you say - they found their ways, they were settled, and I got better. Little by little, day by day.

Int: It sounds like the family is really the center of your network but also a source of worries and stress.

Part: Center of my world, yes, even then the stress, the asthma I had was all because of that.

Int: Did you have any other health issues other than asthma?

Part: No nothing else, I didn't have anything else. Oh – and also, I was a little depressed too at that time.

Int: How did you know you were depressed?

Part: Because when I was in Germany, uh, there also I was the only one when I came first. Then my mother and my brother came. Until they came, I was - every night before they came, I was crying every night for them, worried about them, wondering what would happen to them. At the same time, there was fighting going on in the country, Afghanistan. And so slowly, slowly, I just wanted to be bymyself. And I would ask my husband to take my kids out and let me be. I would be sleeping, for a little bit.

Figure 2

Categorization and Messy Map Sample

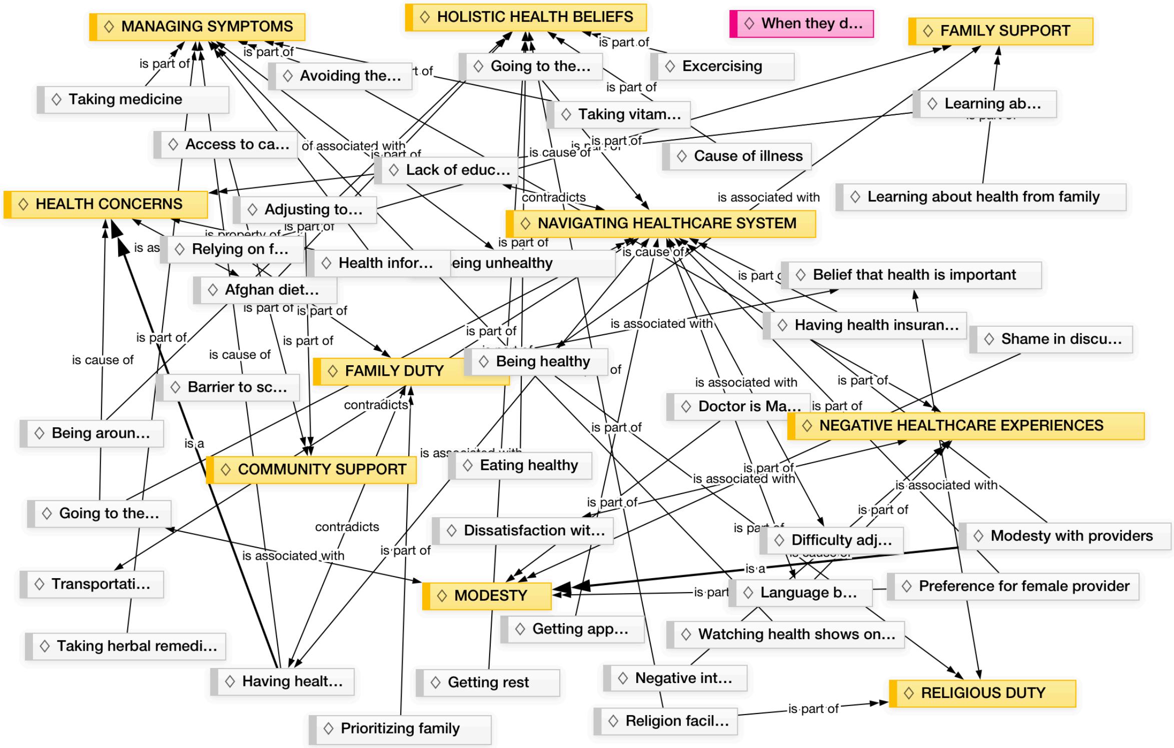
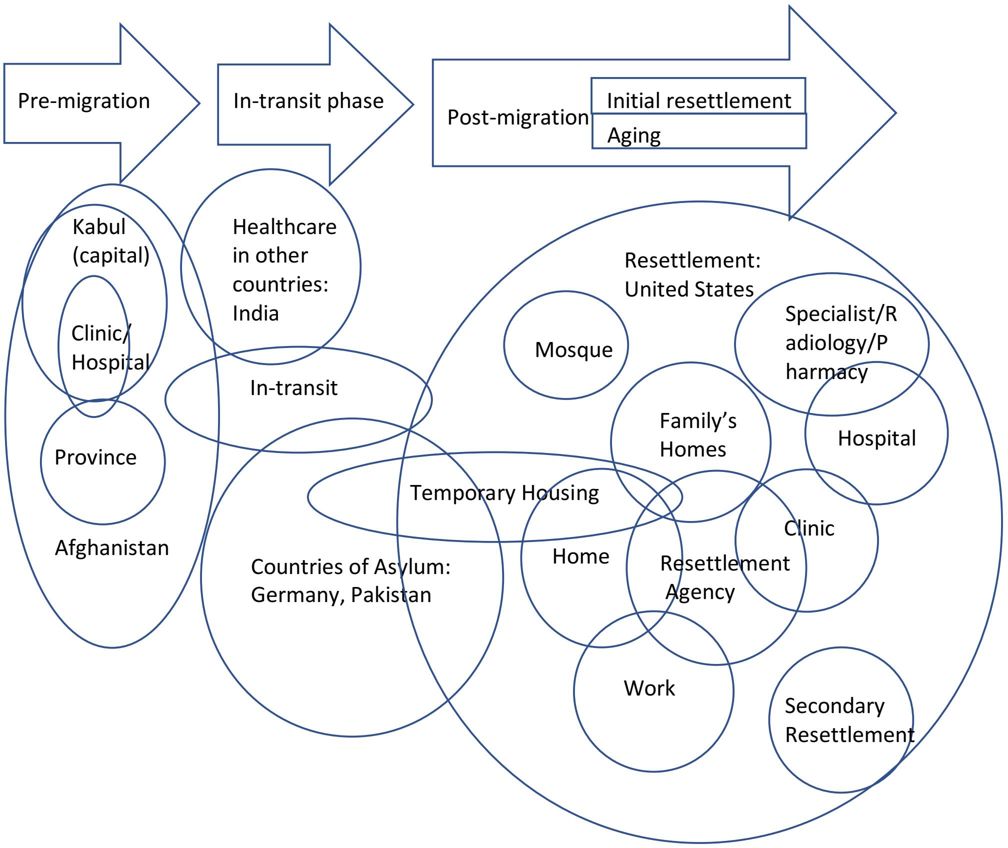


Figure 3

Social Worlds and Arenas Analysis



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Chapter III

Sociocultural Factors of Breast and Colorectal Cancer Screening among Afghan Refugee Women

The purpose of this study was to examine sociocultural factors that influenced breast and colorectal cancer and screening among middle-aged and older Afghan women resettled in the United States. A focused ethnography methodology was employed, using semi-structured interviews with Afghan women over the age of 50 (*n* = 14) and their family/caregivers (*n* = 5) residing in San Diego County. Atlas.ti was used to inductively code interview data. Initial codes were reduced to focused codes that were grouped into categories. Each category was analyzed for specific patterns. The categorical findings on breast and colorectal cancer screening are reported here. This study found that Afghan women held beliefs about cancer that had 1) connotations of a '*dangerous and deadly disease*', grounded in women's personal or extended family's experiences with cancer. These beliefs influenced women's expectations about the screening process and reported 2) barriers to screening and healthcare as fear of diagnosis and discomfort associated with screening procedures as well as poor/inadequate communication with providers. Despite these beliefs and fears, women emphasized that (3) '*women should not be scared'*, reporting patient empowerment through knowledge, reminders and making '*duaa*' (prayer). The results from this study emphasizes the role of provider recommendation, family involvement and religious coping in facilitating screening behaviors.

Key words: Mammography, colonoscopy, cancer screening, refugee women

Introduction

Breast cancer (BC) and colorectal cancer (CRC) account for the most common cancers diagnosed in women in the United States (US) and among the top leading causes of cancer-related death in the country (Centers for Disease Control & Prevention [CDC], 2017). Despite the overwhelming evidence that early detection of localized BC and CRC tumors lead to a 93-100% survival rate (National Cancer Institute, 2016), there are many women who are less likely than others to get mammography or colonoscopy screening (Jackson & Vega, 2016; Peek & Han, 2004). Immigrant women are less likely than US-born to report having a recent mammogram, as well as to adherence to recommended screening guidelines (Bhargava et al., 2018). Refugee women represent a particularly vulnerable segment of the immigrant population and maybe even less likely to regularly use preventive health services than immigrant women (Morris et al., 2009). This is especially concerning since about 3 million refugees have been resettled in the US in the past few decades (Pew Research Center, 2018). Over the past decade, progress has been made in increasing screening rates among women in the US, however, disparities remain, particularly among immigrant and refugee women from Muslim majority countries (Hasnain et al., 2014; Bhargava et al., 2018). Unfortunately, there is a lack of established research on resettled refugee women's perceptions of cancer and cancer screening beyond their initial resettlement period after government-sponsored health insurance has ended (Morris et al., 2009).

One ethnic minority group overlooked in studies of preventive health and cancer screening is Afghan refugee women. According to study by Shirazi et al (2013), Afghan women residing in California have low reports of mammogram use compared to NHW and other ethnic minority groups. In their study, authors found that almost 34% of Afghan women (*n* = 53) reported never having had a mammogram. While 66% of women reported ever having a mammogram, only 50% of the entire sample reported having a mammogram within the past 2 years. (Shirazi et al., 2013). An earlier ethnographic study among Afghan women in San Francisco Bay Area reported that 43% of Afghan women in their sample had ever had a mammography and 27% had screened in the previous two years (Lipson et al., 1995). These rates contrast mammography screening rates within the past two years of 67% among Asian, 66% among Black and 62% among Hispanic populations in the U.S. (Shirazi et al., 2013). This research identified barriers to screening such as limited English proficiency and low health literacy (Shirazi et al., 2013).

A review of the literature reveals that there is a paucity of published research on CRC screening and use of colonoscopy among Afghan populations. However, other studies available among other Muslim-majority immigrant populations report low CRC and BC screening rates in ME populations. Research has found that Muslim immigrants and refugees are less likely to perform one of the recommended colorectal cancer screening tests, colonoscopy, sigmoidoscopy or FOBT (Al-Amoudi et al., 2015; Szczepura et al., 2008). The low rates of CRC screening observed in these studies are concerning given the rising incidence of CRC among ME populations and the potential benefit of early screening and detection (Alhurry et al., 2017).

Social and Cultural Factors

Religion and family may be important levels of influence on Afghan women's health behaviors. The emphasis of the family as the most important social unit in Afghan culture suggests that the social and cultural environment may have influences on Afghan refugees' preventive health behaviors and health outcomes (Russo et al., 2015). Majority of Afghans are Muslim and practice unique cultural-religious customs and beliefs that influence their health practices and behaviors (Morioka-Douglas et al., 2004; Russo et al., 2015). Other research reports religious beliefs and cultural values influences BC screening behaviors among Muslim immigrant women in the US (Padela et al., 2015).

Conceptual Framework

Social contextual factors play a significant role in the adoption of preventive health behaviors. Social-ecological (SE) models recognize that decisions about engaging in preventive health behaviors can be influenced at the interpersonal, institutional, community and policy levels (Emmons, 2007). Several studies have found that interpersonal factors such as family and social support are associated with BC and CRC screening (Honda & Kagawa-Singer, 2006; Lee et al., 2014). Institutional level factors, such as endorsement of BC or CRC screening by a primary care physician, have also been shown to influence participation rates (Cole et al., 2002; Padela et al., 2015).

This study attempts to expand on the limited research of resettled refugee women by examining Afghan refugee women's perceptions of cancer and sociocultural factors that influence screening behaviors. The research questions that guided this study included:

1. What are Afghan women's perceptions of BC and CRC?
2. What factors influence Afghan women's BC and CRC screening?

Significance of Study

Querying Afghan refugee women's perceptions about cancer and factors that influence screening is needed since refugee women from Muslim majority countries are underrepresented in health promotion programs. Additionally, this study will be the first to address CRC screening among this population. Most published studies with Afghans focus on newly arrived refugees with high reports of mental health conditions during the early stage of resettlement and little is known regarding women's health behaviors, years beyond their initial resettlement period

(Morris et al., 2009). A preliminary exploration of the role of family members on Afghan women's health behaviors is novel as no previous studies have queried the influence of family members on Afghan women's cancer screening behaviors. Interviews with family members also offer a rich context to Afghan women's social environment.

Methods

Study Design

Using a focused ethnography study design (Creswell, 2006), semi-structured, open-ended interviews were used among age 50 and older Afghan refugee women who were primarily living in San Diego County. San Diego is the largest resettlement region in California where a large community of Afghans reside (County of San Diego, 2016). The present study was part of a larger investigation that explored sociocultural factors associated with Afghan refugee women's health and health behaviors (Shabaik, 2018). The use of a focused ethnography methodology was deemed appropriate for this study, which aims to interpret the subjective experiences of participants from a distinct culture (Wall, 2015). The primary researcher was of Afghan heritage, trained to conduct interviews and had an elementary-level knowledge of Farsi and interviewed women with a trained bi-lingual research assistant. The primary researcher reached out to key informants within the community to refer women to the study in addition to recruiting during community events. An Imam at a local mosque in San Diego announced the study during Friday prayers or evening lectures and the primary researcher was present to gauge women's interest in participating in the study and scheduled an interview at women's preferred time and location. Verbal consent was obtained from each participant prior to the interview and participants were provided a $20 local store gift card after the interview was completed. A semi-structured interview guide was developed, based on previously validated studies of breast cancer screening in refugee women (Carroll et al., 2007; Saadi et al., 2012; Shirazi et al., 2013). This study was approved by the University of California, Los Angeles (UCLA) Institutional Review Board.

Sample

Inclusion criteria for this study included women over the age of 50 born in Afghanistan and have resided in the US for at least 10 years. Inclusion criteria for family members, were any adult family members or caregivers who women identified as having an influence on their health behaviors. Selection of Afghan women were recruited through a combination of purposeful and snowball sampling (Creswell, 1998), by word of mouth and flyers at local mosques and a local Afghan restaurant in San Diego. Participants were referred through an Afghan research assistant and key informants from the community. Based on feedback from the research assistant, some Afghan women chose not to take part due to time constraints. Upon completing interviews, the primary researcher asked women to ask their identified family members to reach out to the primary researcher if interested in participating. A study information sheet with contact information was provided for the family member.

Data Analysis

Interviews conducted in Dari (Farsi) were translated by a research assistant - a previously trained medical doctor and Afghan refugee who was fluent in both Dari and Pashto (Farsi) and trained to conduct interviews by the primary author. Recorded interviews were then transcribed into English by the primary author and a research assistant who were also bilingual. Random selections of interview recordings were also assessed by a native speaker (an English-Farsi educator) for transcription accuracy to consider alternative translations of the data. Slight translation discrepancies did not influence major changes in the interpretation of the data. Transcripts were imported into the Atlas.ti software to facilitate data coding and analysis.

First cycle coding was employed inductively and descriptively (Saldana, 2013), resulting in a total of 165 initial codes. Using various code clustering techniques such as grouping similar codes and creating ‘messy maps’ to explore meaningful processes, tensions, explanations, causes, and consequences (Corbin & Strauss, 2008; Saldana, 2009), redundant and extraneous codes were eliminated; 35 codes resulted. Second cycle coding was employed to elicit relations among the 35 codes which developed into 7 categories. Themes that illustrate meaning were extracted from categories. Constant comparison, where each new finding that emerged during data analysis was compared to existing findings, was used throughout the process (Lewis-Beck et al., 2004). Refer to Table 1 for a detailed coding tree of emergent themes.

To increase trustworthiness during data collection and analysis, experienced qualitative researchers provided input for training the research assistant and performing data analysis. Additionally, the researcher’s assumptions and positionality were tracked in analytic memos and reflexive notes throughout the study process. The researcher used the process of member checks as a method to validate participants’ responses. Triangulation of data results was also achieved through key informant interviews (Cohen & Crabtree, 2008). Communicating with a cultural informant during data analysis also provided an increased understanding of participants’ descriptions and researchers’ interpretations.

Results

Participant Characteristics

Sociodemographic information can be found in Table 2. The average age of women over 50 (*n* = 14) was 62.7, and they have resided in the US for an average of 26 years, (range from 14 to 38 years; SD = 9.36). Majority of women in this study had either MediCal or Medicare health coverage, indicating below poverty income level for women. While most women (*n* = 12) had at least one mammogram and a recent mammogram within the past two years (*n* = 8), the majority of women had never had a colonoscopy (*n* = 8) and FOBT (*n* = 9). Among women over the age of 50, 28% had a family history of BC, while 14% had a family history of CRC. The primary author also interviewed five women's family members. The average age of family members was 36.6 (*n* = 5) and all were 1.5 or second-generation daughters.

Theme 1: Connotations of a '*Dangerous and Deadly Disease*'

Symptoms and screening. A cancer diagnosis was described by some women as not being common in Afghanistan. One participant stated, "…. but it wasn't that much diagnosis, not a lot of facilities [to diagnose cancer], nothing. So, it was very rare, that also in the end, when it had damaged to the full." Another participant stated:

> Since it wasn't cured in Afghanistan, they come here with that mentality. And here also, in the beginning, during those years, it wasn't that much. But, now it is better… Those days, nobody knew. When they had cancer, they would just put it in their head that they are dying.

Women described a range of beliefs about BC and CRC, mostly regarding its symptoms and association with death while emphasizing the need for more information and importance of screening early for treatment. Most women described cancer in terms of having symptoms such as feeling a lump in the breast, pain and stomach problems that might indicate having cancer. For example, a participant stated, "When they feel something hard in their breast or they have pain, they need to go to the doctor and treat themselves on time." Most participants also emphasized the importance of breast self-exam, more than a mammogram. For example, a 50-year-old participant stated, “My doctor checked everything and said there’s nothing there. So, she told me just check yourself and I told her if there’s nothing there I don’t want to do the mammogram.” Another participant stated:

> They [women] need to do the check-up themselves using their hand and if they feel something hard in their breast. They need to go to the doctor immediately. Then, the doctors know what to do. It’s not good for them to wait for so long to go to the doctor.

Another woman commented:

> Yes, when I go to the doctor, they tell us how to check yourself to make sure that we do not have breast cancer. We are given guidelines on how to check ourselves while taking shower (like how to use our hand and hold it to do the check up) to make sure that we do not have breast cancer.

Most women reported receiving a colonoscopy or FOBT as a result of having had symptoms. A participant with history of stomach cancer described, “…I didn’t have any signs or symptoms. The only symptom I had, was acid reflux. The doctor diagnosed me with that. And after I came back from Turkey, I was not able to eat, I was a little nauseated, and I asked the doctor to check it. And that’s when they found [cancer]”.

One participant later explained that she had personally known a woman who had a lump in her breast for some time, and when she finally saw a doctor, she soon died of late stage breast cancer. The participant stated:

> No, I do not know. For majority, it runs in the family or they do not care about it at the beginning, and they refer to the doctor when it is too late. Most women

don’t know how to do self-exam. And the most important is to go to the doctor. It’s better to take care of it from the very beginning.

Similar beliefs about having symptoms that prompt screening were also described by other women: “Yes, those who have issues with their intestinal or stomach, when they go to the doctor, they are being asked to do colonoscopy.” Another woman indicated “The colonoscopy was because I was having it for my heart burn, very [bad] acid reflex.” Another participant described, “Yes, my father had colon cancer. When my sister told us about it, we were really sad. We prayed and made duaa [prayers] for him. I was really nervous because sometimes I have a pain in my stomach, here [points].”

Fear of diagnosis. Most women feared cancer and associated cancer with death. One participant described, “Anybody who knows if they get any kind of cancer, will get upset or depressed because they will feel like they will die. Anyone who gets cancer will die.” Negative feelings about cancer in general were echoed by a majority of women, as described by one woman, “Everybody is scared of it, they don’t want to talk about it, even if they have, they don’t say it to others that I have this problem or something like that. And, why, I don’t know.” Another participant stated, “I pray to God that I never develop cancer. I am very scared of it.”

Cause of cancer. Most women described a range of perceived beliefs about cancer etiologies (Table 4). The most commonly reported cause for BC was perceived as having family history, mental stress and poor diet. For example, one participant stated, “I know that mostly it can be genetic. In my family, no one had it so far.” Another participant stated, “It’s [breast cancer] because of all of these artificial foods and pesticides and unnecessary medicine.” A few women were unsure and requested information, “I don’t know, is it infection? I don’t think it’s infection, but maybe. I don’t know, maybe when there’s a lot of people in the family that have it, you will have it too." An 83-year-old participant recalls how her sister had developed BC, stating "My sister had cancer. In Afghanistan, she had it… One day, she told my brother, brother I am feeling something in my breast… My brother knew this may be cancer, and nobody was in that house except my sister and brother. I think that cancer is created by… sadness, and anger… and my sister was alone." Another participant stated, "They need to know and be aware of this dangerous and deadly disease. This way, they can avoid things that cause cancer."

A 60-year-old participant explained how she believes family issues and stress may increase the risk for developing cancer:

> I think the mental stress is the major cause of cancer to develop. I think stress play a primary role in causing cancer. In countries, where high technology is used, life is very busy and people work like machine. They get lots of stress. People do not have time to take care of themselves and spend time with their family, with husband or with wife and kids. Nowadays, people go to work and come home, spending two hours in traffic and that is life is.

Through interviews, few women described sources of mental stress related to family problems and difficulty adjusting to the US, as one participant illustrated: "Having family problems, having lots of pain and sorrow and lots of stress contribute to developing breast cancer in women." Another participant described:

> I don't know why she got the cancer, maybe she went through some things with her family. She was in her 50s and because her husband passed away and her daughter got married and moved away to a different state, maybe she was depressed or had anxiety.

Preventing cancer. Some women believed that cancer was not preventable and others were unsure about it. For example, one participant stated, “You can’t prevent it [breast cancer], you just must catch it early”, while another stated “There’s no prevention [for colorectal cancer].” Some women had the same beliefs about preventing BC and CRC, as stated by one participant: “The same way that they develop breast cancer, they can develop intestinal cancer.” A 60-year-old participant who has had a mammogram stated, “The only thing I can do is to pray to Allah [God] so that I do not develop cancer because the cause of cancer is not clear yet.”

A participant explained her beliefs about overcoming fear to screen for BC for early screening and treatment:

> It's very scary both for the person who has it [cancer] and who hears about it. It causes hopelessness. When we hear, it’s hard for us. It is very hard for those who have it and we try to cheer them. They can go to the doctor. There is cure for cancer if it’s not acute and it is treated on time. Otherwise, it’s hard.

Second generation family members, who were all daughters women identified as their caregivers or having an influence on their health and health decisions (*n* = 5), described negative perceptions of cancer in general within their families and older women having low knowledge of cancer prevention. One family member illustrated:

> For my aunt, we did a Quran *khatem* [prayer event], when she was diagnosed. We do that, yea, unfortunately, preventing it, they don’t think about those things. My youngest aunt, when she heard, she did genetic counseling and removed her ovaries because of that. So, she’s the only one that think about those things. But my [older] aunt and my mom, they don’t want to do it, as prevention. Prevention is not seen, obviously, everyone is different.

Hearing about cancer or experiences with a family member who had a cancer diagnosis, appeared to significantly influence beliefs about the cause of cancer. For example, negative feelings about cancer associated with death was a result of having personally known someone who died of cancer. A participant, aged 66, described an experience with a death of someone who previously lived with their family in Afghanistan:

> Like a lady that was in our house, she was working for our grandfather, and then she stayed with the family, she raised my father, she raised me, so she was still there, still old, one day she [had] bleeding, we took her to the hospital, and said this is full blown cancer and we can't do anything, just take her home. We took her home, poor lady, was suffering, from pain, from everything, just laying down there, not being able to eat properly we were just putting food in her mouth, until she died there. So, there wasn't any prevention, or preventative thing. Not even treatment.

Another participant described how devastated they were to find out about her sister's early stage breast cancer.

> Yes, my sister, it was like 10 years ago. It was a shock for us because we were all very healthy. She lives in Texas, and I got a phone call that she didn't even feel anything during her normal checkup but the doctor said she has a very low [early] stage of breast cancer, but they caught it early. When I received the call, I was very devastated, because we've never had that in our family, and I started crying because I was here and she was in Dallas. We all flew out to support her.

Theme 2: '*Like Sheep and Fish*': Poor Communication and Healthcare Experiences

Apart from women who had no problems with getting a mammography or colonoscopy, some women identified barriers to initial screening and ongoing screening. The most commonly reported barrier was lack of information about cancer and screening in general and the need for more awareness. Most women reported difficulty with English language as the barrier to receiving information about BC and CRC, while some women described difficulty receiving this information due to a ‘silence’ around talking about cancer. Unpleasant healthcare experiences also influenced women’s trust in providers and intention to screen. Some women described receiving unclear and delayed explanations about diagnosis and screening results, while others identified pain and embarrassment associated with the procedure.

Talking about cancer. For some women, sharing information about cancer with others was difficult due to perceptions about keeping health issues private but at the same time, some women felt it was important to share information to increase awareness. One participant stated, “Some of them, don’t even tell their immediate family because they don’t want make them upset or worried or cause them worry, but that’s real. Some other ones, out of shame, or something bad that happened to them, that they don’t want anyone else to know about it.” One participant emphasized the importance of talking about cancer: “It will be a good idea to communicate with a neighbor or a friend and if someone knows, and even if they have pain they can tell them to go to the doctor and get testing, instead of being late.” Another participant illustrated:

> It is hard, when you think that you have it [breast cancer]. I have experience of having a cyst in my breast. I had one for months that I had that thing, because the doctor had always showed me how to check and all that stuff, and I checked and it was a hard thing there. I didn’t want to tell anybody that I had it. I didn’t say anything. And I just went. And the reason why I said earlier that the reason (for

> not telling others) was to not worry somebody else, is because I didn't want to worry everybody. So, I went to see what happens. And if something is there, then I will tell them, and why should I tell them ahead of time and make them worry.

A daughter illustrated her experience with talking about cancer within her family:

> I don't know if all across the board, but it's just that word [cancer], is highly associated with, this person may die, so in our culture, we really freak out about that word. It's comes from being ashamed to share it sometimes. So, I've seen, like in my family for instance, someone had passed away and nobody knew about the cancer. There's this level of keeping your pride and not looking weak, even though having the disease in our religion, requires people to pray for you, to be there for you and help you, some people don't want to be associated with that. They don't want to be seen as not strong or suffering, and especially with an illness that you do not have any control over is something you keep under wraps, it's something that you want to go through it and solve it and move on with your life. It's why people want to keep it hidden, it also has a lot to do with the area that the person has cancer in. I recently experienced this where I have a friend whose father had surgery, and I was going to visit him, and asked my mom to come along, because of the area of where he had his surgery and that he might be ashamed and not want me to visit. And so, my mom didn't even go, but culturally, there's a specific type of connotation.
>
> Another family member explained:
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> When it comes to healthcare, they're [my family] is really conservative… So, when it comes to breast cancer, we really don't sit around and talk about

> breasts… this is just within my family, and I know that for other Afghan families, they may be more open minded or even more conservative about it. From my own experience, this cultural norm really does impact our health.

A second-generation participant stated:

> It's funny, actually, my mom taught me when I was younger when the doctor recommended [a Pap smear], my mom said 'no, she doesn't need one'. And at point, being young, she said 'no you don't need anyone going down there, it's fine'. You know, so you have that perception, but later on for her, she said she was more comfortable going to the doctor for a Pap smear after having children. I've had conversations with her about this, like, she's had three children and doctors have already seen her down there.

Having conversations about mammography with husbands or sons depended upon women's comfort level with talking about women's breasts or other private parts and husband's level of education. A family member stated "If they [Afghan men] have a close relationship with their wives, and explains to them the benefits that it's good to always be screened one a year, then yea. I guess it depends on how close a husband and wife are and their communication level". Another participant stated, "Men are not that much educated either, they are educated enough that they know the language, but they're not educated in [women's] health stuff."

Poor/Inadequate communication with providers. "The religion and culture is not the problem, it's the language," stated one participant. Another explained:

> And all the time, the big issue, was we don't understand the language. That was the big problem, our life here is about the language. We went, to courses, to learn

> English. And after that, we slowly learned English, not as good [as] the kids, but after the kids [were] born, we missed the courses and we were too busy.

Some women described expecting providers to provide correct explanations and diagnosis of their screening results. Not having met these expectations resulted in further distrust of providers. Couple women recalled previous experiences with cancer misdiagnosis. One participant stated:

> I will eventually do mammogram. However, I am trying to delay it for a year. One of my cousin's did CT scan who I spoke with recently, the result showed that he developed cancer, but the doctor did not read the result. After two years, he had problem in his kidney and went to the doctor. They did X-ray and they compared his result with the results that he did two years, unfortunately, the doctor determined and found out that he developed cancer two years, but the doctor did not see it or read it. Then, he immediately did surgery.

Another participant stated:

> Oh, I don't know how they couldn't figure it [cancer diagnosis] out. Because at that time, I probably had blood in my stool and the doctors didn't check it. I was anemic for years and years and couldn't figure it out. My family doctor never tried to figure it out, that was the big, big issue. … For me, right now, it's very hard for me to trust them. The one [family doctor] that is currently helping me during this time, I respect them and trust them. But before, I was really disappointment. How can I miss this? But what can I do?

Delay in communication and waiting for results also negatively influenced women's screening experiences and caused distress for some women. One participant stated, "Yes, yes, after the second or third time it became easier. I still hate the waiting, I get a lot of nervousness about it." Another participant stated,

> I was OK, but I was worried every night. I was thinking about what it will be, what will happen and everything. It makes you think about the future life, and everything, you know. You think like, "I will be dying, what should I do", and what and all the things you would need to take care of and all of that stuff. Then when the results came it was negative.

One participant described a provider's unclear message about her results caused her to believe she had cancer:

> …All night [after receiving the mammogram] and until I talked to the doctor, I had really bad experience and awful feelings, I thought I was dying and I wrote to my son about everything after my death. Actually, they told me that I needed to do the exam again since the first exam was not taken correctly and it was not clear. I am telling you this story, because I want the doctors to know that they need to be clear about their patient' diagnosis. The way that the doctor wrote me to contact them sounded that I my mammogram was positive and I thought I developed cancer.

Discomfort, pain and embarrassment.

Fear of pain and discomfort was a concern for women who have had a mammogram. For example, 'The first time I had a mammogram, I was so scared because everyone says it's a very painful procedure and I went to [the] hospital for that first time." Another participant stated, "For the first time, when I did mammogram, I hate it because my breasts were lumpy and their equipment was not good at that time. When they were pressuring my breasts, it was very painful.” Other participants described their reasons for delaying their next mammography, as stated by another participant, “Yes, I have. Although it was in 2013, my doctor asked me to do it again and I said no I don’t want to do it again. It was really painful for me.”

Another participant described extreme discomfort during a biopsy:

> I was told that they would take a tissue from my breasts for the exam. It was the worst system to do the exam and it was my worst and bitter experience that I had since they make women lay on the table and pull women’s breasts down like sheep breasts and enter a very thick needle and as if they are fishing in their breasts. Until, the needle enters to a particular point and take the tissue. It was the worst and painful experience.

A 58-year-old participant who had never had a colonoscopy stated, ‘I prefer the stool blood test because I don’t want to go through that [colonoscopy]. The way the doctor described it to me sounds awful. I’d rather do this every year.” Another participant described her reason for not having had a colonoscopy and stated, “I haven’t had another colonoscopy because they never had a woman doctor available.” Another participant stated, “Well, if the provider is going to be female, it [having a mammogram] will be good, it will make us more comfortable, if it’s a man, then we won’t feel comfortable.”

Feeling comfortable with a female provider, was a general preference for most women seeking healthcare, regardless of the type of service received. It was especially important for when women’s sensitive areas are to be examined, exposed or touched but was comprisable in emergency situations. For example, “I’ve never had a male doctor, but in case of emergency I will go to a male doctor even if it’s a pap smear or colonoscopy, if its urgent.”

Family members described the importance of addressing their mothers' comfort level and preferences during the process of screening. One daughter stated, "She [my mom] prefers women, actually she's, OK with a male physician if he's working with outside her body, like that neurologist was just checking her head and barely touching her. But if it's inside her body then she will ask for a woman doctor." Another family member stated:

> I know that for my mom and grandmother, my family is very in tune with their healthcare now, like my mom just went and got her colonoscopy even though she's very hesitant, it's just the whole process, I think it's just the modesty issue and being embarrassed, and getting a mammogram, and makes them uncomfortable and less inclined to get one. Like if they needed an MRI, there's no hesitation. Whereas, there's the whole process of taking your clothes off, so this modesty issue needs to be factored into the process of screening where women are made to feel comfortable.

Theme Three: 'Women Should Not Be Scared' - Empowerment Through Support and '*Duaa*'

Despite barriers to screening, most women acknowledged the importance of cancer screening. A participant stated, "Actually, everyone should get checked for mammogram, especially for someone who has a mom or grandmother who has breast cancer, and they should also do a self-breast exam." Another participant stated, "They [women] should not be scared. They need to go to the doctors whether they are married or not and check. Before it's too late and kill them, it's better to go and treat themselves." Women who have had a recent mammogram or colonoscopy, described empowerment factors that helped them overcome barriers to screening through providers' reminders, motivation from family, and religion.

Health system reminders. Receiving recommendation and reminders through providers and health systems was an important facilitator for mammography, colonoscopy and FOBT screening. A participant stated, "Especially, the ones that come new [to the US], they need that information and encouragement and reinforcement and all that stuff." Most women were prompted to have a mammography screening by recommendation from their provider. A participant stated, "the doctor calls me every day to do mammogram." Another participant stated, "My doctor told me I needed one so that's why I did". One participant described, "When I see my physical doctor, she told me to get a mammogram to not get cancer. The doctor she gave me a mammogram and told me I don't have a cancer." Although less reported, few women described receiving similar recommendations and reminders for colonoscopy and FOBT test. One participant stated, "I don't know why I got it done, but it wasn't painful and it wasn't pleasant as well." Another participant stated, "Yes, every year we do it [FOBT]. I don't remember when to do it or to ask for it, but Kaiser sends the package, we take it and send it back to them and they send the results."

Supportive and prompt communication by providers also empowered some women to repeat screening. "I did not worry because when I talked to the doctor, the doctor told me just to do it for the second time since the first time it was not clear. The way the doctor told me made me comfortable to do the exam for the second time. Then, it was normal." Another participant described the need for a timely response:

> When the screening was over, I asked the nurse about the result. I was told that the doctor would discuss it with me. I was scared and worried and asked them to make an appointment as soon as they could so that I could see the doctor to know about the result.

A family member emphasized the need for improved communication between providers and her mom and stated, “I think eye contact. Introducing yourself. People would come in and bark at my mom … it’s people’s manners that need to improve. Acknowledging the human being in front of you. Like if you don’t want a man touching you... It’s just a preference of an older woman.”

Family support. Most women identified that their husbands and close family members were a source of encouragement for healthy behaviors, and in some cases, were also sources of information for them. One participant stated “It is necessary that the family members advise them [screening] as well as listening to the TV. They need to listen and put it in practice.” A participant reported going to her married 28-year-old son for support, but prefers to talk to her older sister for women-specific issues. She stated, “Yea, I am more comfortable with my sister, she is a woman, she understands, she is older than me, she has a lot of experience. She is a smart woman.” Another participant stated, “When I had a colonoscopy, I was really scared, but when I was done, my son was there and the doctor said there was nothing. Before that I was so scared I was shaking. Then the doctor told me in ten years I can repeat.”

Family members interviewed, who were adult daughters, confirmed their roles as advocates for their parents in explaining health information, as stated by a family member, “We’re [daughters] usually the ones who help my mom go to her appointments”. For a 42-year-old family member who primarily grew up in the US, having the experience of having had the mammogram herself also helped her to promote the importance of the screening within the family. A 38-year-old participant stated that after getting married and having children, “it was me who would ask [my mom] with questions about my private health and she would then start to tell me about her experiences, never when I was younger”.

Some women identified family members as sources for health information. For example, a participant stated: “they can ask doctors or ask family members like their sister or daughter, they can ask questions and educate themselves.” However, some women identified other informal sources of information. One participant stated: “Sometimes I watch [Afghan channel] TV and doctors talk about and I listen to it. The doctor goes on the TV and people asks questions and I get information about health on there, I listen.” Another participant stated, “I collect the information from TV and from doctors and health programs about breast cancer.” Some women get information through other members of the community, as one participant stated, “I watch health programs on TV and when I socialize, I listen to others and ask questions about their sickness and ask what the doctors tell them.”

Coping through prayer. Most women who had had a screening, experienced intense fear during the process, as stated by a participant, “My daughter had a cyst. And I was worried about her. She didn’t tell me, first few days, and then she told me. And she went and did the biopsy and it was nothing. It is hard, and scary. Not hard, it’s scary.” Coping through the screening process through prayer was reported by most women who underwent mammography screening. A participant stated, “I always pray and seek help from Allah and I was doing so at that time [mammography].” Another participant stated, “I was praying. I have anxiety and when

I am in such situations, I pray to Allah [God] and it helps and it makes me relaxed." Another participant illustrated:

> I was worried myself, and if it is [cancer], probably I will die, and if it's my fate, nobody can prevent that. So, then I will go [get the mammogram]. I was always making, duaa [prayers] and having trust in God, that, of course it helped me during that time, but at the same time I was worried of course.

Some women felt relieved to know results of their screening because they were able to take ownership of their health. One participant stated, "In our religion, we have to take care of our health, it is our responsibility." A family member further describes the effect that screening had on her mom and stated, "Of course, even though my mom dreads getting that [mammography], the whole thing it makes her nervous. But I think that she feels good about herself afterwards, like she did something good for her health." Another participant described her feelings after receiving results of her screening:

> When I heard about the result, I felt relaxed and happy. I thanked God for not having it and I prayed that everyone stays health and no one gets sick or develop cancer… As far as I know, in our religion there is no such thing that prevents women from doing breast cancer screening. In our holy book [Quran], it is written that both women and men should take good care of their health. Our religion never prevents them.

Discussion

This study improves our understanding of social and cultural factors that influence BC and CRC screening among resettled Afghan refugee women. Specifically, cultural beliefs about cancer, interpersonal relationships with providers, family, and religion, influenced women's perceptions about cancer and cancer screening. Previous research with Afghan women and mammography screening supports our findings that identify religion and husbands as having an influence on women's screening behaviors (Shirazi et al., 2013). This study offers new insights on CRC screening and expands the understanding of culture-specific beliefs of how cancer is perceived as an illness and family members influence women's health and screening. This study also provides information that could be used to design culturally appropriate health promotion interventions directed at increasing preventive cancer screening rates among resettled refugee women.

Cultural belief systems of Afghan women may not align with health professional's explanations or explanatory models of illness, which may impact on women's health and illness behavior (Rajaram & Rashidi, 1998). Growing research has examined the impact of socio-culturally mediated beliefs on preventive cancer screening. Researchers have examined explanatory models for a variety of illnesses including diabetes, arthritis, and cancer among Latina, South Asian and Arab women (Cabassa et al., 2008; Tirodkar et al., 2011; Cohen et al., 2013). Kleinman refers to these socio-culturally based belief systems as explanatory models, a product of social, cultural, and historical factors among groups (1980). They are held by both individuals and health providers that provide an explanation for the process by which an illness is patterned, interpreted and treated. Often, these conceptions of illness are loaded with emotional meanings and stem from cultural beliefs and values (Rajaram & Rashidi, 1998). A lack of understanding women's cultural explanatory model may result in ineffective health promotion strategies used to enhance screening and prevention behaviors among minority populations.

One of the main themes that emerged in this study was that early detection for cancer starts with the identification of symptoms such as a lump or pain. For example, Afghan women emphasized the importance of practicing breast self-exams (BSE) to identify early-stage breast cancer and when to go to the doctor, more than regular mammograms. Current expert recommendations discourage BSE because it has not demonstrated its ability to reduce mortality rates from BC (United States Preventive Services Task Force, 2018). Having symptom-based beliefs about cancer screening may negatively impact women's health because screening is most effective before the appearance of symptoms. Obtaining or practicing screening prior to the start of symptoms was not discussed by women, yet is an essential point for providers to teach patients, because often, it may be more difficult to treat and cure malignancy by the time symptoms appear. Additionally, less invasive methods for screening may benefit women who experience more distress and discomfort with screening procedures such as regular FOBT screening but is underused by women in this study. Additionally, women in this study reported concerns over acid reflux and other related symptoms and its association with colonoscopy. This finding may have important implications for primary care providers who have patients from countries where the most common cancers are BC and gastric cancer. There is a need for further research for preventive screening strategies in the US for endoscopy for high-risk population subgroups, particularly among immigrants from Asia (Choi, 2014).

In this study, interviews with women emphasized the need to address practical barriers to preventive screening such as language, miscommunication, and consideration for women's preferences which resulted in dissatisfaction with care, rather than blaming culture or religion for the lack of preventive care practice. Previous research has shown that preference for female providers is a barrier to using health services. This study's findings suggest that women's preference for female providers was perceived to be an act of agency, rather than a barrier to care. Women reported that although their religion allows women to be seen by male providers, they are more comfortable being seen by female providers and have this expectation. These findings are supported by previous research in BC screening in Afghan and Arab immigrant women (Shirazi et al., 2013; Saadi et al., 2015).

This study provides newer insights on empowerment factors for repeat screening. Women reported having health system reminders for screening, family support and making '*duaa*' [praying], promoted the use of screening and coping with anxiety and distress through the procedure until receiving results, making it easier for them to repeat the next screening. Interviews with family members also offered a richer context of women's social influences. Family members provided insights on their role in advocating for their mothers while encouraging preventive health care behaviors. Older Afghan women expected to have issues acknowledged and being treated with dignity during the screening process, as research suggests that older age has important status markers that deserve respect, but is distinguished by the generational expansion of social roles (Omidian, 1992). In addition to age, social experiences of getting married and having children also promote status within the Afghan family (Omidian, 1992). For example, in this study, most participants identified their daughters as family members who had a major influence on their health and health decisions, and daughters happened to be second generation adult children with increased life experiences of meeting major social milestones such as marriage and having children. Previous research with Afghan women identifies gatekeepers, mainly husbands, as important persons who influence women's health care decisions (Lipson et al., 1991; Shirazi et al., 2013). These findings help re-consider family dynamics and the potential for receiving support from second generation Afghan family members as influencing factors to preventive screening.

Other factors such as media and health policy may also play a role in influencing and empowering women's increased access to preventive health services. Majority of women in this study are low-income and have Medicare health coverage. Prior to the passage of the Affordable Care Act (ACA) in 2010, screening mammography and colonoscopy were both covered benefits under Medicare but beneficiaries had to pay a percentage of coinsurance or copayments for mammography and colonoscopy. Additionally, a recent study shows that there was a significant increase in mammography and colonoscopy uptake after ACA coverage (Cooper et al., 2016), which may explain why 12 women have had at least one previous mammogram.

Implications

This is an important topic because the present study aims to contribute to the understanding of social and cultural factors for improving breast cancer screening among community agencies and health clinics that implement population-based strategies for increasing mammography and CS screening use. This study also increases our understanding of influences on resettled refugee women's preventive screening behaviors, years after resettlement. With on-going wars in the Middle East and Africa and the refugee crisis exacerbates, these findings may be important to consider for other resettled refugees from Muslim-majority countries. The results from this study may be used to address barriers to screening beginning using recommendations for: (1) providing a culturally tailored awareness program at the community level, (2) using a family-centered approach; and (3) consideration of the use of health navigators, who are able to identify women's physical, emotional and cultural needs and build trust to help them access appropriate resources to meet these needs.

Limitations

It is important to consider that the study focuses on a specific cohort of middle-aged and older adult Afghan women who have resided in the US for over ten years where factors significant in this study are specific to their context and generalizability is limited. Although women identified other family members as having an influence on their health, the primary author only interviewed adult daughters due to their openness to interview, therefore perceptions of husbands or male relatives were not included in this study. To analyze the extent to which the findings of this study could be transferred to other local realities, it is important to consider that participants of this investigation were older women of low socio-economic status and were selected through purposive sampling.

Conclusion

In summary, this study demonstrated that there are a combination of social-ecological factors at the individual, interpersonal and social and cultural levels of influence, that facilitated and/or prevented women from getting mammography screening. Health system reminders and family support appeared to be important facilitators of mammogram screening. Health care providers should use culturally appropriate strategies to better inform women about the importance of mammogram screening and the limitations of BSE. The socio-cultural factors found in this research should be considered when designing and implementing BC screening strategies for resettled refugee women.

Table 1

Qualitative Code Schema

THEME	IN VIVO DESCRIPTION	CATEGORIES	CODES
Connotations of a 'dangerous and deadly disease' **[cancer beliefs, attitudes/knowledge]**	"…this dangerous and deadly disease." "only God knows…" "When we hear, it's hard for us." "When we hear, we pray for them." "When I hear, I get scared." "If there's nothing there I don't want to do the mammogram".	Symptoms and screening Fear of diagnosis Preventing cancer	Being at risk for cancer Cause of cancer Treating cancer Comparing US to Afghanistan Negative feelings about cancer screening Negative feelings about cancer Knowing someone with breast cancer Knowing someone with cancer who died Knowing someone with colon cancer Talking about cancer Shame associated with illness*
'Like sheep and fish': Poor communication and healthcare experiences **[barriers to screening and adherence]**	"I had to have someone guiding me through it" "…like sheep and fish." "it's not pleasant"	Poor/inadequate communication Talking about cancer Discomfort, pain and embarrassment	Language barrier Transportation barrier Having a biopsy Having had a mammogram Having had a colonoscopy Having had a FOBT Having had a Pap smear Getting colonoscopy for GI issues

			Feeling inhuman Having pain* Distrusting doctors* Delaying cancer screening
'Women should not be scared' – Empowerment through support and 'duaa' **[empowerment factors to repeat screening]**	"it was very easy" "…I was always making, duaa [prayers] and having trust in God"	Health system reminders Family support Coping through prayer	Motivation for screening Sources of health information (family and religion) Learning from doctors and nurses* Provider recommendation in screening /relations: provider /relations: community Having a biopsy Having had a mammogram Having had a colonoscopy Having had a FOBT Having had a Pap smear Feeling comfortable with provider* /relations: health system* /relations: spirituality /culture: religion and spirituality

Table 2

Participant Characteristics of Afghan Women and Family Members (n = 19)

Afghan women (n = 14)	Age range	Mean = 62.7 (SD = 11.19)
	Married	64% (n = 9)
	Below high school	57% (n = 8)
	Medical/Medicare	71% (n = 10)
	Years in the US	Mean = 23.4 (SD = 9.4)
Family member (n = 5)	Age range	Mean = 34
	Daughter	100% (n = 5)
	College educated	100% (n = 5)

Table 3

Screening Behaviors of Afghan Refugee Women > 50 (n = 14)

Screening	**Percent of women**
Never had a mammogram	14.2%
Mammogram within past 2 years	42.8%
Mammogram over 2 years	42.94%
Never had a colonoscopy	57.2%
Colonoscopy within the past 10 years	42.8%
Never had a FOBT	64.3%
FOBT within the past year	28.6%

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Conclusion to Dissertation

The findings of manuscript one integrated commonly reported multi-level influences on resettled refugee women's preventive cancer screening behaviors and found lower rates of screening among refugee women compared to rates among the general host-country's population. This study also establishes that resettled refugees from Muslim majority countries are understudied and underrepresented in health promotion interventions. Underutilization of preventive screening services were associated with commonly reported barriers of low knowledge and awareness of cancer and screening, language difficulty and modesty or preference for female providers. Factors at that influenced the use of preventive screening services included provider recommendations, family support and health system navigators. Other factors reported in previous studies, found a range of cultural and religious factors that were mostly reduced to variables of fatalism, modesty, female genital mutilation (FGM), and sensitivity around sexual health topics (Abdullahi et al., 2009; Pratt et al., 2017; Zhang et al., 2016). Modesty, or embarrassment, as a religious factor, also significantly influenced refugee women's use of preventive screening services and preference for female providers (Carroll et al., 2007; Ghebre et al., 2015).

In manuscript two, this focused ethnographic study found that Afghan women's perceptions of health were not static, but a dynamic interplay of cultural and religious beliefs, corroborating previous studies on Muslim populations residing in the US. Afghan women's holistic health beliefs corroborate previous research with other Muslim groups' beliefs regarding health and disease that incorporate spiritual, physical and psychosocial factors (Padela et al., 2018; Tirodkar et al., 2011). Women described sociocultural factors of family involvement, religion and the cultural emphasis of modesty, were all factors participants described as having an influence in their health and health experiences. This study offers new insights on Afghan women's chronic health issues and concerns, how women identify family members with the most influence on their health as well as older women's concerns regarding fulfilling religious duties such as prayer, wudhu and fasting with chronic health issues, even though Islam, provides leniency for Muslims with health problems.

And finally, manuscript three explored sociocultural factors on women's perceptions of breast and colorectal cancer and screening, specifically among Afghan women over the age of 50. This study improves the understanding of social and cultural factors that influence BC and CRC screening among resettled Afghan refugee women. Cultural beliefs about cancer, interpersonal relationships with providers, family and religion, influenced women's perceptions about cancer and cancer screening. This study offers new insights on women's culturally-informed beliefs about cancer, symptom exploration of screening, and sociocultural factors of religious coping and family support that empower women to repeat screening. Other factors not previously discussed in literature, were identified as Afghan media through television and internet, as well as the improvements in Medicare health coverage, may influence increased awareness and of cancer screening in general for this population.

Overall, the findings suggest that, aging Afghan women in the US experience multiple social and cultural influences on their health and health behaviors. This study provided important insights and expands on previous literature on the concepts of religion and family. These findings provide a comprehensive examination of sociocultural factors that influence conceptions of health, cancer and cancer screening behaviors. Further, these themes are valuable and should be taken into consideration by nurses and health providers. More broadly, the knowledge gained from this dissertation provides directions for utilizing religion-informed and family-centered approaches for future interventions as well as policy initiatives, directions for further research and improvements in the long-term health promotion of resettled refugees in the US.