Impact of Acculturation in Mediating Barriers to Screening Mammography Among Arab American Women

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IMPACT OF ACCULTURATION IN MEDIATING BARRIERS TO SCREENING MAMMOGRAPHY AMONG ARAB AMERICAN WOMEN

A Thesis Presented to
The Faculty of the School of Medicine
Yale University

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<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AAW</td>
<td>Arab American Women</td>
</tr>
<tr>
<td>ANOVA</td>
<td>Analysis of Variance</td>
</tr>
<tr>
<td>ACS</td>
<td>American Cancer Society</td>
</tr>
<tr>
<td>ACSB</td>
<td>Arab Culture-Specific Barriers</td>
</tr>
<tr>
<td>BCS</td>
<td>Breast Cancer Screening</td>
</tr>
<tr>
<td>BI-RADS</td>
<td>Breast Imaging Reporting and Database System Score</td>
</tr>
<tr>
<td>BRCA-1, BRCA-2</td>
<td>Breast Cancer Genes 1 and 2</td>
</tr>
<tr>
<td>BSE</td>
<td>Breast Self-Examination</td>
</tr>
<tr>
<td>CBE</td>
<td>Clinical Breast Examination</td>
</tr>
<tr>
<td>CI</td>
<td>Confidence Interval</td>
</tr>
<tr>
<td>DBT</td>
<td>Digital Breast Tomosynthesis</td>
</tr>
<tr>
<td>GBMMS</td>
<td>Group Based Medical Mistrust Scale</td>
</tr>
<tr>
<td>HIPAA</td>
<td>Health Insurance Portability and Accountability Act</td>
</tr>
<tr>
<td>MANOVA</td>
<td>Multivariate Analysis of Variance</td>
</tr>
<tr>
<td>SD</td>
<td>Standard Deviation</td>
</tr>
<tr>
<td>SEER</td>
<td>Surveillance, Epidemiology, and End Results</td>
</tr>
<tr>
<td>OR</td>
<td>Odds Ratio</td>
</tr>
<tr>
<td>UNS</td>
<td>Under-screened or Never Screened</td>
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</table>
ABSTRACT

Breast cancer is the most common malignancy in women. Early detection and screening (including breast self-examination, clinical breast examination, and mammography) are vital for early identification and treatment, but there are established cultural differences in screening. Arab women have lower screening rates and are more likely to be diagnosed with late-stage disease. Cultural differences can be attributed to medical mistrust and inadequate knowledge. However, the extent to which they impact screening practices is not fully known. **In this cross-sectional study, we assess the rate and regularity of screening mammography in the U.S., comparing Arab versus non-Arab/Hispanic White women. We will also use length of U.S. residency as a measure of acculturation and the Arab Culture Specific Barriers scale to examine barriers to screening mammography among Arab American women.** These efforts will provide insight into cultural factors that influence screening and may suggest specific interventions to promote positive health screening behaviors.
CHAPTER 1: INTRODUCTION

1.1 Background

1.1.1 Overview of Breast Cancer

For decades, breast cancer has been a national hot topic, with thousands of dollars employed in breast cancer research to fund stronger and more efficacious treatments. In 2020, breast cancer surpassed lung cancer and became the most common malignancy worldwide, accounting for over 2.3 million diagnoses in women and over half a million deaths. [1,2] In 2021, approximately 15% of all cancer cases in the United States were breast malignancies. [3] It is estimated that there will be nearly 300,000 cases of invasive disease and nearly 45,000 deaths in the United States throughout 2022. [4]

The most common sites of breast cancer metastasis include lungs, bone, liver, and brain - all of which can cause extensive multi-organ failure. [5] Surveillance, Epidemiology, and End Results (SEER) data between 2011-2017 demonstrated that 5-year relative survival rates progressively decrease with advanced breast cancer staging. Though localized disease had a 99% 5-year survival rate, this dropped to 86% for individuals with regional spread. Those with distant metastases fared even worse, with a mere 29% 5-year relative survival rate. [3] There is a great urgency to plateau this deadly rise in breast cancer and minimize the fatalities that occur at alarming rates.

1.1.2 Breast Cancer Screening Initiatives

Nearly 1 in 8 women will be diagnosed with invasive breast cancer in their lifetime. [6] Global screening initiatives aim to diagnose breast cancer in early stages, when it is curable and thereby has a lower mortality rate. Screening methods include
breast self-examination (BSE), clinical breast examination (CBE), and mammography. Both BSE and CBE are very common screening practices. However, in 2015, the American Cancer Society (ACS) updated breast cancer screening guidelines with research stating there is no proven benefit to regular breast self-examinations or clinical breast examinations. \[^6\] As such, neither are routinely recommended. Western clinicians continue to move away from both, favoring mammography in recent years. Improvements in radiographic imaging include 3D mammography (digital breast tomosynthesis, DBT), which use thinner slices to create three dimensional images to more accurately diagnose tumors. These advances have increased sensitivity and specificity in breast tumor detection. \[^7\] In the United States, mammography has an average sensitivity of 86.9% and specificity of 88.9%. \[^8\] Increased sensitivity can help limit re-test follow up and overdiagnosis. Today, it is widely accepted as the gold standard tool for non-invasive diagnostic imaging to detect breast malignancies.

Consistent mammography screening is the most effective method to reveal early stage disease and increase survival. \[^9\] Screening mammography has been proven to reduce breast cancer-specific mortality for women between 50-69 years. \[^10\] Screening is generally not recommended for advanced age as it may uncover low-risk tumors that do not require treatment. This ultimately causes more harm than good by way of screening costs, immunocompromise, unnecessary radiation (for patients who proceed with treatment) and consequent physiologic symptoms, and negative mental health outcomes resulting from a cancer diagnosis. \[^11,12\] For similar reasons, there is little benefit in screening mammography for women with shorter life expectancy due to comorbid conditions. \[^7\] Nevertheless, screening regularly with highly sensitive imaging, women
with undiagnosed breast cancer are more likely to be diagnosed at early stages when their
disease is more easily treatable and curable. [4,13]

1.1.3 Screening Practices Among the Arab World

Screening mammography is not implemented as frequently within the Arab world, and both CBE and BSE are more common. [14-16] Arab women in the East continue to present with locally advanced disease at younger ages despite newer treatments and earlier screening/detection methods. [17-20] They are less likely to screen regularly and appropriately for breast cancer. Fewer studies analyze breast cancer trends for Arab women living in the United States, although existing data does suggest they are also under-screened, with screening rates lower than the U.S. national average. [21-25]. To understand this, we looked at preventative healthcare practices among other minority populations, which may provide insight to similar roadblocks that Arab American women face.

Multiple minority populations living in the United States report several barriers to screening. These include psychological barriers (fear of diagnosis, lack of knowledge or awareness, fatalism, medical mistrust, modesty, and embarrassment), communication and language barriers, financial burdens and accessibility, and more. [20,26] As a result, the death rate (per 100,000) for various female minorities including Black and non-Hispanic White Americans with breast cancer is higher in both groups than in White women (29.2 and 21.2 versus 20.6, respectively). [3]

Routine screening is essential in decreasing breast cancer-related mortality. There is a clear need to boost screening practices among minority women who may be at
increased risk for advanced disease, although the specific barriers to screening among Arab American Women (AAW) are not yet fully understood. The Arab Culture-Specific Barriers (ACSB) is a validated questionnaire that examines barriers to screening among Arab women. The instrument was originally validated in 2008, obtaining data from Arab women over the age of 50 living in Israel (Palestine) and assesses five sub-scales: environmental barriers, cultural beliefs concerning cancer, body exposure barriers, social barriers, and body unease. It has only been used in a handful of studies that assess the unique health-related obstacles AAW face. [27]

An existing study has employed the ACSB tool and found relationships between mammography screening and ACSB variables; however, the data obtained only reflected AAW originating from one of three Arab countries (Jordan, Lebanon, and Egypt) living in Los Angeles, California. [28] Utilizing the ACSB in this study will allow researchers to better explain the impact culture may have on screening habits in AAW with varying lengths of residency in the United States. Results from this study can better provide clinicians with insight they need to approach their patients in a culturally sensitive way, promote preventative screening, and maximize positive healthcare outcomes.

1.2 Statement of the Problem

Most existing literature examines barriers to breast cancer screening among Arab women living in Arab countries. Studies that focus on AAW have sampled niche populations that do not adequately reflect the extensive diversity of the Arab American population. To our knowledge, no studies to date have compared Arab American women to non-Arab/Hispanic White women. Use of the latter as a model for comparison would
allow researchers to ascertain the gap in minority-based care, which can then be targeted in future interventions.

It is imperative to understand how cultural differences impact screening habits in Arab women with different degrees of acculturation, especially as they are more likely to present with advanced disease and may have poor health literacy. This can refine their medical care via targeted interventions that break these barriers in order to increase mammography screening for Arab American women, thereby decreasing the cancer burden this population faces.

1.3 Goals and Objectives

Our goal for this study is to compare the rate of mammography screening between Arab American women and non-Arab/Hispanic White American women. Additionally, we aim to examine whether health-related cultural stigma is associated with breast cancer screening practices between Arab American women who have lived in the United States for different lengths of time. To do this, we will implement the Arab Culture-Specific Barrier, which is a validated instrument that examines barriers to mammography screening in Arab American women.

1.4 Hypothesis

After adjusting for confounders, we hypothesize that there will be a statistically significant proportional difference in mammography screening practices (both ever-mammography screening and screening within the appropriate timeframe per ACS guidelines) between Arab women and non-Arab white women living in the United States.
We also hypothesize that there will be a statistically significant mean difference in cultural barriers to screening among Arab women who have lived in the United States for different lengths of time. We expect a greater association between cultural barriers to mammography screening, and lower mammography rates for women with a shorter length of U.S. residency.

1.5 Definitions

*Arab:* The term “Arab” encompasses individuals who are ethnically Arab. This includes the following 22 countries: Algeria, Bahrain, Comoros, Djibouti, Egypt, Iraq, Jordan, Kuwait, Libya, Lebanon, Mauritania, Morocco, Oman, Palestine, Qatar, Saudi Arabia, Somalia, Sudan, Syria, Tunisia, United Arab Emirates (UAE), and Yemen.
1.6 References


CHAPTER 2: REVIEW OF THE LITERATURE

2.1 Introduction

In order to evaluate existing literature on screening practices and culture in Arab American women, a detailed and systematic review of the literature was performed from December 2021 through April 2022. The databases PubMed, OVID (Medline), and the Cochrane Medical Library were utilized. Primary searches included the following key terms, searched independently and in combination using and/or functionality: breast cancer, breast neoplasm, breast tumor, breast malignancy, breast cancer screening, cancer screening, preventative screening, mammography, mammogram, early detection of cancer, Arab, Middle East, Middle Eastern, Eastern, Muslim, stigma, culture, barrier, and cultural beliefs. These were further filtered by both year published and full text availability. International studies were included in the final review, although all articles were limited to English-language only. Resources from reference lists of studies extracted from the initial search were also incorporated. Titles and abstracts were reviewed first to assess relevance to the proposed research study. Texts were then fully read and analyzed before including them in the literature review.

2.2 Review of Empirical Studies

The data collected during our literature review is divided into four main categories. The first includes breast cancer risk factors and general screening recommendations per American Cancer Society (ACS) guidelines. From there, we delved into the existing research on Arab American Women in the United States and barriers to breast cancer screening within this population. Because there is limited data on our target
population, we looked to other populations to better inform our understanding of barriers to screening. This led into our third and fourth categories. The third incorporates screening and preventative health practices within other minority groups, and the fourth incorporates breast cancer screening practices among Arab women living in the East. The below flowchart helps diagrammatically organize these categories and provides the framework for our literature review.

**Figure 1.** Four Main Categories of Comprehensive Literature Review

### 2.2.1 Screening Guidelines in the United States and BI-RADS Scoring

Screening mammography allows for early detection of breast cancer, with studies showing it can reduce breast cancer mortality by at least 20%. [1,2] Mammograms detect between 2-8 tumors per 1,000 mammograms. Although sensitivity decreases with increased breast tissue density, refined imaging techniques such as digital breast tomosynthesis (DBT) can obtain three-dimensional images that better visualize tumors while minimizing false positives as a result of breast density. [3] Additional breast cancer screening modalities include ultrasound (US) and MRI. [4]
For women with an average risk of developing breast cancer, the American Cancer Society recommends annual mammograms between 40-54 years of age. Women 55 years or older can then screen biennially. For women with a high risk of developing breast cancer, ACS recommends annual breast exams beginning at 30 years of age.\textsuperscript{[3,5]}

Women are risk-stratified based on predisposing risk factors for breast cancer. These include: personal or family history of breast cancer, prior chest radiation, \textit{BRCA1} or \textit{BRCA2} (breast cancer genes 1 and 2) mutations, early age at first menses, advanced age at first pregnancy, nulliparity, current age, and postmenopausal hormonal therapy.\textsuperscript{[6]}

The Breast Imaging Reporting and Data System (BI-RADS) scoring system categorizes mammography, US, and MRI results.\textsuperscript{[7]} Table I illustrates BI-RADS scoring. Together, breast cancer awareness in addition to consistent screening aid in the detection of early stage breast cancer, which improves prognoses and disease-free survival rates.

<table>
<thead>
<tr>
<th>Category</th>
<th>Results</th>
<th>Next Steps</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Incomplete</td>
<td>Requires additional image evaluation and/or prior images for comparison</td>
</tr>
<tr>
<td>1</td>
<td>Negative; the risk of cancer diagnosis within 1 year is 1%</td>
<td>Follow with routine screening</td>
</tr>
<tr>
<td>2</td>
<td>Benign; the risk of cancer diagnosis within 1 year is 1%</td>
<td>Follow with routine screening</td>
</tr>
<tr>
<td>3</td>
<td>Probably benign; the risk of cancer diagnosis within 1 year is 2%</td>
<td>Follow with routine screening or short-term follow up</td>
</tr>
<tr>
<td>4</td>
<td>Suspicious; the risk of cancer diagnosis within 1 year is 2%-95%. 4a: 2%-10% risk of diagnosis within 1 year 4b: 10%-50% risk of diagnosis within 1 year 4c: 50%-95% risk of diagnosis within 1 year</td>
<td>Follow with tissue biopsy</td>
</tr>
<tr>
<td>5</td>
<td>Highly suggestive of malignancy; the risk of cancer diagnosis within 1 year is 95%</td>
<td>Follow with tissue biopsy</td>
</tr>
<tr>
<td>6</td>
<td>Known biopsy—proven malignancy</td>
<td>Follow with medical or surgical management as clinically appropriate</td>
</tr>
</tbody>
</table>

\textbf{Table 1. BI-RADS Scoring from Mammography, Ultrasound, and/or MRI results}
2.2.2 United Status Census and Healthcare Implications

The US census categorizes Arab Americans as White. This classification combines their demographics with other non-Hispanic White populations in survey data, causing them to become a masked population whose specific health status is poorly understood. [8-12]

Existing studies show that Arab immigrants have fewer early detection screening tests. [8,9,13-16] As the Arab American population continues to grow annually, there is also an increase in the number of under-screened women who will be at increased risk of later developing advanced-stage breast malignancies. Since census data shows White Americans have the highest mammography screening rates, Arab American women are thus a vulnerable population whose specific needs are not well understood or documented in literature. There is an additional lack of culture-specific interventions, which could increase screening practices and foster positive preventative health behaviors.

2.2.3 United States-Based Studies

2.2.3.1 Introduction

The second block of our literature review focuses on four main studies that discuss screening practices in the Arab American world and the factors that may affect BCS. All studies included AAW who self-identified as ethnically Arab during data collection and belong to at least 1 of 22 countries: Algeria, Bahrain, Comoros, Djibouti, Egypt, Iraq, Jordan, Kuwait, Libya, Lebanon, Mauritania, Morocco, Oman, Palestine, Qatar, Saudi Arabia, Somalia, Sudan, Syria, Tunisia, the UAE, or Yemen.
On average, Arab women have denser breasts than their non-Arab counterparts. Women with denser breasts have an increased risk of developing breast cancer in comparison to the average woman. Because dense tissue can mask underlying cancers, women with dense breasts also have higher rates of interval cancers; that is, cancers that appear within months of a negative screening examination. As such, regular and prompt screening measures are crucial for Arab women to reveal cancers before they have progressed into a less treatable disease.

The studies we found showed mammography rates among Arab American women are much lower than the United States average of 66.7%. A study in Detroit, MI, home to the densest population of Arabs in America, showed that only 43% of participants between 40-49 years (156/365) had received a mammogram at least once in their life. A separate study in California showed only 51.8% participants in the same 40-49 year age group had ever received a mammogram. National studies have shown that Arab American women have lower motivation to participate in mammography screening in comparison to other minorities living in the United States.

Many studies highlighted similar variables that were associated with breast cancer screening, both negatively and positively. The most common ones were lack of knowledge or breast cancer awareness, lack of privacy, financial barriers, medical mistrust, fatalism, religion, and length of U.S. residency.

Barriers to breast cancer screening (including but not limited to modesty and a desire to limit body exposure, self-imposed fatalism, socioeconomic barriers, and fear of diagnosis) have cultural and religious roots. Both Islam and Arab culture emphasize covering intimate body parts (known as ‘awra). This may prevent women
from exposing their breasts for clinical examination or diagnostic imaging, especially if either are done by male providers. \textsuperscript{[14,27]} Arab women also have high and unmet health insurance needs, which prevent adequate medical care, including screening and treatment. \textsuperscript{[10]} Arab women are not always recommended to partake in breast cancer screening, suggesting that health care providers are not adequately educating their patients on the risks of breast cancer and the benefits to regular screening. Studies also suggest that healthcare providers may be less motivated to recommend screening mammography to Arab or Muslim women due to perceptions of increased religiosity and conservativism. \textsuperscript{[25]} Those who are recommended to partake in screening may lack the finances or time to do so. \textsuperscript{[10,28,29]}

\subsection*{2.2.3.2: Religion}

U.S. studies showed conflicting data regarding religion; it was both negatively and positively correlated to breast cancer screening. Some barriers included the belief that medical care should only be sought for illness and not preventative management. Other barriers included fatalism and a religious obligation to put others’ needs before their own.

However, religion was also associated with positive screening habits as Muslim women felt obligated to care for their bodies as best as they could, believing it to be a loan from God. This promoted preventative screening. \textsuperscript{[30]} A California study obtained a convenience sample of 316 Jordanian, Egyptian, and Lebanese American women over the age of 40, who completed a survey that combined sociodemographic data with the Arab Culture-Specific Barriers (ACSB). There was a statistically significant association
between religion and mammography screening ($\chi^2 (1, N = 316) = 6.45, p = .01$). Religion was significantly associated with perceived benefits of mammography screening; as above, both Christian and Muslim women felt a religious duty to guard their health and bodies appropriately. However, Muslim women had lower odds of partaking in screening mammography examination than Christian women (OR = 0.5, 95% CI = [0.3, 0.9], $p = .01$). [8,9]

**2.2.3.3: Breast Cancer Awareness, Financial Barriers, Breast Exposure, Language, and Acculturation**

A study comparing unmet socioeconomic needs among minority populations in the U.S. reported that Arab American women had the highest level of unawareness regarding their breast cancer staging or disease progression when compared to Latinos and Caribbean Immigrants of African Descent (CIAD) (67% versus 35% and 26%, respectively). [10] Insufficient knowledge regarding breast cancer was also seen to negatively influence screening practices among Arab American women.

Of the 316 women that participated in Alatrash et al.’s study, only 63.9% (N = 202) had ever had a mammogram. A common theme was lack of privacy and embarrassment regarding exposure. 41.2% of Jordanian women reported “I don’t have privacy to perform the exam”. Roughly 35% reported “embarrassment of exposing body” in front of both male and female doctors. 72.4% of Muslim women in the study stated that they did not have the privacy to perform breast self-examinations. [8]

Both time and finances were seen to negatively impact trust in the medical system. 43.8% of Jordanian women reported “Distance and difficulty in reaching the
clinic” and 41.3% reported “It’s difficult to undergo regular mammography tests because it takes time”. 36.9% of Egyptian women marked “financial expense” as a barrier to screening. [8]

70.2% of Muslim women reported “Having a breast exam done by a health care provider will improve your chances of a successful recovery from the illness” as a screening benefit. Additionally, 68.6% of Muslim women and 32.7% of Christian women responded “Undergoing a mammography can give you confirmation that you are healthy and lessen concerns”. 32.7% of Christian Arabs also checked “If you don’t undergo regular breast exams by a health care provider then your health will be hurt more” and “Undergoing a mammography can give you confirmation that you are healthy and lessen concerns” (32.7%) [8,9] These results showed that Arab women do recognize benefits to screening, including earlier diagnoses and improved health outcomes.

Lebanese women noted fewer barriers than Jordanian women in the study. Since Lebanese populations migrated to the United States earlier than both Jordanian and Egyptian populations, observed data could be an effect of acculturation. [8,9] Higher degrees of assimilation may have resulted in increased familiarity with breast cancer screening practices both directly and indirectly by way of increased English comprehension and proficiency. This would also increase healthcare access in the United States.

The study had numerous limitations; as a cross-sectional study, screening incidence not be established. The study was also single-centered, comparing only a small subset of the Arab-American population localized to one city. The Arab American population is incredibly diverse, encompassing over twenty countries, and is rich in
cultural heritage and practices. Additional data on an expanded population is needed to boost generalizability.

A Detroit-based study between June-July 2014 sampled 196 Arab American Women, who completed questionnaires that merged a tailored Group-Based Medical Mistrust Scale (GBMMS) with ACSB to assess how cultural barriers may intensify medical mistrust and yield poor screening practices among Arab American women. The GBMMS had twelve total questions within three domains: suspicion of healthcare providers/systems, lack of support, and Arab inequities. Composite scores were obtained for these three domains to determine severity of medical mistrust. Composite scores were similarly obtained to determine ACSB to breast cancer screening through seventeen questions over four domains: environmental barriers, social barriers, religious barriers, and body unease barriers. Composite scores were calculated by summing total scores for each domain and dividing by the number of questions in each.

This study did not show high levels of medical mistrust. Composite scores included M = 1.9 for suspicion of healthcare providers/systems, M = 2.2 for Arab inequities, and M = 2.3 for lack of support. However, 35% of participants documented that they did not believe doctors have the best interests of Arabs in mind. An additional 40% were neutral for this question.\textsuperscript{[31]}

The study did show higher composite scores for culture-related barriers to screening, with the highest barrier being religion (M = 2.7 with a SD 0.9). “Reading verses from the Qur’an can help cure cancer” showed 48% of participants in agreement and 36% neutral. However, this does not mean that participants believed reading from their holy texts was sufficient in curing cancer and did not reflect their willingness to
partake in medical treatment in combination with prayer; therefore this response may have skewed the composite score in the religion domain. Overall, the study did not find a statistically significant association between religion or culture factors with medical mistrust, although it certainly suggested a lag in screening rates among the population. Language and financial concerns as cultural barriers both carried the most weight for environmental barriers to BCS (total internal consistency for environmental barriers $\alpha = 0.84; 95\%$ CI $[0.80, 0.87]$), with 20% and 40% of participants endorsing language and finances as barriers to screening, respectively. Inability to fully converse with healthcare providers increases miscommunication and can thus contribute to medical mistrust. This bolsters both Alatrash studies, which also reflected financial barriers to screening.

Limitations once again include convenience sampling and non-random sampling, both of which introduce selection bias. Additionally, the majority of Arab women in this study were Muslim, which limits religious diversity as it did not take Arab Jews or Arab Christians into consideration. The study also aimed to assess how a possible association between cultural barriers to BCS and medical mistrust but did not obtain any data on prior BCS practices within study participants, so the role that medical mistrust and cultural barriers have played in prior screening practices was not examined in this study.

A Chicago-based study between August 2013 through January 2014 obtained 240 surveys from self-identified Muslim women over the age of 40 belonging to different ethnic groups, including “Arab”, “South Asian”, and “African American” to ascertain rates of ever-mammography and CBE. It also evaluated recent screening mammography uptake (within the past 2 years) and its association with Islam (modesty, religiosity, and
perceived religious discrimination in healthcare settings), fatalism, breast cancer
knowledge, and sociodemographic characteristics. 36% of women (85/234) had not
received a mammogram within the past 2 years.

This study was similar to others in that it showed individuals with longer periods
of U.S. residency and higher education were more likely to have had a mammogram in
their lifetime. Women who lived in the U.S. for over 11 years (versus under 10 years) had
approximately five times the odds of obtaining a mammogram in their lifetime (11-20
years, OR = 5.0, and >20 years, OR = 5.2, p < 0.01). Although this study was not specific
to Arab American women, the increase in odds for those with longer U.S. residence
suggests that women born in the U.S. and over the age of 40 would have higher odds of
screening per ACS recommendations. [32]

Study limitations include creating surveys that were only in English. Language is
a persistent barrier to screening across numerous ethnic groups, so these results were not
reflective of the entire Muslim population. Additionally, non-random selection (as
participants were solely acquired from Muslim organizations) allows for selection bias
and may not be as generalizable or representative of all American Arabs.

2.2.3.4 Medical Mistrust

Although the Jaffée, et al., 2021 study did not reflect high levels of medical
mistrust among Arab American women, results from other studies show that medical
mistrust is prevalent within the Arab population, potentially originating from the
aftermath of the September 11 attacks in New York City. After the attacks, Arab men and
women alike reported increased levels of discrimination, abuse, and violence. They also
reported inadequacies in their care and incorrect assumptions made during healthcare appointments by their providers.\[^{33}\] These assumptions included not understanding English, presumed ignorance regarding their own health, domestic abuse by their partners, and more. However, this study was published in 2008, mere years after the 9/11 bombings when the U.S. had seen a sharp rise in both islamophobia and Arab-specific racism. To determine if this belief persists, other studies that analyzed medical mistrust were reviewed. Padela et al., 2014 did show that perceived religious discrimination was negatively associated with mammography screening over the past two years (OR 0.79; \(p < 0.05\)).\[^{32}\] This study had participants from multiple ethnic backgrounds who self-identified as Muslim, including Arab women, and although it may be reflective of some Arab women’s beliefs and experiences, it is not specific to AAW. Further studies that examine medical mistrust among Arab Americans are needed to extract updated information and help discern their present beliefs.

**2.2.3.5 Fatalism**

In regards to fatalism, Alatrash et al., 2019 and 2021 studies showed 35.3% of Arab women believed “Having a breast exam is pointless because if they find something it’s already too late”.\[^{8,9}\] Shah et al., 2008 reported numerous similar beliefs, with some women marking “I think cancer is from God. It has no reasons. If there were causes, I would go [get screened]” and others, “We try to read and follow up annually on mammograms. We do the best we can but the rest is up to God”. They also believed that their prognoses were ultimately dependent on God’s decisions as God was their sole healer.\[^{33}\] Fatalism has religious ties, and debunking religious barriers to screening in a
culturally sensitive manner can potentially rectify fatalistic beliefs and improve mammography uptake.

2.2.3.6 Conclusion

Overall, literature showed that AAW do not participate in mammography screening as often as ACS guidelines recommend. This lag in screening is due to a host of reasons, including socioeconomic difficulties, language barriers, fatalism, and lack of knowledge/breast cancer awareness. There is conflicting data regarding religion and medical mistrust within this population. Minimal data was found on the role that acculturation may have in promoting regular screening mammography. As a result, we looked to other minority populations and regions to learn more about general screening practices and barriers.

2.2.4 Screening Practices Among Minorities

Only a few studies reviewed BCS practices among AAW. We therefore expanded our search to screening practices among other minority groups to better inform our understanding of screening barriers. Despite the known benefits of screening, minority and underserved populations have persistently low screening rates.\(^{[34]}\) Low screening is in part due to lack of knowledge, language-specific barriers, and healthcare and health insurance related barriers, concerns that minority populations face at higher rates.\(^{[10,23,26,33,35-39]}\) We saw similar barriers with our target population; notably, lack of knowledge and language-specific barriers. The next segment of our literature review incorporates articles that discuss screening practices and other preventative care measures.
beyond breast cancer (which include cervical and colorectal cancer screening) across minority groups and underserved populations in the U.S.

2.2.4.1 ENCORE\textsuperscript{plus}: A Longitudinal Cohort Study

ENCORE\textsuperscript{plus} was a national health-promotion program between July 1995 to June 1996 that sought to improve breast and cervical screening practices for underserved women. Overall study results showed the importance of tailored programs to improve knowledge on screening practices and enhance uptake among underserved and at-risk populations.

The study predominantly comprised of African American, Hispanic, and White women who were low-income, had low educational attainment, or lacked insurance. Patients self-reported data through baseline and follow-up questionnaires. Data showed that less than 30\% of program participants were adherent with the ACS’s Pap guidelines for screening. 56.1\% (15,427/21,569) were overdue for a Pap during the program intake, and 64.7\% (13,958/21,569) were overdue for a mammogram during the program intake.

Screening completion rates were obtained to determine program effectiveness. This was done by analyzing the proportion of women eligible for screening who participated in a screening test within 6 months of the education program. After accounting for a loss to follow-up, 62.2\% of 9,045 participants had obtained a Pap smear, and 87.7\% had obtained a mammogram.\textsuperscript{40}

Participants self-enrolled in this study, which meant the study did not collect a random selection of individuals. They also self-reported data through questionnaires, which limits generalizability and increases risk of recall bias. Nevertheless, the study
showed how tailored interventions are essential to heighten screening uptake for underserved populations in the United States.

2.2.4.2 CARES: A Matched Cohort Study

Cancer Awareness: Ready for Education and Screening (CARES) was a Toronto-based intervention program that took place between May 2012 to October 2013 (with an additional eight months of follow up). It aimed to increase breast and cervical cancer knowledge and screening practices for female immigrants, refugees, and low-income residents via educational workshops and lessons and assistance with appointment scheduling and transportation.

Participants consented to furnishing anonymous, medically verified information regarding their cancer screening activity prior to the educational sessions. CARES and control Pap smear cohorts included women between 21-61 years of age. CARES and control mammography cohorts included women between 50-74 years of age. Women who had not participated in Pap or mammography screening within 36 months were considered never-screened/under-screened (UNS). Over the seventeen-month study period, 1,993 women participated in 145 educational workshops held in 20 different languages (including English, Arabic, Farsi, Tamil, Urdu, Mandarin, Cantonese, Bengali, Vietnamese, Spanish, Portuguese, and more). 372 of those women were in the CARES cohort, with 331 of them eligible for Pap and 206 of them eligible for mammography at study start. This was an approximated 1:3 matched cohort study, with 969 and 603 matched controls for Pap and mammography, respectively. At final analysis of intake
data, 35% of CARES (118/331) were UNS for Pap, and 48% of CARES (99/206) were UNS for mammography. \[41\]

By the end of the study period, 26% of UNS CARES participants had received Pap smears and 36% received mammograms, in comparison to 9% and 14%, respectively. Odds Ratios for screening within the 8 month follow up for UNS versus controls were 5.1 (95% CI = 2.4, 10.9) for Pap and 4.2 (95% CI = 2.3, 7.8) for mammography. \[41\] UNS CARES participants were therefore five times more likely to obtain a Pap and four times more likely to obtain a mammogram than their matched controls.

This study did not exclude women with a prior medical history of breast cancer, cervical cancer, or hysterectomy, individuals who may be more or less vigilant about screening. Additionally, women self-enrolled into the CARES program. This self-selection bias may have contributed to higher screening percentages when compared to controls during the follow up period, as participants could have been more motivated to screen. However, the study minimized selection bias when possible, and randomly sampled individuals within a group who had “unique matching combinations” for their control groups. Overall, these data again suggest that providing personalized educational programs in ways that overcome financial and language barriers could enhance screening uptake for marginalized and underserved populations.

**2.2.4.3 Additional Studies**

The Health Belief Model (HBM) is a framework that combines two beliefs of health-related behaviors: 1) the need to avoid disease and 2) the idea that specific
decisions and health-related actions can prevent or treat disease. It combines multiple components to better understand barriers to screening/disease prevention in populations. These components incorporate perceived severity of an illness, perceived susceptibility of an illness, perceived benefits of screening or partaking in other disease prevention strategies to minimize the risk of illness, perceived barriers to screening or partaking in other disease prevention strategies, cue to action that precipitates positive health-related habits, and self-efficacy to successfully advocate for oneself and partake in positive health-related habits. [42]

This model was adjusted to encompass breast cancer screening in an Israel-based telephone study that targeted Arab women who identified as Christian, Druze, or Muslim. It emphasized perceived susceptibility to and severity of breast cancer, benefits of and barriers to both mammography and CBE, and health motivation. Multivariate analysis of variance (MANOVA) was used to analyze health beliefs and barriers to both CBE and mammography. 52.9% (128/242) of participants over the age of 41 years were entirely unscreened or had not received a mammogram in over five years. Barriers to screening included a belief that breast cancer is incurable and that mammograms are a health hazard. [25] These barriers spanned religions, prevalent among Druze, Christian, and Muslim women. However, more Christian women over the age of 41 years had a mammogram than Muslim or Druze women ($\chi^2(4) = 12.7$, $p<0.05$). Mammography recommendation by a healthcare provider significantly predicted screening among participants ($\chi^2(1) = 4.40$, $p < 0.05$).

This study did not show a significant association between religion, religiosity, or economic status and mammography screening. Economic status may not be a screening
barrier due to healthcare policies in Israel (Palestine), which grant women free access to biennial mammography screening. [43]

A number of articles were examined to discern colorectal cancer (CRC) screening practices within African Americans. A 2007 systematic review of medical mistrust and colorectal cancer screening within an African American population showed have the highest incidence of colorectal cancer - including early-onset colorectal cancer - and higher mortality. [44,45] ACS guidelines have recently updated to recommend CRC screening at 45 years (rather than 50 years). The American College of Gastroenterology similar suggests screening at 45 years for non-Hispanic Black populations as a result of this increased incidence. [46,47] Florida-based CDC reports from 2018 showed only 53% of African Americans had reported colonoscopy adherence in comparison to 69% of White Americans. [48] Previously reported colonoscopy screening barriers include lack of knowledge, procedure-related embarrassment, and fear of a positive result. [49,50] Research has also shown that African Americans, who have poor health insurance coverage and/or healthcare access, face greater hurdles in obtaining screening tests. [51]

2.2.4.4 Conclusion

These studies echoed each other and provided sufficient evidence that minorities face similar barriers to numerous screening practices. This highlights the need for our study as a way to better understand the layers of screening barriers within our own population of interest. Once fully established, we can begin intervention-based studies to magnify screening rates within Arab American women.
We concluded our literature review by evaluating Middle Eastern and North African (MENA) based studies on BCS practices. This was done to determine whether Arab women have additional and specific screening barriers that may yet be uncovered. In investigating international studies, we also better informed our understanding of Arab-specific barriers from an additional angle, and created a thorough foundation for our study methodology.

2.2.5 Breast Cancer and Screening in the Arab World and Barriers to Care

Eastern guidelines vary from the ACS, though most still include some combination of breast self-examination, clinical breast examination, and/or mammography. For example, Qatari guidelines recommend monthly BSE at 20 years, yearly CBE at 35 years, and annual mammograms for women over 40 years. [52] In Morocco, women are biennially screened with CBE once they are 40 years old and referred to centers for additional testing/imaging if CBE yields a positive screen. [53]

Among Arab women, the mean age of breast cancer is years younger than in non-Arab White women, and the former are more likely to present with a higher stage disease. [13,16,54-56] This may explain why Qatar continues to recommend BSE and CBE for younger women who are not yet eligible for mammograms. In Lebanon, 47% of breast cancer cases in 2010 were diagnosed in women under the age of 40. [23] The mean age at breast cancer diagnosis is 52 in Lebanon [13] and 52.7 in Jordan, in comparison to a mean age of 63 in the U.S. The mean age at diagnosis in Morocco is 49.5 years. [53] Numerous other studies implemented in the East reflect this, and attempt to puzzle this unique
population’s barriers to screening. Resulting data primarily indicated inadequate knowledge regarding breast health and consequent underutilization of screening.

A study comparing breast cancer incidences in the Middle East with the United States used SEER data, which collects information on cancer incidence and mortality throughout the United States. The percentage of breast cancer in-situ was higher in American women (20.5%) than in Jordan (2.8%). The percentage of women diagnosed with advanced disease (describing regional or distant spread) was higher in Jordanian women (71.8%) than in American women (54.6%). This supported prior data that showed Arab women have a higher incidence of late-stage disease at diagnosis.

A cross-sectional study in Beirut, Lebanon that assessed level of knowledge and attitude towards breast cancer in addition to screening behaviors showed that 81.7% of the 371 participants were afraid to obtain a mammogram out of fear of getting bad news. Cost was a barrier to screening for over half (53.4%) of participants. Higher educational attainment was correlated with increased knowledge regarding breast cancer, with educated women having 78% better practices than those with lower educational levels (p=0.002). The women in this study were more knowledgeable about breast cancer symptoms and mortality than treatment or curability; emphasis on detecting breast cancer rather than generalized information regarding breast cancer and screening by clinicians and other healthcare providers may thus contribute to the fear and fatalistic beliefs that many Arab women report.

A study in Qatar found that while nearly 91% of 1,063 participants (N = 964) had a basic understanding of breast cancer, the percentage of participants who were aware of screening practices was much lower (28.9% were aware of BSE, N = 307, 41.8% were
aware of CBE, $N = 444$, and 26.4% were aware of mammography, $N = 281$). Only 7.5% of participants ($N = 81$) had basic knowledge regarding mammography screening guidelines, had participated in a clinical breast examination, and knew how to self-examine their own breasts. Over half of participants had not participated in any form of breast cancer screening. This is especially concerning given the recent shift away from CBE and BSE and towards mammography for breast cancer screening, which elicited the lowest awareness response rate. Results from this study highlighted the aforementioned concern that Eastern providers may be prioritizing breast cancer symptomatology and associated complications without adequately educating their patients on screening practices or encouraging them to partake in these screening practices.

An additional Qatar-based study identified the prevalence of “no pain, no illness”: some women did not seek care unless they were experiencing physical symptoms; screening an uncommon practice for those who felt well. This suggests that women were not well informed on the characteristics of breast tumors, which are often irregularly shaped but painless masses. Poor health literacy could logically contribute to a lack of screening, which could then contribute to late detection and therefore, advanced stage diagnoses. This echoed similar study results, where African American minorities reported a lag in CRC due to lack of knowledge in addition to El Asmar et al. 2018, where studies reflected only partial understanding of breast cancer screening, symptomatology, mortality, and treatment.

Using Pearson’s $\chi^2$ testing for bivariate analysis, study results found that both awareness and breast cancer knowledge were related to breast cancer screening
participation. Breast cancer awareness was significantly related to mammography screening participation ($\chi^2 (1, N = 695) = 12.82, p = 0.00$), and basic knowledge regarding screening was also significantly related to mammography screening participation ($\chi^2 (1, N = 695) = 28.94, p = 0.001$). There were increased odds of participating in breast cancer screening for individuals who had been previously educated and recommended to screen by a clinical provider, such as a nurse or physician.

Qatari government provides all residents with free or subsidized healthcare, irrespective of nationality. As such, financial barriers to screening were not as prevalent as the study expected or as pressing as data from prior studies had suggested. Increasing patient-provider transparency in addition to implementing public education on the importance of breast cancer screening could amplify screening and aid in the early detection of cancer in parts of the East.\textsuperscript{[52]}

Although the United Arab Emirates (UAE) also provides free screening services and subsidized screening with health insurance, women underutilize these resources. Results from a UAE-based cross-sectional study showed that less than half of total participants ($N = 247$) screened for breast cancer using mammography ($44.9\%, N = 111$), BSE ($34.1\%, N = 41$), or CBE ($49.4\%, N = 122$). 42 participants believed that mammograms were only done upon experiencing physical symptoms or concerns, again reflecting an inadequate understanding of breast cancer and associated symptoms among the general population, including the asymptomatic. Approximately half of participants who never had a mammogram ($44\%, N = 60$) or CBE ($45\%, N = 56$) admitted to a lack of knowledge regarding screening tools, reiterating that individuals are not adequately informed on breast cancer or corresponding screening techniques. This was reinforced by
data showing 63% of individuals who never received a mammogram had never been counseled on breast health (this value was statistically significant, p = <0.001).

Additional reasons included “I do not know how” (27.5%, N = 33 for BSE) and “never heard of it” (34.2%, N = 41 for BSE, 44.8%, N = 56 for CBE, and 44.2%, N = 60 for mammography). A third of participants incorrectly explicated breast lumps, believing them to result from hormonal changes or breastfeeding rather than from breast tumors.

81% (N = 103) 41.3% (N = 50) and 82.6% (N = 92) of women who practiced BSE, CBE and mammography, respectively, had screened because a healthcare provider had encouraged them to do so. This demonstrates the influence that providers have over their patients, and one more highlights the importance of personalized care to improve breast cancer screening regularity.

Limitations of this study included convenience sampling to obtain participants, which decreases generalizability. Random sampling would have enhanced generalizability of these results for all UAE women. In addition to this, self-reported data via questionnaires may yield recall and selection biases. Study results could have been strengthened if participant responses were validated through medical records.

In sum, this review helped broaden our knowledge on Arab-specific and general minority populations’ screening practices and barriers. Irrespective of region of residency, Arab women persistently present with breast cancer of greater severity and at younger ages. This escalates concern over the low screening rates in this population. Arab women’s genetic makeup contributes to dense breast tissue, which carries an additional risk of breast cancer itself but can also prevent inhibit standard imaging from detecting tumors. For these reason, it is vital to ensure Arab American women are
regularly participating in highly sensitive screening mammography. We must first fully comprehend the barriers to screening that these women face in order to rectify this lag and improve BCS practices among the Arab American population.

2.3 Review of Methodology

This section reflects the methodology used to validate our proposed study.

2.3.1 Study Design and Instrumentation

Although some studies already utilize intervention-based educational programs to augment screening uptake within AAW, most studies are still qualitative or used mixed methods on this population in an attempt to flesh out their specific barriers to screening. The majority of articles incorporated in this review were cross-sectional, matched cohort, or prospective in design. Interventional studies often implemented religious-based educational training sessions to debunk myths/worries and expand breast cancer knowledge. These sessions varied in length and frequency and often had some degree of follow-up period lasting roughly 6-8 months, during which participants were probed on post-study screening decisions. However, prior study results have suggested that length of U.S. residency may affect the severity of screening barriers, so these existing interventions may only be applicable to certain groups of Arab women.

For the above reason, this study follows a cross-sectional, survey approach over a two year time frame, during which questionnaires will be deployed at a single point in time. The proposed study aims to evaluate the association between Arab culture-specific barriers to breast cancer screening with degree of acculturation, measured by length of
U.S. residency. As a two-part study, we additionally aim to sample non-Arab/Hispanic White Americans in order to compare the rate and regularity of screening mammography between the two groups, since Arab women’s specific health-related needs are poorly understood as a result of U.S. census masking.

Because most studies were limited to a small population of Arab Americans living in one city or state \cite{8,9,11,20,25,30,33} and results were not as generalizable, our proposed study is both multi-city and multi-state to enhance financial, religious, and ethnic diversity among participants. This will be more representative of the Arab American population, which hails from numerous countries within the Middle East and North Africa and is exceedingly diverse.

Similar to examined studies, ours will begin with questions regarding sociodemographic characteristics. These include age, race, preferred language, English literacy/fluency, country of birth, religion, marital status, financial status, health insurance status, and length of U.S. residency. To exclude individuals who may be at increased risk of breast cancer (as they may have increased awareness of breast cancer risks and be more vigilant about regular screening), some questions will inquire about known risk factors, such as family history of breast cancer, prior chest radiation, or known $BRCA$ mutations. \cite{6} Questions will also cover general screening practices. There will be two questions to gauge these practices: 1) if participants have had at least one mammogram within their lifetime, and 2) if they have received a mammogram within the past year (for those between 40-54 years) or within the past two years (for those who are 55 years or older). Additionally, it will utilize the ACSB instrument. ACSB implements 17 items regarding barriers to clinical breast examination and mammography, with
multiple domains: *environmental barriers* (e.g. cost, access to clinic, language, clinic exposure); *social barriers* (loss of status among family/friends, employment); *religious barriers* (cancer is a test from God, reading verses from Qur’an cures cancer, etc.) and *body unease barriers* (discomfort with body, breasts, exams). The survey will be furnished using a 5 point Likert Scale, with 1 indicating *strongly disagree* and 5 indicating *strongly agree*. Existing studies assessed raw data but multivariate analysis methods used mean scores for further review. As such, composite scores will be determined by summing total point values for each domain and dividing by the number of questions in each domain. Final scores will thus be a continuous variable between 1 and 5. An example of the Likert scale with scores for each response can be reviewed in Appendix A.

### 2.3.2 Selection Criteria

Study participants must be (self-identified) Arab women over 40 years old (to ensure that they are eligible for a mammogram) without a past or present history of breast cancer. They must be able to speak, read, and write in either Arabic or English so that they can complete our questionnaire. However, our study is two-fold; our second portion requires data collection from a different population. For that portion of the study, study participants will also include (self-identified) non-Arab/Hispanic White women over 40 years old without a past or present history of breast cancer. They must be able to speak, read, and write in English.

Exclusion criteria will include a history of breast cancer, any chronic disease that requires frequent follow up with a provider (such as ESRD, severe cardiac disease,
cirrhosis, or other malignancies). These could affect screening practices and/or would not represent individuals with an “average” risk of breast cancer. Additionally, we will exclude those with a serious mental illness that would make them unable to understand and complete the informed consent process. Exclusion criteria will be consistent for both study populations.

2.3.3 Primary and Secondary Outcomes

For the first part of this study, we will be assessing the difference in screening mammography between Arab American women and non-Arab or Hispanic White American women. The independent variable is self-identified race (Arab vs non-Arab/Hispanic White), and the outcome variable will be mammography screening. We will examine the proportion of women between 40-54 who have had a mammogram over the past year and the proportion of women over 55 who had had a mammogram within the past two years, as per ACS recommendation. Additionally, we will look at proportion of ever-mammography screening, obtaining data on the percentage of women who have screened at least once throughout their lifetime. In doing this, we can examine differences in screening behaviors between both study groups.

For the second part of this study, we will utilize the Arab-Culture Specific Barriers instrument, a validated tool used to assess barriers to breast cancer screening. Years lived in the United States (<5, 5-9, 10-14, 15-19, 20-24, 25-29, 30-34, 35-39, 40+ years or born in the U.S.) will be used as a measure of acculturation. We will measure which aspects of Arab culture are the greatest barriers to screening mammography and whether degree of acculturation yields differences in breast cancer screening practices.
Sociodemographic variables will include age, race, preferred language, health insurance status, marital status, socioeconomic status, educational attainment, country of birth, religion, and English literacy/proficiency. Each will be operationalized differently based on prior studies. Age is a continuous variable. Race will be categorized into 23 groups, one for each of the 22 countries that make up the Arab world and one for “other (please specify)”. As mentioned previously, these countries include Algeria, Bahrain, Comoros, Djibouti, Egypt, Iraq, Jordan, Kuwait, Libya, Lebanon, Mauritania, Morocco, Oman, Palestine, Qatar, Saudi Arabia, Somalia, Sudan, Syria, Tunisia, the UAE, and Yemen. Participants can mark as many of the groups to which they belong. Preferred language will be dichotomized into either English or Arabic. Health insurance status will be dichotomized into either insured or uninsured. Country of birth will be dichotomized into United States or other. Religion will be dichotomized into Muslim/Druze or Christian/Coptic. We recognize that some participants may not be religious and that there is a large Jewish and Agnostic Arab minority; however for this study we will be sampling from religious institutions (mosques and churches) so we will only provide two possible options so as to further compare religious as a potential barrier to screening. Marital status is a categorical variable, with options including single (never married), married, separated/divorced, or widowed. Educational attainment will be categorized into four groups: less than high school, high school, some college (without a degree), or college degree or higher (Associate’s, Bachelor’s, Master’s, Ph.D, MD, or other). Household income will be categorized into five groups: < $25,000 yearly, $25,000-$50,000 yearly, $50,000-$75,000 yearly, $75,000-$100,000 yearly, and > $100,000 yearly. English proficiency will be categorized into six groups per the Interagency Language Roundtable
(ILR) scale: 0 (no proficiency or knowledge of the language), 1 (elementary proficiency, can form basic sentences or answer straightforward questions), 2 (limited working proficiency, can carry casual and simple conversation), 3 (professional working proficiency, able to speak at a normal speed and has an extensive vocabulary), 4 (full professional proficiency, can carry conversations with ease but may occasionally misspeak), and 5 (native/bilingual). [61]

2.3.4 Confounding Variables

Confounding variables are those that are associated with both the exposure and outcome variables and are not in the causal pathway between the two. In this study, there are several confounding variables. These include medical mistrust, perceived religious discrimination, socioeconomic status, and psychological distress. The association between cultural barriers and screening mammography for Arab American women may be distorted by these variables. For example, Arab American women who self-identify as Muslim or are incorrectly perceived as Muslim may have heightened mistrust in the medical system as a result of the recent rise in Islamophobia. They may avoid healthcare institutions because of this, and participate in fewer screening examinations. In those who are not Muslim or have not experienced Islamophobia, there may not be an association between culture and breast cancer screening practices irrespective of length of U.S. residency.

Our proposed study will include additional questions regarding these variables in order to better understand and analyze their relationship with our outcome variable. The survey will comprise a series of questions from the GBMMS. This will allow us to
measure race-based medical mistrust to understand how it may affect screening practices. The GBMMS instrument is available for review in Appendix B.

2.3.5 Sample Size

Our sample size calculation includes data from two studies. Padela et. al sampled 234 Muslim, female participants living in Chicago and found that 77% had obtained a mammogram at least once in their life. [30,32] Alatrash et al.’s study showed that 63.9% (202/316) had ever obtained a mammogram. [8,9] We decided to use the latter value as Alatrash’s population more closely mirrored our proposed population than did Padela’s, which sampled Muslim women of multiple ethnicities.

However, we also aim to examine regularity of screening mammography; that is, whether our target population is participating in screening mammography as often as recommended per ACS guidelines (annually or biennially depending on age). In Padela et al.’s study, showed that only p = .36 (85/234) were currently up to date with their recommended mammography screening. We also included this value in our final sample size calculation to ensure that our sample size would provide accurate data for both variables.

Prior studies that included a sample size calculation used an alpha of 0.05 and powered their study to 80%. These parameters were therefore used to calculate our sample size, which we determined using the Statulator software. Our final calculation is provided for reference in Appendix G.
2.3.6 Patient Recruitment, Screening, and Data Collection

Recruitment will occur in California, New York, And Michigan, the three states with the greatest Arab population. A multi-centered trial will improve generalizability. We will sample participants from religious institutions - mosques and churches - to attempt to better control for religion as a confounding variable. The mosques include both Shi’a and Sunni sects to encompass a wide variety of populations, although selection bias is unavoidable with a cross-sectional study. Mosques and churches were chosen in the same towns or cities to match financial status between both study populations.

Recruitment will take place by distributing and posting in-person flyers within mosques and churches to gauge interest. These flyers will include dates that research assistants will be present to enroll those who are interested in participating. On those dates, eligible participants will be handed in-person surveys to complete. In mosques, questionnaires will be deployed in both Arabic and English based on patient preference during initial screening. Participants will self-report questionnaire responses. To maintain confidentiality, questionnaires will not request identifying information such as names or dates of birth. We will review all surveys for age and self-identified ethnicity to ensure responses can be included in final data analyses. All questionnaires will be screened and reviewed to ensure participants meet eligibility criteria before including their results in the study’s data analysis.
2.3.7 Statistical Analysis

Continuous variables will be reported as means with standard deviations (SDs). All composite ACSB scores will similarly be reported as means with SDs. Categorical variables will be reported as frequencies/proportions.

Student t-tests will be used to analyze continuous variables, and Pearson’s χ² test will be used to analyze categorical variables and compare observed results (as proportion of women who have had a mammogram in the past two years and ever-mammogram screening) from hypothesized results. Odds Ratio and Multiple Regression Analysis will be used to control for confounding variables.

2.4 Conclusion

The studies included in this review provide the framework for the methodology behind our proposed study. This literature review demonstrated inconsistencies between study results regarding cultural barriers to breast cancer screening. Some articles reported religion as a motivator for BCS, while others reported a negative association between religion and screening. Other studies reported varying degrees of medical mistrust among the Arab American female population.

Despite interventions that have aimed to increase awareness and intention to screen for breast cancer, a disparity remains within this at-risk population that is not fully understood. To our knowledge, only three studies to date have utilized the ACSB to better understand associations between cultural barriers and screening rates, and as above, all reported conflicting data regarding religion and medical mistrust. Those who employed it did not specifically assess how length of U.S. residency may impact
screening practices. Existing studies sample small groups of Arabs and are not
generalizable to the Arab American population at large. The Chicago and LA studies
were the only two that looked at length of U.S. residency, and found that longer stay was
associated with fewer barriers to screening and more frequent screening, suggesting that
acculturation may indeed play a role in screening uptake.

Nevertheless, all studies assessed in this review appreciated lower rates of
screening mammography among Arab and Arab American women. This is especially
concerning given that they are at increased risk for aggressive disease at younger ages,
but are not participating in screening habits frequently enough to prevent advanced
disease at diagnosis. This study is proposed in order to fill the gap in the literature and
provide a more comprehensive understanding of cultural barriers to breast cancer
screening among Arab American women. In doing so, clinicians can explore new
methods that improve BCS.
2.5 References


CHAPTER 3: STUDY METHODOLOGY

3.1 Study Design

We propose a two year, multi-centered, cross-sectional study to evaluate the association between U.S. residency as a measure of acculturation and cultural barriers to mammography screening among the Arab American population. We will also compare screening rates between Arab American women and non-Arab/Hispanic White women. Our study will obtain baseline sociodemographic characteristics including age, race, preferred language, health insurance status, marital status, socioeconomic status, educational attainment, country of birth, religion, and English literacy/proficiency. It will additionally utilize the Arab-Culture Specific Barriers instrument to address factors that may hinder mammography screening. The ACSB questionnaire will only be distributed to Arab women in this study. GBMMS will be included in the final questionnaire for Arab women to account for possible confounding variables. As a cross-sectional study, there will be no follow-up with participants.

3.2 Study Population and Sampling

For the two groups in our proposed study, the population will include Arab (and, discretely, non-Arab/Hispanic White women) over the age of 40 without a past or present history of breast cancer. They must be able to independently complete questionnaires, which will be provided in English or Arabic language only. Exclusion criteria include those unable to provide informed consent, past or present history of any cancer, chest radiation, chronic disease, or BRCA mutations. Table 2 demonstrates full inclusion and exclusion criteria for study participants.
### Inclusion Criteria

- Arab women over the age of 40 without a history of breast cancer
  - *Also: non-Arab/Hispanic White women over the age of 40 without a history of breast cancer*
- Ability to speak, read, and write in either English and/or Arabic

### Exclusion Criteria

- Past or present history of cancer
- Present history of chronic disease, such as ESRD, severe cardiac illness, cirrhosis
- Family history of breast cancer
- Prior chest radiation
- Known *BRCA* genetic mutations
- Serious mental illness that prevents full comprehension of informed consent process

### Table 2. Eligibility Criteria

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td><strong>Inclusion Criteria</strong></td>
<td><strong>Exclusion Criteria</strong></td>
</tr>
<tr>
<td>Arab women over the age of 40 without a history of breast cancer</td>
<td>Past or present history of cancer</td>
</tr>
<tr>
<td><em>Also: non-Arab/Hispanic White women over the age of 40 without a history of breast cancer</em></td>
<td>Present history of chronic disease, such as ESRD, severe cardiac illness, cirrhosis</td>
</tr>
<tr>
<td>Ability to speak, read, and write in either English and/or Arabic</td>
<td>Family history of breast cancer</td>
</tr>
<tr>
<td></td>
<td>Prior chest radiation</td>
</tr>
<tr>
<td></td>
<td>Known <em>BRCA</em> genetic mutations</td>
</tr>
<tr>
<td></td>
<td>Serious mental illness that prevents full comprehension of informed consent process</td>
</tr>
</tbody>
</table>

### 3.3 Subject Protection and Confidentiality

This study will first obtain Institutional Review Board (IRB) approval from the Human Research Protection Program at Yale University. After approval, physical consent forms will be given to each participant outlining the reason for this study and ensuring participant confidentiality. A copy of the consent form is included in Appendix C. Informed consent will be obtained prior to beginning the survey. Participation is voluntary and refusal will be respected; participants may abort the study before completing the questionnaire if they so choose.

Study personnel will complete Health Insurance Portability and Accountability Act (HIPAA) training to guarantee participant confidentiality. They will additionally sign a Pledge of Confidentiality, which is also available for review in Appendix C. The study will thus be in accordance with HIPAA requirements. All participant data will be deidentified to maintain anonymity and secured in a locked cabinet before uploading it.
onto computer software. Paper surveys will be shredded before discarding. Uploaded information will be stored on an encrypted and password protected university computer. All data included in the publication will be de-identified. Data will be deleted appropriately in compliance with Yale policy when this study is complete.

3.4 Recruitment and Data Collection

Participants will be recruited from numerous mosques and churches throughout California, New York, and Michigan. These three states have the greatest Arab population within the U.S. [1] Mosques include Masjid Annur Islam Center (CA), Islamic Center of Orange County (CA), Islamic Center of Southern California (CA), Islamic Center of America (MI) Al-Islah Mosque (MI), Islamic Cultural Center of New York (New York, NY) and Islamic Association of Long Island (NY). Churches include St. Patrick’s Cathedral (NY), Grace Church (NY), Our Lady of Grace Roman Catholic Church (NY), Free Chapel Orange County (CA), Eastside Christian Church (CA), Basilica of St. Anne de Detroit (MI), and Old St. Mary’s Catholic Church (MI).

Recruitment will involve the distribution of flyers to aforementioned mosques and churches with a brief overview of the study topic and dates that research personnel will be present to distribute questionnaires to those who are interested in participating. An example of these flyers is available in Appendix D. At that time, interested participants will be handed in-person surveys to complete, which will take approximately 30-45 minutes to complete. Questionnaires will be available in both Arabic and English.

Study personnel will visit each institution once monthly, on Friday for mosques and Sunday for churches to reach the largest audiences based on observed prayer days.
Study personnel will review all completed surveys to ensure ineligible participants are omitted from the study. The final surveys for each portion of the study are included in Appendix F.

3.5 Study Variables and Measures

3.5.1 Independent Variable

The independent variable for the first part of this study is race – Arab American versus non-Arab/Hispanic White. The independent variable for the second part of this study is degree of acculturation, which will be measured by length of residency in the United States (less than 5 years, 5-9 years, 10-14 years, 15-19 years, 20-24 years, 25-29 years, 30-34 years, 35-39 years, or greater than 40 years). Participants will also be able to check off whether they were born and raised in the United States or elsewhere.

3.5.2 Primary Dependent Variable

Primary outcome variable is screening mammography. Data will be obtained in two ways; first, by examining the proportion of women between 40-54 years of age who have participated in mammography within the past year, and the proportion of women over 55 years of age who have participated in mammography within the past two years (as per ACS recommendation).[2,3] Second, by examining ever-mammography screening to obtain the percentage of women who have participated in mammography for breast cancer screening at least once in their lifetime.
Mammography screening practices will also be assessed in the context of cultural barriers utilizing the Arab Culture-Specific Barriers (ACSB). A review of ACSB is included in Chapter 2. The basic instrument is also available for review in Appendix E.

3.5.3 Secondary Variables

Secondary variables include sociodemographic characteristics: age, race, preferred language, health insurance status, marital status, socioeconomic status, educational attainment, country of birth, religion, and English literacy/proficiency. Chapter 2 provides an in-depth explanation of how each specific secondary variable will be operationalized.

3.5.4 Confounding Variables

Confounding variables include medical mistrust, perceived religious discrimination, socioeconomic status, and psychological distress. To rectify this, our questionnaire will include the GBMMS to understand the degree of race-based medical mistrust within our participants.

3.6 Sample Size Calculation

The calculation was calculated using the Statulator software. This calculation was made based on the assumption that a categorical outcome would be compared for Arab American women and non-Arab or Hispanic White women using a \( \chi^2 \) test. We powered our study to 80% and used an alpha of 0.05. As a cross-sectional study, we will not need to account for attrition or withdrawals as participants will only be approached once.
However, we adjusted for a 65% response rate as seen by Alatrash et.al [4], as not all participants completed their questionnaires.

Alatrash et al.’s studies [4,5] showed that 63.9% (202/316) had ever obtained a mammogram. After inputting these values into Statulator, we found that our study would require a sample size of 355 participants. In Padela et al’s study, only p = .36 (85/234) were currently up to date with their recommended mammography screening. [6] After inputting these values into Statulator, we found that our study would require a sample size of 545 participants.

As we are examining both ever-mammography and screening within a certain time frame as our outcome variables, we opted to round up to ensure that our sample size would accommodate both variables. Based on the aforementioned parameters noted above, our two-tailed study would require a final sample size of 545 participants. Our sample size calculation can be reviewed in Appendix G.

3.7 Analysis

Descriptive features of participants including age and length of U.S. residency are continuous variables and will be reported as means with standard deviations (SDs). Total ACSB scores will be summed and averaged to a composite score, and will similarly be reported as means with SDs. Variables including preferred language, health insurance status, educational attainment, country of birth, religion, race, marital status, English proficiency, socioeconomic status, screening within the past one/two years and ever-screening are categorical and will be reported as frequencies/proportions.
Student t-tests will be used to analyze continuous variables and Pearson’s $\chi^2$ test will be used to analyze categorical variables and compare observed results from hypothesized results. ORs and Multivariable Regression Analyses will be used to assess whether there is a statistically significant association of degree of acculturation with mammography screening in addition to the association of cultural barriers to mammography screening after adjusting for confounding variables as detailed above. A p-value of $< 0.05$ is considered statistically significant.

### 3.8 Timeline and Resources

As a cross-sectional study, data will be obtained at one period in time without any follow up. We will thus utilize the entirety of the given 24 month time period for recruitment and data collection. The proposed study personnel include:

- 1 Principal Investigator (PI) and Co-Investigator to oversee all research operations
- 6 Research Assistants (RAs) trained for recruitment, obtaining informed consent, and are up to date with HIPAA protocols. There will be one each for NY mosques, NY churches, MI mosques, MI churches, CA mosques, and CA churches. Research assistants targeting mosques must also be able to speak Arabic.
- 1 Physician Associate student (Nour Ebid) to participate in questionnaire review, data organization, and writing
- 1 data analyst to perform statistical analyses after the two year data collection time period has concluded.
3.9 References


CHAPTER 4: CONCLUSION

4.1 Advantages and Disadvantages

Increased breast cancer awareness and screening is essential for early detection of disease. 5-year relative breast cancer survival rates decrease rapidly with advanced staging, with a drop from 99% for those with localized disease to 29% for those with distant metastases. \[^1\] In a population that is already at increased risk for diagnosis at younger ages and later stage disease, it is imperative to bolster screening practices to increase disease-free survival rates and quality of life. To our knowledge, no prior studies have compared screening practices within Arab populations and non-Arab/Hispanic White populations. Few studies have utilized ACSB in an effort to understand the barriers to screening that Arab American women face, and all that did targeted small populations or specific ethnic minority groups, which limits generalizability for the vastly diverse Arab population. Some looked at years lived in the United States, but did not analyze how barriers may change with increased length of U.S. residency.

This study will improve our knowledge on which variables may be associated with inadequate mammography screening practices, and the degree that acculturation may play in these practices. If our hypothesis is correct, future interventions that aim to increase breast cancer awareness can be explored.

This study has several limitations. First, it is a cross-sectional study, which will allow us to observe an association but will not allow us to establish a definitive causal relationship. \[^2\] Cross-sectional study designs are also susceptible to numerous biases, including reporting (recall) and selection biases, as participants will be self-enrolling in this questionnaire rather than being randomly selected. They may be more or less inclined
to partake in mammography screening and can thus impact results from data collection. However, cross-sectional studies are not intervention based, and as such, there are no ethical considerations or concerns that this study may aid only one group of participants. Collecting data at one singular time point will minimize attrition.

Cross-sectional studies are also subject to a large number of confounding variables, which may then reflect associations that are not, in fact, present. For this reason, we will use multivariable regression to control for confounding. We will additionally be sampling from religious institutions to attempt to better control for religion. It is also why churches and mosques were chosen in similar cities, to help match socioeconomic status between participants.

Despite these limitations, this study will be the first multi-centered study that obtains data on a large number of Arab ethnic groups, which will be more generalizable to the overarching Arab American population than other studies to date. It will be relatively inexpensive in comparison to other studies, will enable us to review numerous outcome variables at once, and will pave the way for future interventional studies that aim to improve screening mammography uptake.

4.2 Clinical/Public Health Significance

Prior studies have focused on the association between either religion or medical mistrust with screening behaviors among Arab American women. However, they have only ever looked at acculturation as a secondary variable and more research is necessary to better understand the role it may play in screening uptake. To our knowledge, this proposed study is the first multi-centered study that looks at degree of acculturation for
an association between cultural barriers and screening mammography among AAW. ACSB is a relatively new tool that has not been widely used; studies have often focused on other tools and instruments that are not always specific to the Arab population. This study will allow us to better understand the relationship between culture and mammography uptake and lay the foundation for future interventions to specifically target this masked population and increase screening rates among Arab American women. Understanding the unique barriers to screening that they face will also allow for interventions that specifically target clinical providers, to ensure they are knowledgeable on culturally sensitive methods to improve breast cancer awareness and can appropriately personalize care to increase intention-to-screen among their Arab American patients. In dissipating some of the misunderstandings these individuals have regarding breast cancer and filling the knowledge gap on screening practices, Arab American women can participate in mammography screening at rates more consistent with ACS guidelines. Only then can this country move closer towards achieving health equity.
4.3 References

APPENDICES

Appendix A: Likert Scale Questionnaire Options and Point Scoring

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 point</td>
<td>2 points</td>
<td>3 points</td>
<td>4 points</td>
<td>5 points</td>
</tr>
</tbody>
</table>
Appendix B: *The Group Based Medical Mistrust Scale (GBMMS)*

The Group-Based Medical Mistrust Scale

**Instructions:** Below is a list of statements dealing with your general feelings about the healthcare system. Read each item carefully and circle whether you strongly agree, agree, feel neutral, disagree, or strongly disagree with each statement.

<table>
<thead>
<tr>
<th>Item</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Doctors and healthcare workers sometimes hide information from patients who belong to my ethnic group.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. Doctors have the best interests of people of my ethnic group in mind.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. People of my ethnic group should not confide in doctors and healthcare workers because it will be used against them.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. People of my ethnic group should be suspicious of information from doctors and healthcare workers.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. People of my ethnic group cannot trust doctors and healthcare workers.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. People of my ethnic group should be suspicious of modern medicine.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
### Appendix B: The Group Based Medical Mistrust Scale (GBMMS)

<table>
<thead>
<tr>
<th>Item</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>7. Doctors and healthcare workers treat people of my ethnic group like “guinea pigs”.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. People of my ethnic group receive the same medical care from doctors and healthcare workers as people from other groups.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. Doctors and healthcare workers do not take the medical complaints of people of my ethnic group seriously.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10. People of my ethnic group are treated the same as people of other groups by doctors and healthcare workers.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11. In most hospitals, people of different ethnic groups receive the same kind of care.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12. I have personally been treated poorly or unfairly by doctors or healthcare workers because of my ethnicity.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
CONSENT FOR PARTICIPATION IN A RESEARCH STUDY

Impact of Acculturation in Mediating Barriers to Screening Mammography Among Arab American Women

Nour Ebid, PA-SII

Purpose:

You are invited to participate in a research study designed to examine your breast cancer screening practices and existing barriers to screening that may exist. You are being asked to take part in this study because you have expressed interest and meet the criteria for study inclusion. The purpose of this study is to improve our understanding of breast cancer screening practices among Arab American women and the cultural factors that may act as benefits or barriers to screening.

Procedures:

If you agree, your participation will require completing a questionnaire that a research assistant will provide for you. This questionnaire will ask for details regarding your personal life (age, annual income, marital status, years spent in the United States, etc.) and will inquire about your breast cancer screening habits. It will also ask about potential cultural barriers to screening that you may or may not have experienced. In total, we expect that your involvement will require 30-60 minutes of your time.

Risks and Benefits:

You will not have to pay to participate in this study. There are no physical risks associated with this study. However, you may experience discomfort with some of the questions being asked. Although we value 100% participation, you will be able to skip any question that you do not feel comfortable answering. If you need any clarification on a question, a research assistant will be available to explain the question so that you may answer all aspects of the questionnaire to the best of your ability. We will make every effort to ensure your personal responses remain confidential; however there is a possible risk of loss of confidentiality. For this reason, we ask that you do not write your name or full date of birth anywhere along the questionnaire. Although this study may have no benefits to you, we hope that our results will add to the knowledge about barriers to breast cancer screening so that we can improve screening practices among Arab American women.

Confidentiality:

All of your responses will be confidential. Only the researchers involved in this study and those responsible for research oversight will have access to the information that you provide. To
ensure confidentiality, we will not ask you any questions that may contain personal identifiers. We will code your responses to a separate number rather than to your name. We ask that you do not write your name or full date of birth anywhere along the questionnaire.

Except as required by U.S. or state law, we will not release any of your responses outside of the Yale University research team. Examples of situations where we would be legally required to disclose information include abuse of a child or elderly person.

Once you have completed your survey, our research team will upload it onto computer software and then shred the paper responded before discarding. Uploaded information will be stored on an encrypted and password protected Yale University computer. All data included in the final publication will be de-identified. Computer stored data will be deleted appropriately in compliance with Yale policy when this study is complete.

**Voluntary Participation**

Taking part in this study is completely voluntary. You can choose to take part, or you can choose not to take part in this study. You can also refuse to answer any question without penalty. You also can change your mind and abort this study at any time. Your decision to participate or to abort this study will not have any effect on your relationship with Yale New Haven Hospital or Yale University.

**Questions:**

If you have any questions about this study, you may contact the principal investigator, Nour Ebid, at 646-XXX-XXXX or nour.ebid@yale.edu.

If you have questions about your privacy rights, you may contact the Yale Institutional Review Boards at (203) 785-4688 or email hrpp@yale.edu.
Documentation of Informed Consent

Your signature below indicates that you read and understand this consent form and the information presented and that you agree to be in this study. By signing this form, you authorize the use and/or disclosure of the above information for purposes of this study.

You will be provided with a copy of this consent form.

Participant Printed Name ___________________________ Participant Signature ___________________________ Date ________________

Person Obtaining Consent Printed Name ___________________________ Person Obtaining Consent Signature ___________________________ Date ________________
Pledge of Confidentiality

I__________________________, through my involvement with and work on Impact of Acculturation in Mediating Barriers to Screening Mammography Among Arab American Women will have access to data which contains confidential information that respondents generally perceive as personal and private. I understand that access to this confidential information and data carries with it responsibility to guard against unauthorized use and to abide by the data security plan. To treat information as confidential means to not divulge it or make it accessible to anyone who is not a project member. Such a disclosure would violate the confidentiality promised to participants and would violate University ethics policies.

I agree to fulfill my responsibilities on this project in accordance with the following

1. I agree to not permit non-project personnel access to the data, either electronically, in hard copy or orally.
2. I agree to not attempt to identify individuals except in those cases where it is necessary in accordance with my role on the research project.
3. I agree that in the event I inadvertently uncover the identity of an individual, I will maintain the highest level of confidentiality of this information, make no use of the knowledge and inform the study’s Principal Investigator.

__________________________________________  
Name

__________________________________________  
Signature

__________________________________________  
Date
HELP US LEARN ABOUT BREAST CANCER SCREENING PRACTICES IN YOUR COMMUNITY!

If you are an Arab-American woman over the age of 40 without a history of breast cancer, you may be eligible to participate in our study.

Interested in learning more? We will be here at the Islamic Cultural Center of New York City on the following dates in 2022:

<table>
<thead>
<tr>
<th>Date</th>
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<tbody>
<tr>
<td>Friday, June 3rd, 2022</td>
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<tr>
<td>Friday, July 1st, 2022</td>
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<tr>
<td>Friday, August 5th, 2022</td>
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<td>Friday, September 2nd, 2022</td>
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<tr>
<td>Friday, October 7th, 2022</td>
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<tr>
<td>Friday, November 4th, 2022</td>
</tr>
<tr>
<td>Friday, December 2nd, 2022</td>
</tr>
</tbody>
</table>

If you have any questions, please feel free to contact Nour Ebid at nour.ebid@yale.edu.
Appendix E: Arab Culture Specifics Barriers to Breast Cancer Screening (please note that this was the original, proposed scale, which included a fifth domain prior to validity testing)

<table>
<thead>
<tr>
<th>Factor 1: Exposure barriers</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>A male physician examining my breasts embarrassed me</td>
<td>1.</td>
</tr>
<tr>
<td>A female physician examining my breast embarrassed me</td>
<td>2.</td>
</tr>
<tr>
<td>Body exposure is forbidden by religion</td>
<td>3.</td>
</tr>
<tr>
<td>I fear being seen at the clinic</td>
<td>4.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Factor 2: Social barriers</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Fear pity by others</td>
<td>5.</td>
</tr>
<tr>
<td>Fear disrespect by my family</td>
<td>6.</td>
</tr>
<tr>
<td>Fear losing my job</td>
<td>7.</td>
</tr>
<tr>
<td>Fear my husband’s detachment, resentment</td>
<td>8.</td>
</tr>
<tr>
<td>Fear neglecting my family</td>
<td>9.</td>
</tr>
<tr>
<td>Fear losing my friends</td>
<td>10.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Factor 3: Religious beliefs concerning cancer</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer is a way of punishment by God</td>
<td>11.</td>
</tr>
<tr>
<td>Cancer is a way of atonement for bad deeds by God</td>
<td>12.</td>
</tr>
<tr>
<td>Cancer is a trial by God</td>
<td>13.</td>
</tr>
<tr>
<td>Reading religious writings assists healing</td>
<td>14.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Factor 4: Environmental barriers</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Language and communication</td>
<td>15.</td>
</tr>
<tr>
<td>Distance and accessibility of the clinic</td>
<td>16.</td>
</tr>
<tr>
<td>Cost of the examinations</td>
<td>17.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Factor 4: Uneasiness with own body</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel embarrassed looking at my body</td>
<td>18.</td>
</tr>
<tr>
<td>I feel embarrassed touching my body</td>
<td>19.</td>
</tr>
<tr>
<td>I have no privacy to examine my body</td>
<td>20.</td>
</tr>
<tr>
<td>I do not know my body sufficiently to recognize changes in it</td>
<td>21.</td>
</tr>
</tbody>
</table>

67
Appendix F: Final Survey - Non-Arab/Hispanic White

These questions will inquire about general socioeconomic characteristics in addition to breast cancer screening practices and known risks for breast cancer (if any). You may ask the research assistant for clarification for any questions you may have. You may skip any question that you do not feel comfortable answering.

1. How old are you? __________ years

2. Which religion do you identify with? Please choose only one answer.
   - ☐ Christianity/Coptic
   - ☐ Islam/Druze

3. Do you have a family history of breast cancer?
   - ☐ Yes
   - ☐ No

4. Have you ever received chest radiation in the past or are you currently receiving chest radiation?
   - ☐ Yes
   - ☐ No

5. Do you have a known BRCA-1 or BRCA-2 mutation?
   - ☐ Yes
   - ☐ No
   - ☐ Unknown

6. Have you ever received a mammogram for breast cancer screening?
   - ☐ Yes
7. If you are between 40-54 years, have you received a mammogram in the past year?
   ☐ Yes
   ☐ No

8. If you are over 55 years old, have you received a mammogram in the past two years?
   Yes / No
The first set of questions will inquire about general socioeconomic characteristics in addition to breast cancer screening practices and known risks for breast cancer (if any). You may ask the research assistant for clarification for any questions you may have. You may skip any question that you do not feel comfortable answering.

1. **How old are you?** __________ years

2. **Where were you born?** Please choose only one answer.
   - ☐ United States
   - ☐ Other

3. **What is your ethnicity?** (Please check all that apply)
   - ☐ Algeria
   - ☐ Bahrain
   - ☐ Comoros
   - ☐ Djibouti
   - ☐ Egypt
   - ☐ Iraq
   - ☐ Jordan
   - ☐ Kuwait
   - ☐ Libya
   - ☐ Lebanon
   - ☐ Mauritania
   - ☐ Morocco
   - ☐ Oman
   - ☐ Palestine
   - ☐ Qatar
   - ☐ Saudi Arabia
   - ☐ Somalia
   - ☐ Sudan
   - ☐ Syria
   - ☐ Tunisia
   - ☐ United Arab Emirates
   - ☐ Yemen
   - ☐ Other (please specify __________________)

4. **How many years have you lived in the United States?**
   - ☐ <5 years
   - ☐ 5-9 years
   - ☐ 10-14 years
   - ☐ 15-19 years
   - ☐ 20-24 years
   - ☐ 25-29 years
   - ☐ 30-34 years
   - ☐ 35-39 years
   - ☐ 40+ years or U.S. born
5. Which religion do you identify with? Please choose only one answer.
   ☐ Christianity/Coptic
   ☐ Islam/Druze

6. What is your preferred language? Please choose only one answer.
   ☐ English
   ☐ Arabic

7. What is your level of English proficiency? Please choose only one answer.
   ☐ 0 (no proficiency or knowledge of the language)
   ☐ 1 (elementary proficiency, can form basic sentences or answer straightforward questions)
   ☐ 2 (limited working proficiency, can carry casual and simple conversation)
   ☐ 3 (professional working proficiency, able to speak at a normal speed and have an extensive vocabulary)
   ☐ 4 full professional proficiency, can carry conversations with ease but may occasionally misspeak)
   ☐ 5 (native/bilingual)

8. What is your annual household income?
   ☐ < $25,000 yearly
   ☐ $25,000-$50,000 yearly
   ☐ $50,000-$75,000 yearly
   ☐ $75,000-$100,000 yearly
   ☐ > $100,000 yearly
9. **Do you have health insurance?**
   - ☐ Yes
   - ☐ No

10. **What is your highest level of education?**
   - ☐ less than high school
   - ☐ high school
   - ☐ some college (without a degree)
   - ☐ college degree or higher (including Associate’s, Bachelor’s, Master’s, Ph.D., MD, or other)

11. **What is your current marital status?**
   - ☐ single (never married)
   - ☐ married
   - ☐ separated/divorced
   - ☐ widowed

12. **Have you ever received chest radiation in the past or are you currently receiving chest radiation?**
   - ☐ Yes
   - ☐ No

13. **Do you have a family history of breast cancer?**
   - ☐ Yes
   - ☐ No

14. **Do you have a known BRCA-1 or BRCA-2 mutation?**
□ Yes
□ No
□ Unknown

15. Have you ever received a mammogram for breast cancer screening?
□ Yes
□ No

16. If you are between 40-54 years, have you received a mammogram in the past year?
□ Yes
□ No

17. If you are over 55 years old, have you received a mammogram in the past two years?
□ Yes
□ No
The next set of questions asks about possible barriers to breast cancer screening. Please answer whether you agree with each statement, with 1 indicating you *strongly disagree* and 5 indicating you *strongly agree*. You may ask the research assistant for clarification for any questions you may have. You may skip any question that you do not feel comfortable answering.

1. **Reading verses from the Qur’an/Bible can help cure breast cancer.**

2. **Traditional medicines can cure breast cancer.**

3. **Because of my religion, I believe that breast cancer is a test from God.**

4. **Because of my religion, I believe that a breast cancer diagnosis is a punishment.**
5. If I were diagnosed with breast cancer, I would fear being abandoned by my husband or partner.

6. If I were diagnosed with breast cancer, I would fear losing my job.

7. If I were diagnosed with breast cancer, I would fear losing the respect of my family.

8. If I were diagnosed with breast cancer, I would fear losing my friends.

9. Distance or difficulty getting to a clinic has prevented me from screening for breast cancer with a mammogram.
10. Financial cost of diagnostic imaging has prevented me from screening for breast cancer with a mammogram.

11. Language or communication difficulties have prevented me from screening for breast cancer with a mammogram.

12. The fear of being spotted at a clinic by someone I know has prevented me from screening for breast cancer with a mammogram.

13. A religious ban on body exposure has prevented me from screening for breast cancer with a mammogram.
14. I feel uncomfortable looking at my own body.

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<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
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15. I feel uncomfortable touching my breasts.

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<th>Strongly Disagree</th>
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<th>Agree</th>
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16. I do not have the privacy to perform a breast examination.

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<th>Strongly Disagree</th>
<th>Disagree</th>
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<th>Agree</th>
<th>Strongly Agree</th>
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17. I do not know how to look for changes in my breasts.

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<th>Strongly Disagree</th>
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The last set of questions asks about general feelings about healthcare systems. Please answer whether you agree with each statement, with 1 indicating you strongly disagree and 5 indicating you strongly agree. You may ask the research assistant for clarification for any questions you may have. You may skip any question that you do not feel comfortable answering.

1. **Doctors and healthcare workers sometimes hide information from patients who belong to my ethnic group.**

![Strongly Disagree Disagree Neutral Agree Strongly Agree]

2. **Doctors have the best interests of people of my ethnic group in mind.**

![Strongly Disagree Disagree Neutral Agree Strongly Agree]

3. **People of my ethnic group should not confide in doctors and healthcare workers because it will be used against them.**

![Strongly Disagree Disagree Neutral Agree Strongly Agree]

4. **People of my ethnic group should be suspicious of information from doctors and healthcare workers.**

![Strongly Disagree Disagree Neutral Agree Strongly Agree]
5. People of my ethnic group cannot trust doctors and healthcare workers.

6. People of my ethnic group should be suspicious of modern medicine.

7. Doctors and healthcare workers treat people of my ethnic group like guinea pigs.

8. People of my ethnic group receive the same medical care from doctors and healthcare workers as people from other groups do.

9. Doctors and healthcare workers do not take the medical complaints of people of my ethnic group seriously.
10. People of my ethnic group are treated the same as people of other groups by doctors and healthcare workers. In most hospitals, people of different ethnic groups receive the same kind of care.

11. I have personally been treated poorly or unfairly by doctors or healthcare workers because of my ethnicity.

Thank you for your participation in our research study! Once you have completed this survey, you may hand it over to the research assistant. If you would like to withdraw your participation, you may hand your incomplete survey to the research assistant, who will discard of your responses appropriately. Your responses will not be shared with anyone or included in the final study.
Appendix G: Sample Size Calculation

Level of Confidence

Expected Proportion

Precision or Margin of Error

Adjust for Response Rate

Anticipated Response Rate:

Sample size for an expected proportion of 0.36 at 5.0% absolute precision is 545.
BIBLIOGRAPHY


