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## Understanding Female Somali Noncollege Graduate Immigrant's Experiences With Cervical Cancer Screening Services

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# Walden University

College of Health Professions

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Rachel Anyu-Lainjo

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Walden University  
2021

Abstract

Understanding Female Somali Noncollege Graduate Immigrant's Experiences With  
Cervical Cancer Screening Services

by

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MA, St. Mary's University, 2012

BS, St. Mary's University, 2009

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

PhD Health Services – Leadership

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## Abstract

Healthcare disparities exist in cervical cancer screening worldwide particularly in women of East African descent compared to non-African women. Previous research has investigated the reasons for low participation in cervical cancer screening among Blacks, minorities, and immigrant populations. Limited research has focused on immigrant women in the United States of America, specifically immigrants from Somalia who currently live in St. Cloud, Minnesota. The purpose of this qualitative study was to understand the perception of Somali immigrant women ages 25 - 45 years who have not earned a college degree and their lived experiences with cervical cancer screening. Two conceptual frameworks were used in this research: Thomas and Penchansky's theory of access and Leininger's culture care model. Data were collected via face-to-face or virtual structured interviews which was then transcribed verbatim, and themes developed. Three research questions guided the study, which included: understanding the lived experiences of Somali immigrant women on accessing cervical cancer screening services; how awareness of cervical cancer screening services may impact access; and the role of acculturation in the experiences of cervical cancer screening. Key findings from this study included the themes (a) accessibility to provider, (b) accessibility to screening, (c) influence of mentors/family role models, (d) emotional and physical discomfort, (e) lack of awareness, (f) enhance understanding, (g) lack of trust in the healthcare system, and (h) importance of religious beliefs. The participants' suggestions and recommendations could be used to improve the relationship between patients and providers as well as increase cervical cancer screening rates in this population.

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## Dedication

This dissertation is dedicated to my late father Mr. Joseph Anyu whom I wish was alive to see what his little girl has accomplished in life. I also dedicate this to my lovely mother Mrs. Calista Anyu who worked hard to provide a roof over the family's head and made sure we never lacked a basic necessity. I am not sure how you did it as a widowed mom but thank you! Finally, I am dedicating this work to my husband Mr. Keafon Lainjo who stood by my side unconditionally. Thank you!

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## Chapter 1: Introduction to the Study

### **Introduction**

Understanding female Somali noncollege graduate immigrant's experiences with cervical cancer screening services was an important study because cervical cancer is preventable in most cases via routine cervical cancer screening or Pap smear. This research invited immigrant women of Somali decent between the ages of 25-45 years who did not have a four-year college degree to participate in individual interviews regarding their lived experiences with cervical cancer screening. The interviews were recorded, transcribed, and analyzed for trends and themes. The research provided an understanding that could be used by healthcare providers in the future to enhance cervical cancer screening practices that could increase the number of Somali women in this demography. The increased screening could mean an increased detection of precervical abnormalities and treatments will prevent or reduce any future diagnosis of cervical cancer.

Chapter 1 includes the background for this research, the problem statement, purpose of the study, and the three main research questions. The two conceptual frameworks included the Thomas and Penchansky theory of access (Saurman, 2015) and the Leininger's culture care model (2005) were used to guide the study and its discussions. Chapter 1 additionally includes sections on the nature of the study, definitions of essential terms, assumptions made, the scope and delimitation of the study, limitations of the study, as well as the study's significance. The chapter concludes with a summary section.

## **Background**

Cervical cancer is a type of cancer that originates in the cells that line the cervix which is the lower part to the uterus commonly referred to as the womb (American Cancer Society [ACS], 2016). Anatomically, the cervix is the part of the body that connects the uterus to the vagina creating the birth canal (ACS, 2016). Cervical cancer is primarily caused by the human papillomavirus (HPV) (ACS, 2016). Cervical cancer is a severe disease affecting women across the world and in the United States (U.S.) as well. The ACS (2016) estimated that in the United States in 2018 approximately 13,240 women were diagnosed with cervical cancer and of those, 4,170 died. Pap test is the screening used to diagnose cervical cancer during routine cervical cancer screening. Cervical cancer was once listed as one of the primary causes of cancer death in women in the United States, but due to increased cervical cancer screening, this is no longer the case. “This screening procedure can find changes in the cervix before cancer develops. It can also find cervical cancer early – when it is small and easier to cure” (ACS, 2016). Women between the ages of 35 through 44 years old compose the largest demographic of the cervical cancer diagnosis; however, this does not mean that women out of this range are not affected by cervical cancer (ACS, 2016). Women over 65 years old account for more than 15% of cervical cancer cases in the United States (ACS, 2016). Cervical cancer is rarely diagnosed among women who have regular cervical cancer screening or Pap tests before they turned 65 years of age (ACS, 2016). Cervical cancer most often affects Hispanic women in the United States followed by Blacks/African Americans (ACS, 2016).

Cervical cancer screening among women of East African descent by ranking is an urgent concern since cervical cancer is the second most common cancer-causing death among these women. Cervical cancer was on a steady rise with 75,000 new diagnoses and 50,000 deaths in sub-Saharan African countries annually (Bouassa et al., 2017). Cervical cancer is a preventable disease and therefore, should not account for so many deaths among East African women as well as within the Somali community (Ghebre et al., 2015).

Abdikarim, Atieno, and Habtu (2017) published cervical cancer death records and estimated that there were 266,000 deaths worldwide which translated into 7.5% of all the female cancer-related deaths in 2012. The report stated that almost 9 out of 10 cervical cancer deaths (87%) occurred in less developed countries such as Kenya, Somalia, and others (Abdikarim et al., 2015). A review and study of previous research completed on the importance of cervical cancer screening showed an emphasis on accessibility to screening especially lack of health insurance to cover for Pap smear screening procedure cost. Multiple researchers have focused on a single program for minority patients as a means to improve cervical cancer screening around the world, but the single approach has not been successful. In this research I adopted some of the previous approaches; however, I focused on Somali women who have not earned a four-year college degree and their lived experience as related to cervical cancer screening.

### **Problem Statement**

Cervical cancer kills 275,000 women annually worldwide, and nearly 90% of deaths occur in low and middle-income countries (Collins, Holcomb, Chapman-Davis,

Khabele, & Farley, 2014). According to Collins et al. (2014), there were nearly 530,000 newly diagnosed cervical cancer cases each year across the world. Aggressive cervical cancer screening, such as yearly screening for high-risk women, has helped in reducing diagnoses of cervical cancer in women compared to regular screening, which depends on patient's preference and willingness to return for screening. Aggressive screening in the United States has resulted in a steady decline in cervical cancer diagnoses since the 1970s (Collins et al., 2014). Despite all these improvements and a reduction in cervical cancer, there exists a wide disparity in cervical cancer rates between Whites and Blacks. Collins et al. analyzed the SEER report which indicated that between 2005 and 2009 the adjusted cervical cancer rate was 2.2 for White women and 4.3 for Black women. This is twice the number of deaths related to cervical cancer in Black women compared to the White women. The 5-year cervical cancer survival rate for White women was 72% and for Black women was 61% indicating a survival disparity of 11% associated to a variety of factors including, but not limited to, the quality of care (Collins et al., 2014).

The National Institute of Health (NIH) published the SEER statistics which indicated a diagnosis incidence of 7.4 per 100,000 persons for Whites and 8.4 per 100,000 persons for Blacks in the United States (NIH, 2015). The mortality rate published was 2.2 per 100,000 for Whites and 3.7 per 100,000 for Blacks according to the SEER report (NIH, 2015). According to Ghebre et al. (2015), the incidence of cervical cancer for Somali women was 34.8 new cases, and the mortality was 22.5 compared to 6.6 new cases and mortality rate of 2.5 for all women in North America in 2012. The 2009 SEER report reviewed in Ghebre et al. (2015) showed 4.3 new cases for

Black women, and in 2012 it showed 34.8 new cases for Somali women. A review of the SEER 2009 report on cervical cancer highlighted a 20-point difference in the mortality rate for cervical cancer between Somali women and non-Somali women in North America, (Ghebre et al., 2015). Early cervical cancer screening is a critical component when it came to prevention of cervical cancer and related deaths.

A disparity exists between screening rates of White women versus Black women in the United States; however, African born Somali women are severely lagging in preventive screenings (Ghebre et al., 2015). Somali women have the lowest participation rate in cervical cancer screening partially due to limited English proficiency within the Somali Community (Idehen et al., 2017). Furthermore, low screening participation among Somali or Muslim women was found to be related to unfamiliarity with screening possibly due to the unavailability of the screening program, lack of understanding of healthcare practices, or lack of screening affordability in their country of origin (Idehen et al., 2018). Cervical cancer screening statistics continue to show a disparity among women of White, Black, and Hispanic descent. Ghebre et al.'s (2015), research conducted on cervical cancer screening among Somali women listed among its limitations that the study was carried out only among educated Somali women.

### **Purpose of the Study**

The purpose of this research was to understand the lived experiences of Somali immigrant women who did not have a four-year college degree with obtaining cervical cancer screening services in St. Cloud, MN. The study focused on African born Somali women ages 25 - 45 years old who did not have a four-year college degree and their



experiences related to cervical cancer screening in St. Cloud, Minnesota (MN). Prior studies conducted in the Somali community of St. Cloud, MN included women who were college graduates. This study was out to provide a foundation for understanding Somali women immigrants without a four-year college degree's motivation to keep a routine cervical cancer screening schedule. This research looked at the lived experiences of Somali women who had not completed a four-year college degree and their cervical cancer screening patterns. This research was original because there is little research that has looked into the lived experiences of Somali women who had not completed a four-year college degree and why cervical cancer screening rates was lower among this population.

### **Research Questions**

The following three research questions were addressed using a qualitative methodology to better understand female Somali noncollege graduate immigrant's experiences with cervical cancer screening services.

**Research Question 1:** What are the lived experiences of Somali immigrant women without a four-year college degree, accessing cervical cancer screening? (e.g., availability, accommodation, affordability, and accessibility).

**Research Question 2:** How does the awareness of services impact cervical cancer screening among Somali immigrant women without a four-year college degree?

**Research Question 3:** What is the role of acculturation in the experiences of Somali immigrant women without a four-year college degree in obtaining cervical cancer screening?

### **Conceptual Framework for the Study**

This study was guided by two conceptual frameworks known as the Penchansky and Thomas theory of access (Saurman, 2015) and Leininger's culture care model (2005). The six dimensions of the Penchansky and Thomas, also Saurman frameworks was used to guide the research and the interview questions to understand the lived experiences of Somali immigrant noncollege graduate women's experiences with cervical cancer screening.

The Penchansky and Thomas theory of access was first defined in 1981 by Penchansky and Thomas to explain access as a degree of fit when it came to the user and the service. Penchansky and Thomas explain that the closer the fit, the closer the access to care. There are five dimensions of access including availability, accommodation, affordability, accessibility, and acceptability. These dimensions were relevant to the study and could all affect cervical cancer screening rates among Somali non-college graduates in St. Cloud. Penchansky and Thomas (1981) defined dimensions of access as accessibility referred to the location, distance or the time needed for the consumer to seek service; availability looked at the supply and demand; acceptability was the consumer's perception of service; affordability was the cost involved; accommodation was the changes made by the organization such as after hour services. Saurman (2015) added awareness to Penchansky and Thomas' framework and looked at the effectiveness of communication that occurs between the patient and the healthcare provider.

Leininger's culture care model was useful in discovering the health needs of diverse patients with different cultures. The model looked at diversity in clinics,

communities, and hospitals. Leininger's culture care model overview recognized culture "as a major influence upon human expressions related to health, illness, wellbeing, or to face death and disabilities." (Leininger & McFarland, 2002, pg.1). The model covered a broad range of influencers and research enablers; however, in this research, I focused on the acculturation enabler. The acculturation enabler assisted in determining the level of acculturation and the role of culture in receiving care (Leininger, 2005). The acculturation enabler was shown to be significant; the level of acculturation predicted the level of patients' willingness in receiving care. This research used the acculturation enabler to ask open-ended questions that seek to understand acculturation as well as the lifestyle patterns of the participant regarding their experiences with cervical cancer screening. The framework allowed for a broader and better understanding of cultural influences that may play a role in the Somali immigrant noncollege graduate women's experiences with cervical cancer screening.

### **Nature of the Study**

The study is a qualitative research (QR), which is research that offers a variety of strategies and different styles of the research question. Qualitative research are known as "real-world inquiry," and this type of research prides itself on "carefully looking, listening, recording, and contextualizing people's 'real-world' experiences" (Henwood, 2014, pg. 19). According to Moustakas (1994), phenomenological research interviews are interpreted spirally or circularly in order via an understanding of the lived experiences of a selected group or community. Phenomenological studies and interviews seek to understand lived experiences by looking at the historical, cultural, and social experiences

of the person who participates in the study while minimizing the researchers who interpret the data. According to Strauss (2012), phenomenological research focuses on a specific group of people; for instance, the elderly or the homeless. This research focused on Somali immigrant women without a four-year college degree ages 25 to 45 years old and their experiences with cervical cancer screening. This research conformed to a phenomenological approach because it sought to understand the lived experiences of a group related to a specific context. I listened to the experiences of Somali women immigrants without a four-year college degree about their cervical cancer screening experiences, described them, and presented them in writing. Many questions were used with probing and follow up questions to understand the lived experiences of the selected demography.

Demographic data was collected such as age, level of education, ethnicity, country of birth and address to ensure the targeted research group is selected. The research planned to understand the lived experiences of female Somali noncollege graduate immigrants with cervical cancer screening services; therefore, participants were recruited based on qualified guidelines of the research parameters. Data was gathered via face-to-face as well as virtual interviews and a recording device if allowed by the participant. The interview was transcribed for the participant to review and approve or edit. Once the participant approved the transcription for accuracy, the researcher then analyzed the data by looking at similarities and grouping them into common themes.

## Definitions

*Acculturation:* Leininger (2005) defined acculturation as the degree to which an immigrant is traditionally or is non-traditionally attached to their culture, or the values and the general lifestyle of their new home.

*Cervical cancer screening:* The American College of Obstetricians and Gynecologists (ACOG) (2017) defined cervical cancer screening as a screening test that locates cell changes in the cervix that could potentially cause cervical cancer. Cervical cancer screening includes a Pap smear screening and for some women an HPV test screening.

*Cervical Cancer:* This is when cervical cells over some time become abnormal and grow out of control and invade deeper tissues of the cervix. In the long run, the abnormal cells can spread and invade other organs in the body cause the individual to be sick as well as depressing their immune system (ACOG, 2017).

*Cervix:* The opening to the uterus which is located at the top of the vagina is the anatomical part referred to as the cervix (ACOG, 2017).

*DNA:* Deoxyribonucleic acid.

*Health disparity:* According to Health People 2020 (2018), health disparity is the difference closely related to social, economic, as well as environmental disadvantage. Health disparities turn to plague most people who have experienced more significant challenges and obstacles as a result of systematic injustice such as race, age, gender, religion, sexual orientation, and geographic location.

*HPV:* HPV is an acronym for human papillomavirus which is a virus transmitted from one person to another during sex. The virus has no symptoms and takes several years to erode and infect cervical cells into abnormal or pre-cancerous cells (ACOG, 2017).

*Immigrant:* An immigrant is a person or anyone who moved from their birth country to another country and permanently reside there or may become a citizen of the new country in the long run (UC Berkeley, 2018).

*Pap smear:* cervical cancer screening which involves cervical cytology (the study of the cells collected from the cervix and examined under a microscope in a laboratory) is also known as Pap smear (ACOG, 2017).

*Somalia:* Somalia is a country in East Africa located on the horn of Africa in the far eastern part on the map. Somalia has been torn apart by civil war since 1991 which destroyed infrastructure including healthcare (Britannica, 2018). The people of Somalia are known as ‘Somali’ and are primarily Muslims.

### **Assumptions**

Several assumptions were made before conducting this study. It was assumed that the participants would be willing to share information regarding their demographics such as place of birth, gender assigned at birth, and age. It was assumed that the participants in this study would answer questions during the face to face and virtual interview honestly about their lived experience with cervical cancer screening or a Pap smear exam. Another assumption was that all participants will grant consent for the researcher to record the interviews for transcription later to ensure accuracy. During this research, an inclusion

criterion was that all participants will have healthcare insurance and the testing cost will not be a factor keeping them away from obtaining routine cervical cancer screening.

### **Scope and Delimitations**

This study focused on female Somali immigrants who had not completed four years of a college degree. The scope of the study was that participants selected ranged between the ages of 25 through 45 years old. The participants' gender was female assigned at birth to ensure that they have a cervix and a uterus. Participants were immigrants from Somalia who had resettled in St. Cloud, MN and must have completed at least one Pap smear since the arrival to the United States. The scope of this study was guided by the recommendations from the ACS (2012) stated as follows:

All women should begin cervical cancer screening at age 21. Women between the ages of 21 and 29 should have a Pap test every three years. They should not be tested for HPV unless it is needed after an abnormal Pap test result. Women between the ages of 30 and 65 should have both a Pap test and an HPV test every five years. This is the preferred approach, but it is also OK to have a Pap test alone every three years. Women over age 65 who have had regular screenings with normal results should not be screened for cervical cancer. Women who have been diagnosed with cervical pre-cancer should continue to be screened. Women who have had their uterus and cervix removed in a hysterectomy and have no history of cervical cancer or pre-cancer should not be screened.

The delimitation of participants' ages 25 – 45 years old was because the ACS (2018) stated that cervical cancer turns to be diagnosed in midlife and frequently among

women ages 35 through 44 in the United States. This study included participants from 25 years old because in speaking to Somali women in St. Cloud, MN, it was their perception that sexual activities start earlier back in Somalia due to an increase in child brides. Early onset in sexual activities increases the risk of HPV transmission and behaviors such as early marriages are complicated by common practices of polygamy. Somali women who understood the importance of cervical cancer screening were concerned that although child bride is unlawful in the United States, some of its practices such as sex with a minor is not frowned upon in some Somali communities.

The study participants was limited to St. Cloud, MN and therefore, may not represent the lived experience of all female Somali immigrant' view in other parts of Minnesota or the United States. The resultant delimitation for this study also decreases its ability to be generalized to all Somali female immigrants of this demography across the United States instead it should enhance understanding that will be used in the future to improve cervical cancer screening in the targeted demography.

### **Limitations**

A limitation of this study was that the researcher relied on the honesty and truthfulness of the participants and it was possible for participants to relate inaccurate information to the researcher during interviews. The study concentrated on female Somali immigrants and did not factor the fact that some of the female Somali immigrants may have lived in different countries as refugees and may have acculturated to the practices of the asylum camps or host countries such as Kenya, Sudan, Ivory Coast, or even Canada prior to relocating to St. Cloud, MN.



An acknowledging bias from the researcher is that the U.S. government does not care about immigrant's health and therefore, lacks the passion for designing a system that goes aggressively towards bridging cervical cancer screening disparity, particularly in Minnesota. This researcher bias was controlled by sticking to the research questions, and no personal opinions were injected as side comments during the interviewing phase. The recording device allowed the researcher to review conversation and eliminate any conversations where bias was demonstrated.

### **Significance of the Study**

The gap in the existing research on cervical cancer is the lack of research among Somali women without a four-year degree. According to the United States Census Bureau, less than 28.6% of the residents of the city of St. Cloud, MN are college graduates (United States Census Bureau, 2017). In a city with 28.6% of college graduates, the educated guess is that the number is lower in the Somali community. Cervical cancer screening disparity is significant and daily discussions by providers at CentraCare Health (CCH) in St. Cloud Hospital focuses on cervical cancer screening. Weekly health care providers meetings emphasize the fact that it is more challenging to convince Somali born women without a four-year college degree of ages 25 - 45 years to keep a routine cervical cancer screening schedule than those with a college degree. This research complemented the research by Ghebre et al. (2015) regarding Somali female college graduates in St. Cloud, MN. Isaacs, Valaitis, Newbold, Black, and Sargeant (2013) looked at minorities and healthcare cancer screening in Canada but did not isolate

Somalis and cervical cancer screening; nonetheless, this study could be helpful as a comparison tool when analyzing the findings of other study.

An understanding of the lived experiences among Somali immigrant women without a four-year college degree related to performing routine cervical cancer screening would be useful to primary care providers. An understanding of lived experiences could lead to adaptations and solutions to enhance patients' experience which could allow for increased cervical cancer screening. Social change will occur if more Somali immigrant women without a college degree get routine screening, this means an increase in preventive medicine, early detection, and increased survival chance from cervical cancer and therefore, a healthier community of Somali women.

### **Summary**

Chapter 1 defined a cervix and cervical cancer along with other related terms. The chapter also provided a background of the study which builds from the premise and defines the criteria for selection of participants. Socioeconomic and geographic factors such as age, sex, level of education, place of birth and current place of residence were determining criteria for the selection of participants for this study. Cervical cancer kills 275,000 women annually worldwide, and nearly 90% of deaths occur in low and middle-income countries (Collins et al., 2014). According to Collins et al. (2014), there are nearly 530,000 newly diagnosed cervical cancer cases each year across the world.

Chapter 2 presents a literature review to underscore the importance of cervical cancer as a deadly but preventable disease. The literature provides an in-depth look at the statistics related to Black/African American women and their low screening rates for

cervical cancer including those of East Africans; mainly Somali women which was even lower (Ghebre et al., 2015). The literature review looked at healthcare and screening practices back in the country of origin (Somalia) that may have migrated with the women to their new residence in St. Cloud, MN. The stages of developing cancer was reviewed in chapter two to better understand the onset, progress, and timeframe of the disease. The two conceptual frameworks of Penchansky and Thomas Theory of Access (Saurman, 2015) and the Leininger's Culture Care Model (2005) used for this study will also be discussed.

## Chapter 2: Literature Review

### **Introduction**

Cervical cancer has steadily remained the second most common type of cancer among females of East African descent including Somali women and results in a high level of mortality (Ghebre et al., 2015). Political unrest in Somalia in the 1990s led to many Somalis resettling in other areas of the world including in the United States, particularly St. Cloud, MN. Somalia's population is on the rise, and this means an increase in cervical cancer incidences and therefore posing an urgent need to explore health care behaviors and practices (Ghebre et al., 2015). It is important to remember that cervical cancer is a preventable disease though 275,000 women die annually worldwide from the disease, and nearly 90% of deaths occur in developing countries (Collins et al., 2014). As noted previously, according to Collins et al. (2014), there are nearly 530,000 newly diagnosed cervical cancer cases each year across the world. The purpose of this research was to understand the lived experiences of Somali immigrant women who did not have a four-year college degree with obtaining cervical cancer screening services in St. Cloud, Minnesota (MN). The study focused on African born Somali females' ages 25 - 45 years old who did not have a college degree and their experiences with primary care and cervical cancer screening.

The literature review on cervical cancer screening and Somali women provided some understanding of behaviors that may have influenced and continue to influence screening rates in the new habitat in the United States. Past literature did not explore an understanding of the lived experiences among a specific group of women who do not

have a four-year college degree; therefore, allowing a gap. An understanding of this selected demographic's lived experience, and their perception of cervical cancer screening may provide the key to increasing screening in the future.

This chapter did review the healthcare screening practices and infrastructure in Somalia and the current practices and expectations in the United States. The chapter utilized literatures from past research studies which were limited and did not address the proposed research questions put forth by this study. The literature review was used to align the conceptual framework of Panchansky and Thomas theory of access (Saurman, 2015) and the Leininger's culture care model (2005).

### **Literature Search Strategy**

The literature review for this study was conducted using a variety of search engines such as Walden University database to access ProQuest, Science Direct; several peer-reviewed journals and articles on Sage. Organizations such as the CDC, the ACS, the Office of Minority Health, WHO and MDH were utilized throughout this research. The articles published were within the last five years preferably; however, a few were beyond such as articles discussing conceptual frameworks. Another source of database search used was from Google Scholar and ProQuest past dissertations which were used as an example to understand/accomplish my dissertation requirement. Researched keywords or key phrases included; *world incidence of cervical cancer, high cervical cancer mortality regions, cervical cancer screening, low cervical cancer screening population in the United States, Somali cervical cancer screening, cervical exams, women of color cervical cancer screening, reason for low cervical cancer screening in Somali women,*

*reasons for increasing cervical cancer in sub-Saharan countries, cultural belief and cervical cancer screening healthcare in Somalia, stages of cancer, and improving cervical cancer screening in Somali women.* This literature review highlighted the low rates of screening among African American women and Somali. There were a limited number of articles addressing Somali cervical cancer screening rates; however, African American women suffer a similar low screening rate although better than Somali women. Past articles reviewed on Somali women across the world provided valuable insight to be observed on the outcome of the lived experiences of Somali women and cervical cancer screening.

The literature review followed several themes such as literature on conceptual frameworks used in this study, the Panchansky and Thomas theory of access and the Leininger's cultural care model. The rest of the literatures were organized in themes which included: General information on cervical cancer and screening in the United States, Cervical cancer screening in Somalia (East Africa), and low Somali rate of cervical cancer screening.

### **Conceptual Framework**

Saurman's adaptation of Panchansky and Thomas' theory of access (Saurman, 2015) and Leininger's culture care model (Leininger, 2005) were significant in understanding participants' lived experiences towards cervical cancer screening.

Panchansky and Thomas' theory of access was first defined in 1981 and was modified by adding *awareness* as a concept in 2015 by Saurman. A phenomenological approach was

most fitting in gaining a deeper understanding of lived experiences for Somali women who have had cervical cancer screening in the past but did not return in the future.

### **Penchansky and Thomas Theory of Access**

Penchansky and Thomas theory of access was chosen as part of the conceptual framework for this study to understand if lived experiences show that the closer the fit between the patient and their healthcare professional, the closer the access to care. The Penchansky and Thomas theory of access has five dimensions of access which included availability, accommodation, affordability, accessibility, and acceptability (Penchansky & Thomas, 1981). These dimensions were relevant to this study and could all affect cervical cancer screening among Somali non-college graduates in St. Cloud. Penchansky and Thomas (1981) defined dimensions of access as accessibility, which referred to the location, distance or the time needed for the consumer to seek service; availability looked at the supply and demand; acceptability was the consumer's perception of service; affordability was the cost involved; accommodation was the changes made by the organization such as after hour services. Saurman (2015) added awareness to Penchansky and Thomas' framework to look at the effectiveness of communication that occurs between the patient and the healthcare provider. These dimensions mentioned above and the addition of awareness was a factor used to explore Somali women's lived experiences with cervical cancer screening. The dimensions were applied in this research study through seeking an understanding of how location, distance and time needed for Somali immigrant women non-college graduates affected their cervical cancer screening behavior. Availability looked at the supply and acceptability of healthcare providers,

particularly related to female providers and ethnically similar healthcare providers, also a dimension of Leininger's model and how this affected these women from accessing cervical cancer screening. Affordability was addressed through interview questions related to cost, availability of health insurance, and how these related to the Somali immigrant woman non-college graduate's choice to obtain cervical cancer screening. Accommodation looked at the relationship that existed between the selected Somali women and the healthcare organization in terms of resources for cervical cancer screening (Penchansky & Thomas, 1981).

In strong consideration for a conceptual framework was the health belief model (HBM) although it was not a final selection for this study. The HBM is a useful model when looking at positive outcomes related to provider-patient adherence to treatment emphasizing behavior, socioeconomic factors and interpersonal relationship between the provider and the patient. HBM did not look at how past experiences or behavior might affect the patient's response regarding future healthcare decisions. The Penchansky and Thomas theory of access was more fitting to understanding decisions about cervical cancer screening, unlike the HBM which was more applicable to understanding decisions regarding treatment outcomes.

Penchansky and Thomas theory of access was used by Akinyemiju, McDonald, and Lantz (2015) in a South African study on cervical cancer. The findings were that 1 in 4 women (25.3%, n = 65) who visited the health care center or facility within 12 months admitted to having cervical cancer screening (Akinyemiju et al., 2015). The patients who saw a medical doctor (73.1%) compared to a midwife or nurse (45.9%) had better



screening rates (Akinyemiju et al., 2015). Availability of medical doctors was an essential component of access to care and cervical cancer screening.

### **Leininger's Culture Care Model**

Leininger's cultural care model was the second framework chosen to serve as part of the conceptual framework for this study. This model was fitting for this study of understanding Somali women's lived experience with cervical cancer screening because it looked at diversity in communities, clinics, and hospitals and the health needs of patients from different cultures (Leininger, 2015). Leininger's model covered a broad range of influencers, and for this research, the acculturation enabler was of utmost importance. Acculturation was defined by Leininger (2005) as the degree to which an immigrant is traditionally or is nontraditionally attached to their culture, or the values and the general lifestyle of their new home. The Leininger's acculturation enabler helped assess the level of acculturation and the importance of culture in Somali immigrant women's experiences with cervical cancer screening. The theory was initially shown to predict the patients' willingness to receiving care (Leininger, 2015). The acculturation enabler factored the traditional as well as the non-traditional lifestyle binding on the patients or on a particular group of people. The data collected from using the Leininger's acculturation assessment was analyzed in the research finding (Leininger, 2015). The research questions for this study allowed for a generation of open-ended interview questions which the participants' response demonstrated the level or degree of acculturation of Somali immigrant women which could be a factor in improving cervical cancer screening in the future. Transcultural nursing concepts by Leininger has become

today's nursing emphasis. Medical services are greatly influenced by factors such as cultural adaptation and acculturation due to migration (Leininger, 2015). Global migration comes with an introduction of new and varying culture. This is the case of Somali immigrants who have to accommodate western medicine and their cultural beliefs and practices. The healthcare providers' understanding of trans-cultural issues and the patient's ability to understand their new cultures was reflected in how they respond to the research questions.

Steeffel (2018) used Leininger's theory of cultural care in a cultural humility study to show its importance in nursing and healthcare. The study suggested three nursing actions which aimed at maintaining the "patient's culture, make accommodations for it, and/or repattern cultural ways that may be unhealthful" (Steeffel, 2018, p. 27). Cultural humility may not always be visible, but the study found that without incorporating cultural humility in nursing and healthcare, there will be a deficit or no care. Leininger's theory of culture was used in conjunction with cultural humility, and it was concluded that without an understanding in cultures, there was bound to be a misunderstanding between patients and provider. Healthcare practices misunderstanding can easily influence the return rate for screening or seeking healthcare services (Steeffel, 2018).

### **General Information on Cervical Cancer and Screening in the United States**

In describing studies related to the constructs of cervical cancer screening in Somali population and chosen methodology as well as methods consistent with the scope of the study, a general understanding of cervical cancer and the importance of screening is vital. According to NCCC (2018), cervical cancer is a female related cancer which

starts in the cervix, and it is estimated to be responsible for 13,000 diagnoses in women in the United States annually. It is the fourth most commonly diagnosed cancer in women in the world; however, it is “one of the most preventable types of cancer” (NCCC, 2018). HPV is responsible for 99% of all cervical cancers and is a sexually transmitted disease (NCCC, 2018). There are more than 100 types of HPV, but two types of HPV account for 70% of all cervical cancers and they are HPV-16 and HPV-18 commonly referred to as “high-risk HPV types” (NCCC, 2018). It is important to note that most of the low-risk HPVs do not cause cancer and the immune system usually eradicates it from the body or subdues it within two years of being infected (NCCC, 2018). By age 50, 80% of women have been infected by some form of HPV, either low risk or high risk, cervical cancer is typically diagnosed in women between the ages 35 and 44 (NCCC, 2018).

Cervical cancer deaths occur in the United States far less frequently than countries in Africa and other developing countries of the world. The death rate continues to decline in the United States at approximately 2% per year due to increase in cervical cancer screening (Pap smear) which includes screening for high risks HPV- 16 & 18 and immunizing against HPV (NCCC, 2018). There are five stages of cervical cancer ranging from stage zero through stage four (NCCC, 2019). The stages of cervical cancer as described in NCCC (2019) include,

Stage 0: Carcinoma in situ. Abnormal cells in the innermost lining of the cervix.

Stage I: Invasive carcinoma that is strictly confined to the cervix.

Stage II: Locoregional spread of cancer beyond the uterus but not to the pelvic sidewall or the lower third of the vagina.

Stage III: Cancerous spread to the pelvic sidewall or the lower third of the vagina, and/or hydronephrosis or a nonfunctioning kidney that is incident to invasion of the ureter.

Stage IV: Cancerous spread beyond the true pelvis or into the mucosa of the bladder or rectum.

### **Cervical Cancer Screening in Africa (Somalia)**

According to the WHO (2017), cervical cancer accounted for 22% of female cancer diagnoses in Africa. To better understand the burden of cervical cancer in Africa, “34 out of every 100,000 women are diagnosed with cervical cancer while 23 out of every 100,000 women die from cervical cancer every year. This figure compares with 7 out of every 100,000 women diagnosed with cervical cancer and 3 out of every 100,000 women dying of the disease every year in North America” (WHO, 2017). The WHO along with its researchers has approached the issue of cervical cancer in Africa by promoting routine cervical cancer screening. Pap smear and early treatment for abnormal Pap smear can prevent 80% of future cervical cancers (WHO, 2017). The WHO (2017) reported that many women in Africa do not get routine cervical cancer screening and treatment is not started until the late stages of the disease. Increased access to a healthy diet, physical activity, education against tobacco and harmful alcohol usage are some of the education needed to improve health. Cervical cancer screening via Pap smear has proven as effective in reducing cervical cancer in North America and therefore access to reproductive health screening is paramount tool in the fight against cervical cancer in Africa (WHO, 2017).

The civil war in the 1990s ravaged the infrastructure and healthcare structure of Somalia, Morrison, Flynn, Weaver, and Wieland (n.d.). The civil war destroyed hospitals, clinics, and most Somalis were on the run to safety; preventive health was not a priority. This civil war caused several Somalis to relocate, and Somalis are said to be one of the largest refugee population to be displaced in the world (Morrison et al., n.d.). According to Morrison (n.d.), a third of all the Somali refugees in America live in the state of Minnesota with a high concentration in St. Cloud. Somali immigrants or refugees were said to be less likely to comply with cervical cancer screening, and some of the reasons attributed to the non-compliant are the lack of understanding of the concept of cancer (Morrison, n.d.). Lack of knowledge of preventive healthcare services such as cervical cancer screening from the country of origin (Somalia) has created a situation of lack of trust in western medicine. The healthcare infrastructure in Somalia is dented by a prolonged civil war and the fact that most of the population 59% practice nomadic lifestyle (Qayad, 2008). There are hospitals; however, these hospitals are clustered in urban centers such as Mogadishu and other regional capitals of Somalia. The concept of preventive care is a new concept contrary to the concept in Somalia where there was no preventive health (Qayad, 2008). Religion and gender concordances are a hindrance or a determining factor for Somali women when it comes to choosing a provider. Female patients are hesitant due to religious reason when it comes to receiving a Pap smear from a male provider (Morrison, n.d.).

Samuel, Pringle, James, Fielding, and Fairfield (2009) minority women mainly Somali immigrants were shown to have lower cancer screening rates in some cancers

such as breast, colorectal and cervical cancer. An assessment of Somali women, Caucasian women as well as Cambodian women revealed Somali immigrants had a higher rate of not refusing to participate in cancer screening. The study also showed that the longer the period of residing in the United States, the more Somali women were willing to screen against cancer. The study concluded that any future efforts in improving cancer screening disparity would require community education. Bouassa et al. (2017) published the most recent statistics of cervical cancer in sub-Saharan Africa. While cervical cancer is on the decline in the United States, the disease is steadily increasing in sub-Saharan Africa with >75,000 new diagnoses and 50,000 in mortality per year. The increase in cervical cancer in African women is complicated by the increase in HIV infection which weakens the immune system and creates an inability for the body to eradicate low risks HPV. It was projected that by 2030, >443,000 women would die worldwide and a majority of them will be in sub-Saharan Africa - including countries like Somalia and its immigrants who have been displaced due to the civil war of the 1990s (Bouassa et al., 2017).

### **Cervical Cancer Screening Disparities**

According to Bharel, Santiago, Forgione, Leon, and Weinreb (2015), there exist cervical cancer screening disparities in the United States as well as globally. Cervical cancer is the fourth most diagnosed cancer in the United States with 11,818 new cases and 3,939 deaths in 2010 (Bharel et al., 2015). Women ages 21 through 65 in the United States average a cervical cancer screening rate of 83% and a “mortality rate of 2.4 deaths per every 100,000 women” (Bharel et al., 2015). Homeless women in the United States;

however, had an improved cervical cancer screening rate from 19% to 50% and 7.2 deaths per 100,000 women in 2010 which still indicates a disproportionately lower rate than the accumulative screening of 83% (Bharel et al., 2015). Another study on White Hispanic and White Non-Hispanic women indicated that cervical cancer is the fourth most diagnosed cancer in the United States but it is the second “most commonly diagnosed cancer among women worldwide” according to Khan et al. (2016). In 2015 cervical cancer was estimated to have 500,000 diagnosed cases and it was responsible for a quarter million (250,000) deaths yearly worldwide (Khan et al., 2016). In 2015 Latin American and Caribbean women accounted for 14.6% of all cervical cancer cases reported in the study which translated to 11.9% of the world’s cervical cancer cases diagnosed (Khan et al., 2016). Cervical cancer most often affects low-and-middle-income countries because these countries do not have the resources to provide aggressive cervical cancer screening programs. However, recent years have seen the development of new cervical cancer screening technologies in countries like Paraguay, Peru, Bolivia, Cuba, Brazil, Mexico, and Puerto Rico in the form of HPV and DNA testing (Khan, 2016).

Cervical cancer screening has been well documented as beneficial when it comes to reducing the number of cervical cancer-related deaths, as well as improving survival rates. Despite the benefits of early cervical cancer screening, several developing countries continue to lack the resources to offer affordable screening to women (Kangmennaang, Onyango, Luginaah & Elliott, 2018). A study in Kenya using the socio-ecological framework conducted in 2014 studied the determinants of cervical cancer screening and the knowledge of its participants. A total of 11,138 women were screened among whom

10,333 women were between the ages of 15-49 years old (Kangmennaang et al., 2018). The study concluded that “regional disparities in cancer knowledge and the utilization of cervical cancer screening services” existed (Kangmennaang et al., 2018). Among other reasons contributing to disparities in cervical cancer screening was lack of health insurance creating an inability to pay for needed screening, lack of gender equity programs, educational level influencing understanding, and cultural impact (Kangmennaang et al., 2018).

Odunukan et al. (2015) noted that Somali refugees are documented among the largest of all refugees to resettle in Europe and North America. The relocation of the Somali refugee population came along with properly documented health disparities linked to specific barriers preventing them from seeking health services. There is a patient-provider gender disconnect blamed on poor communication. After studying fifty Somali women and their primary care providers, Odunukan et al. (2015) concluded that Somali women prefer female providers and also prefer female interpreters for their gynecological examinations such as cervical cancer screening.

### **Summary**

A summary of the literature review showed themes such as disparities in cervical cancer screening, particularly among minority women. The few studies found that looked at Somali women and cervical cancer screening showed a much lower rate of screening than other minority women. African immigrants are a part of the United States population and Somalis refugees are one of the largest populations to relocate to North America; therefore, the degree of health disparities cannot be neglected.



The literature review provided an understanding of the specific barriers or factors affecting cervical cancer screening such as limited language proficiency, preference of female providers, and cultural conflict (Ghebre, 2015). Cervical cancer screening guidelines in the United States continue to be updated.

This study looked at the lived experiences of Somali women who had not earned a four-year college degree and their perceptions, attitudes, and behavior towards cervical cancer screening. This study addressed the gap in determining if the level of education is a factor in the understanding of the importance of screening and adherence to regular cervical cancer screening among the Somali community. Knowledge gained from this study would be beneficial in bridging cervical cancer screening disparities within the Somali population and other minority groups particularly from Africa. The outcome of this study would be beneficial in developing culturally sensitive interventions to meet the needs of Somali women particularly among the chosen demographic who may or are currently underserved.

Chapter 3 discusses the research methodology used in conducting the study. The chapter covers information on the selected population for study, the sample size selection and criteria, the research questions. Data collection strategy and the data analysis protocol were reviewed, and finally, any ethical considerations related to this study are presented in chapter 3.

## Chapter 3: Research Method

### **Introduction**

The purpose of this phenomenological study was to understand female noncollege graduate Somali immigrants' lived experiences with cervical cancer screening. Chapter two offered substantial information in the literature presenting the fact that there is a disparity in cervical cancer screening in Somali women (East African women). This disparity has continued even among Somali immigrants who live in St. Cloud, MN. The study looked at Somali women who did not have a four-year college degree within the ages of 25-45 years and sought to understand their lived experiences in an attempt to understand why certain women return for cervical cancer screening on a routine base while others do not return. Chapter 3 includes an introduction, research design and rationale, role of the research, methodology, instrument, interview protocol, data analysis, issues of trustworthiness, and a summary.

### **Research Design and Rationale**

The following three research questions was addressed using a qualitative methodology to better understand female Somali non-college graduate immigrant's experiences with cervical cancer screening services. Here are the questions:

Research Question 1: What are the lived experiences of Somali immigrant women without a four-year college degree, accessing cervical cancer screening? (e.g., availability, accommodation, affordability, and accessibility).

Research Question 2: How does awareness of services impact cervical cancer screening among Somali immigrant women without a four-year college degree?

Research Question 3: What is the role of acculturation in the experiences of Somali immigrant women without a four-year college degree in obtaining cervical cancer screening?

This is a qualitative study that utilized a phenomenological approach guided by two conceptual frameworks. The first framework was Saurman's adaptation of Penchansky and Thomas' theory of access (Saurman, 2015) and the second framework was Leininger's culture care model (Leininger, 2005). These two frameworks were significant in understanding participants' lived experiences towards cervical cancer screening.

A phenomenological approach was most fitting in gaining a deeper understanding of lived experiences for Somali women who had cervical cancer screening in the past but did not return in the future. Phenomenological approaches are used in studies that seek to describe the lived experiences of individuals regarding a concept (Creswell, 2013). It was most effective and suitable for this study because it provided lived experiences of a phenomenon without necessarily explaining or justifying the cause or reason for people's behaviors or actions. The information was simply provided, and readers can utilize such information as they find it fit for a social change.

### **Role of the Researcher**

As the researcher on this study, I did interview participants regarding their experiences in completing cervical cancer screening also known as Pap smear. The interviews were on a face-to-face and a virtual base to allow for interpretation of non-verbal body language. There were opportunities for virtual conferencing interviews and

no exceptions were made for regular telephone interview without virtual option. Face-to-face interviews typically lasted 45-60 minutes while the telephone interviews for participant recruitment lasted only 5-10 minutes. For accuracy, and proper data collecting, I used an Olympus VN-541PC digital voice recorder device with a capacity to record 1570 hours of conversation. I also took notes during the interviews on a participant's reaction during the interview and body language. The interview was transcribed and email to participants for review of the transcripts, and if the participant was unwilling to receive transcript copies via email, a paper copy was delivered to them. I was available to read the transcript to participants if they chose to listen. After participants' approval of transcribed interview, the data was coded for themes and analyzed. The researcher did not have any personal or professional relationship except two identified participants who are ex-coworkers of CentraCare Health. The researcher is not supervising any of the participants in this study. Purposeful sampling was used to select participants, and they were women who volunteer to become participants from the community of St. Cloud, MN and met the selection criteria for the study. According to Palinkas (2015, 42(5): p. 533), "Purposeful sampling is widely used in qualitative research for the identification and selection of information-rich cases related to the phenomenon of interest." An acknowledging bias from the researcher is that the U.S. government does not care about immigrant's health and therefore, lacks the passion for designing a system that goes aggressively towards bridging cervical cancer screening disparity, particularly in Minnesota. This researcher bias was controlled by sticking to the research questions on the interview protocol, and no personal opinions were introduced

as a side comment during the interviewing phase. The recording device allowed the researcher and a research assistant to review conversation and eliminate any conversations where bias was detected. The study used a recorder as a check and balance to achieve an unbiased result. Creswell (2009) stated that researchers should stick to the data collected to allow for proper viewing of the participants' true lived experiences which allows for an unbiased study. The interviews were initially planned to be conducted at St. Cloud Public Library, and there was no conflict of interest as well as no power differentials. However, the actual interviews took place during governor Walz's shelter in place executive order due to the COVID19 pandemic and therefore the Library was closed. Most of the interviews were conducted virtually, I met with the participants for approximately 10 minutes for a meet and greet as well as to collect the signed consent forms at Mogadishu Food Market before the day of the interview. A rapport was established and I got to know them as it is culturally significant to know and ask about their family and how things are going in their family. The encounter did establish a level of trust and a rapport that allowed me to dive reasonably quickly into the research discussion on the day of the interview. The participants did not regard the researcher as a stranger since trust must be earned in the Somali community to allow for full disclosure and free information sharing.

## **Methodology**

### **Participant Selection Logic**

This research was a phenomenological qualitative study which sought to understand lived experiences of Somali immigrants without a four-year college degree

and cervical cancer screening. The identified or targeted population for this study was Somali immigrants and the location selected as the case study was in St. Cloud, MN. In adhering to Polit and Beck's (2012) sampling guidelines, this study aimed at interviewing no more than 23 individuals while maintaining an interview range of 12-20 individuals depending on reaching data saturation. As defined by Saunders et al. (2017), data saturation is a broad term used when conducting a qualitative research that means that data collection has reached a point where no new ideas or themes are emerging. According to Morse (2015), qualitative research utilize data saturation as a means to determine the sample size in a study and this approach is regarded as the most reliable standard that guarantees maximum data collection. I will continue gathering data from participants until an analysis proves that there is no new contribution to the study or saturation has been attained. When this happens, I will stop and that will determine the study sample size (Morse, 2015). Purposeful sampling was used in the selection of Somali women who were immigrants, who did not have a four-year college degree, who lived in St. Cloud, MN and who ranged between the ages of 25 through 45 years old. Flyers were posted at the Mogadishu Food Market, Somali Café, the Islamic Center and at the public library in St. Cloud, MN. Flyers included the researcher's telephone number and email address to contact the researcher. Primary mode for recruitment was via flyers at designated locations with the researcher's contacts such as emails, telephone number. I, Rachel Anyu-Lainjo (rachel.anyu-lainjo@waldenu.edu) recruited two ex-coworkers who volunteered to be part of the study prior to IRB approval. Recruitment relied on posted flyer and word of mouth within the St. Cloud Somali community as well as a

Facebook post. There was a screening process using the screening questionnaire (Appendix A) to verify that participants met the above inclusion criteria such as gender, ethnicity, place of birth, age, level of education, and at least one prior experience with cervical cancer screening. Scheduling options, as well as interview locations, was discussed, and every participant was provided a consent form before the interview for review. The consent form was submitted to Walden IRB.

St. Cloud, MN was selected as a case study location due to the high number of Somali immigrants who call this city home. Rutledge (2008) reported that the Minnesota Demographic Office estimated that 52,400 Somalis lived in the state of MN with more than half concentrated in St. Cloud (Stearns and Benton Counties). The report acknowledged that it is lower compared to the 80,000 estimated by Somali leaders who live in the state of Minnesota. WHO (2017) reported that Africa as a continent accounted for 68,000 cases of cervical cancer caused by HPV. Cervical cancer is 22% of all female cancers and 12% of newly diagnosed. These statistics are exceptionally high because cervical cancer is preventable via pap smears. East Africa holds some of the highest prevalence with countries such as Somalia included. The scarcity of studies to understand the perception and lived experiences of East African women particularly Somali women's attitude towards cervical cancer screening made this study, its chosen city, and the targeted population unique and essential. According to Grieco and Rytina (2011), Minnesota held the highest number of Somali immigrants in the United States. Ghebre et al.'s (2015) researched on understanding barriers to cervical cancer screening were all Somali women college graduates. Somali women with a four-year college degree as a

demographic is a minority part of the Somali community and does not present a realistic understanding of the largest portion of the Somali immigrant female population.

Therefore, this study was among Somali immigrant women without a four-year college degree and this demography represented the majority of Somali women.

### **Instrumentation**

The basis for developing the instrumentation for this study stemmed from a combination of three questions used previously and tested by Ackerson (2008) at the University of Michigan and the research questions for this study. The interview questions for these face-to-face interviews were adapted from Ackerson (2008). Kelly Ackerson developed an instrument with a series of questions (Appendix B) that guided her dissertation research on “African American Women and Low Cervical Cancer Screening Attendance” at the University of Michigan (Ackerson, 2008). Participants were provided with a combination of questions from Ackerson (2008) and self-designed questions for this study (Appendix C).

### **Procedures for Pilot Study**

A pilot study was carried out and involved the guidelines and procedures outlined in this chapter for the main study. The pilot study utilized the same participant selection guide and interview protocol (Appendix C). The pilot study was used to test the validity and credibility of the instruments. Two participants were interviewed during the pilot study phase. Their data was not used in the final study.



### **Procedures for Recruitment, Participation, and Data Collection**

As noted above, flyers for recruitment was placed at places in St. Cloud where Somali immigrant women tend to frequent such as the Islamic Center, the Mogadishu local market and the public library. The flyer included a brief statement which read, “Participants needed for a study seeking to understand lived experiences of female Somali immigrants and cervical cancer screening.” A third section of the flyer carried a subtitle “Are you Eligible” which lists all of the inclusion criteria as; Somali born female within the ages of 25-45 years old who reside in St. Cloud, must have had at least one cervical screening and who have not earned a four-year college degree. The third and final section of the flyer listed my contact information (telephone and email).

Once a participant contacted me, I respond to them via the mode of contact. If I received an email, I responded via email and preferably request the interested participant’s phone number to contact them for further screening to establish inclusion (Appendix A and appendix B). I designed a screening set of demographic related questions as an instrument that assisted in identifying qualified participants for a face-to-face interview (Appendix A). As qualified participants became available, I sought their schedules and arranged a virtual/face-to-face interview. The interview process commenced immediately based on participant’s availability while recruitment continued simultaneously until enough participants were interviewed and data indicated saturation.

The primary and leading data collection instrument for this study was via virtual/face-to-face interviews that were conducted while utilizing open-ended interview questions and follow up questions designed to maximize responses. There were no

regular telephone interviews except during screening phase to recruit participants. The researcher will observe the participant's non-verbal communication queues. The participant's nonverbal communication queues are a crucial part of the study, which is why it is important to conduct a face-to-face interview with the participant. These interviews along with the designed interview questions were used to understand the lived experiences of Somali immigrants with cervical cancer screening. The interviews were in a semi-structured approach which allowed for an in-depth conversation between the researcher and the participants (Creswell, 2013). A semi-structured format allowed the researcher to be flexible with the follow-up questions and the participant might respond better than they would in a structured interview. Jamshed (2014) indicated that there is proven efficacy and benefit in using a semi-structured interview style when exploring participants' perceptions, beliefs and behaviors that may influence cervical cancer screening. In semi-structured interviews the participant answers preset open-ended questions while allowing flexibility to adjust using follow-up questions. The face-to-face interviews were conducted in the span of 45 - 60 minutes per sessions. Jamshed (2014) cautions on the importance of utilizing an "interview guide" which will comprise of core questions and any other associated questions. In order to maximize data collection, it was vital to record the interview and promptly transcribe the recording while my memory was still in peak form.

Consent form was emailed in advance, and the researcher had hard copies to be signed prior to the day of the interview. The interviews were audio recorded and the researcher took extensive handwritten notes during the interview sessions. Participants

were assigned code names such as “Somali 1, Somali 2, Somali 3” ...etc. The interview started promptly because the consent form had been signed and collected earlier. The consent form was verbally reviewed at Mogadishu Market with the participants and the participants were allowed an opportunity to ask questions or opt out of interview or sign the consent form. The interviews questions were arranged in three sections depending on the three research questions. Each research question had probing follow questions. The researcher frequently inquired from participants if they were ok and if any breaks were needed. The researcher used a notebook ledger and a pen to record notes and journal throughout the course of the interview as needed including observable non-verbal cues. Once the interview was completed, the researcher thanked participant and asked if they had any questions. The researcher then proceeded to thank the participant and debrief them on the next step which involved transcribing of the audio recording from the interview. The audio was transcribed within 24-48 hours by the researcher. According to Rubin and Rubin (2012) there are no particular method or techniques to exit an interview but it is important to allow participants an opportunity to make any comments the questions have not addressed. Participants were granted an opportunity by the researcher to ask questions needing clarifications. Participant after each interview was told that if needed, the researcher will contact them for clarification via email or telephone call. Participants received a transcribed copy via email or warm hand off delivery for editing and approval unless they choose to decline.

## **Data Analysis**

This qualitative research utilized a phenomenological approach, and therefore, data analysis consisted of comparing and identifying themes within the interviews. Data analysis was arranged to conform to the conceptual framework laid out in this study. The collected data was transcribed and themes established. A table matrix was created to record themes responses to the three main research questions and a second table responded to all interview questions on the interview guide (Appendix C). Below research questions had participants' responses to the right side of the table for personal analysis;

1. What are the lived experiences of Somali immigrant women without a four-year college degree accessing cervical cancer screening? (e.g., availability, accommodation, affordability, and accessibility).
2. How does awareness of services impact cervical cancer screening among Somali immigrant women without a four-year college degree?
3. What is the role of acculturation in the experiences of Somali immigrant women without a four-year college degree in obtaining cervical cancer screening?

These core research questions helped the researcher gain a deeper understanding, and the lived experiences of Somali immigrants who had not completed a four-year college degree and cervical cancer screening. Moustakas (1994) explained that having someone describe their lived experience provided the interviewer or researcher with a unique and powerful tool called observation. The observer will note the participants'

behaviors when asked questions. Using research questions and added probing questions enabled accurate responses which led to the creation of patterns, codes, and themes during data analysis. No data analysis software was used for this study. The data collected was transcribed and participants had an opportunity to review the transcripts as well as an opportunity to make edits to ensure accuracy. The researcher was the sole administrator of the data collection and data analyzing. The data collected was transcribed by listening to the audio recorder repetitively and typing out the conversation. The researcher played the audio recorder as many times as necessary with pauses to ensure accuracy. Every interview undertook the same transcription process, face-to-face notes and comments regarding non-verbal observations were attached to the official audio transcript for the researcher's personal consideration. Each interview was analyzed by creating themes and categories after which all interviews were analyzed for similarities and differences. The responses were categorized based on how similar the participants' lived experiences were or how entirely different they responded. Saldana (2008) indicated that there are various patterns of coding such as utilizing similarity, frequency, differences, sequence, and causation. In this research I looked at phrase coding and word coding whereby several codes led to a category or a theme (Saldana, 2008). Organizing thoughts involves multiple ways of coding and Saldana (2008) stated that information should be coded when the researcher comes across cultural practices, unique encounters, episodes, cliques, lifestyle changes, ideologies, hierarchy and more. It is important to start the first cycle of coding with emotional coding and value coding

(Saldana, 2008). Every recorded audio data was transcribed and submitted to a precoding and coding phrases for relevant information.

These transcripts are locked in a secure online file and printed copies are locked in the researcher's home base office in a locked cabinet and will be kept for a minimum of five years after the research is completed. At the end of these five years, the data will be destroyed via shredding.

### **Issues of Trustworthiness**

#### **Credibility**

Internal validity also known as credibility was achieved in earlier chapters via a defined strategy established such as the use of targeted open-ended questions, and adhering to an interview guide (Creswell, 2009). According Patton (2002), research that captures the lived experiences of its participants and utilizes triangulation enhances understanding and improves credibility. Therefore, I did utilize triangulation by using multiple data collection approach such as observation of body language, face-to-face interview, and some pre-selection criteria of candidate via questionnaire screening (see Appendix A). The use of two different conceptual frameworks for the study – the Penchansky and Thomas (1981) and Leininger (2015) enhanced credibility. In developing a purpose for this study, several articles and journals were reviewed. This study aimed for a sample size of 12 – 20 participants, allowing for the potential to stretch beyond data saturation. Burkholder, Cox, and Crawford (2016) showed that a typical phenomenological sample size ranges between eight and fifteen participants. The study is

about getting the depth of individuals' perceptions; therefore, it was important to assure that saturation was reached and possibly stretched beyond.

### **Transferability**

External validity, which is also known as transferability, was achieved in this study by detailing all appropriate steps and strategies involved in the participant selection. Transferability is defined as how accurately the results of one qualitative study can be transferred to another. Transferability is best achieved when the researcher details the study description and selects the study participants to meet well define criteria (Creswell, 2009).

The study presents facts and participants' perception as well as lived experiences that although conducted in St. Cloud, MN; the final report could allow for transferability to other geographical locations with caution on generalizing. The understanding of Somali immigrants' lived experience as related to cervical screening is applicable regardless of what state they reside in the United States.

To ensure both internal and external validity, the researcher used multiple data collection tools such as manual note writing and a recorder. Collected data were triangulated during transcription of participants lived experiences based on the responses to the questions. This study was based on a collection of data that described its participants' experiences, and therefore the researcher accepted all responses as truthful. Internal validity was highlighted when the researcher analyzed the data and aligned them into themes and patterns. External validity was ensured via transparency during and after the interview. Consents were collected, and the nature of the study explained to all

participants. The participants had an opportunity to review the transcripts of their interview. The questions were designed in an open-ended format and there are no leading questions. These questions eliminated or minimized the researcher's potential biases which could have threatened the validity of the research. The validity of this study could be threatened by participants being untruthful in recounting their lived experiences or from participants not understanding the questions. Participants were encouraged to be truthful, they were reminded that the study will not identify any of its participants and questions are written in simplified English and were explained repeatedly as needed. The participants were reminded to request breaks if needed and the researcher scheduled interviews over a four-week period. This will allow for a minimum of five interviews per week and transcriptions over the weekend.

Reliability requires that the researcher adheres to a correct interview protocol approved by Walden University when conducting the interviews. I followed the interview protocol and ensured that the interview stayed consistent. Creswell (2009) explained that the importance of following an interview protocol is to keep the study reliable and authentic. It allowed the researcher to capture the unique and authentic experiences of the participants.

### **Dependability**

Dependability is one of the criteria used to determine the trustworthiness of a research and it is used because it establishes the research as authentic, consistent, and repeatable (Connelly, 2016). Dependability is attained by reconciling or verifying the results of a study to the raw data collected during the study (Connelly, 2016). The



researcher is responsible for analyzing all collected data and insured that if another researcher looked over the same data, they would arrive a similar interpretation and conclusion (Connelly, 2016). This ensures that all the data collected during a research study have been analyzed and the findings match the actual research data. Dependability can be established by having an independent third-party researcher conduct an audit (Connelly, 2016). According to Marsden (2013), reliability is aimed at the accuracy of the study while taking into account measurements and procedures. The study's reliability, commonly described as dependability, will establish trustworthiness to ensure the validity, reliability, and transferability. In summation, reliability is concerned in making sure that if the research is duplicated, it will have a consistent result. An important aspect of reliability is transferability, which allows the findings in one research study to be used in other settings or context. For instance, this research will be conducted on Somali women in St. Cloud, MN; however, the findings will apply to other Somali immigrant women in other geographic locations.

### **Confirmability**

Confirmability is the degree to which other individuals can corroborate the results of a particular study (Trochim, 2006). To ensure the confirmability of this research, the researcher will enhance confirmability by maintaining full documentation of procedures. If any instances contradict any previous observations, the researcher will disclose such information, and there will be a data audit which will be used to analyze and recheck data for accuracy. The researcher will disclose existing or potential distortion or bias. These guidelines will allow the researcher to conduct an unbiased interview while maintaining a

neutral position (Trochim, 2006). It is crucial for the researcher to collect credible and reliable information during the data collection phase and will avoid introducing their personal opinion in the research.

### **Ethical Procedures**

There are a few ethical concerns present in this study, such as keeping the identity of the participant confidential. I will use code names to protect the true identity of participants by using Somali1, Somali2, Somali3, and so on. I will secure approval from the Walden University Institutional Review Board (IRB). The study will not commence until the IRB approval has been secured and once the research starts, the information from this study will not be made public in its entirety rather a summary of analyzed patterns will be made available. All participants will be provided with a consent form, and the participants will be required to sign a consent form before the interview session. The consent forms will explain the role of the participants and the role of the researcher. Participants will freely volunteer to be part of the interview and they are free to cancel or suspend the interview without any consequences. Data collected from interviews will be handled with utmost diligence and security. The participants will respond to questions freely and without being coerced. Participants must sign consent and they will be asked for permission to record the interview solely for accurate transcription. If using a recording is declined by the interviewee, I will proceed and will do my best in gathering detailed responses from the questions. Participants will be treated with respect and dignity and all data collected will be locked in a home base office filed cabinet for five years before shredding.

## Summary

This chapter covered the research procedures surrounding the completion of the research.

The chapter also explained the research design and rationale for using the identified design. The role of the researcher in this research was defined as well as the methodology. The process of recruiting participants and issues of trustworthiness such as credibility, reliability, and confirmability were covered. Throughout this chapter, the researcher described the study and a geographical location where the study was conducted.

Chapter 4 includes a description of a pilot study, it presents a summary of data collection in themes and it also provides findings of data collected. The findings also known as data analysis described the reporting process, the codes, themes used, and any discrepant cases observed. The results of each research question were laid out in this chapter. Chapter four contains a summary of the purpose of this study, the methodology used in conducting the research; it covers the findings, limitations of the study and finally it provides recommendations for future research.

## Chapter 4: Results

### **Introduction**

Chapter 4 provides a summary of the results for the interviews carried out among 23 Somali women who reside in St. Cloud, MN. These interviews were part of a research study seeking an Understanding of Female Somali Noncollege Graduate Immigrant's Experiences with Cervical Cancer Screening Services. The purpose of this research was to understand the lived experiences of Somali immigrant women who do not have a four-year college degree with obtaining cervical cancer screening services in St. Cloud, MN. Walden University's approval number for this study is 04-08-20-0493579 and it expires on April 7th, 2021. Three research questions were explored during this interview and they are as follow:

Research Question 1: What are the lived experiences of Somali immigrant women without a four-year college degree, accessing cervical cancer screening? (e.g., availability, accommodation, affordability, and accessibility).

Research Question 2: How does awareness of services impact cervical cancer screening among Somali immigrant women without a four-year college degree?

Research Question 3: What is the role of acculturation in the experiences of Somali immigrant women without a four-year college degree in obtaining cervical cancer screening?

This chapter explains the pilot study, the chapter dives into the main research covering the setting, the demographic, the data collected/analyzed and finally, the chapter concludes with a summary.

### **Pilot Study**

A pilot study with two participants was conducted to test the validity and credibility of the tool developed (see Appendix C). According to Dikko (2016), the purpose of a pilot study is to test the validity as well as the reliability of instruments or questions used to collect data. The pilot was conducted before IRB approval since the IRB guidelines allowed a pilot study to precede if conducted among friends or family. The results are not included in the final analysis for this research. The participants were selected under the same research criteria – female Somali immigrants without a four-year college degree who reside in St. Cloud, MN. The participants were asked all the questions and the interviews were transcribed and reviewed by the student researcher and chair. Although it was determined that the instrument was successful, one probing question was added to the list of questions in Appendix C. The interview was recorded, and a few re-enforcement notations were written on a notepad. The interview was later transcribed in a word document and pilot participants had the opportunity to review the interview transcript. The added probe question surrounds trust issues between healthcare providers and Somali patients, and this question proved to be valuable and provided a variety of responses from the main study participants.

### **Setting**

I conducted my research interviews via four modalities namely – face-to-face (two interviews while observing social distancing guidelines), Zoom, WebEx, and Face Time. I interviewed 23 Somali born females who live in St. Cloud, MN and have at least received one cervical cancer screening exam also known as a Pap smear test in the United

States. The recruitment advertisement was posted at the Mogadishu grocery store and on Facebook, additionally; participants were referred by word of mouth. Unfortunately, due to Covid-19 shelter in place order, the St. Cloud, MN public library was not a recruitment option. The initial study was designed for the interviews to take place at reserved private library rooms; however, in 2020 the Covid-19 pandemic outbreak mandated social distancing and the interview format was adjusted to teleconferencing. The public library and other public spaces were on lockdowns due to the governor's orders in an attempt to control the pandemic. The two participants who were interviewed face-to-face were met in a large conference room on separate days while sitting more than six feet apart and wearing a face mask (Covid-19 distancing guidelines). A copy of the consent form was emailed to participants, then we met at the Mogadishu grocery store and it was signed a few days before the interview.

### **Demographics**

Participants for this study were female born Somali immigrant women who lived in St. Cloud, MN. These were women who have not earned a four-year college degree and must have had at least one cervical cancer screening in the United States. I interviewed women between the ages of 25 – 45 years. Participants accepted for the study all had health insurance and therefore insurance was not a barrier to accessing cervical cancer screening.

Table 1:

*Participant demographics*

Participants	# Years United States	# Years St. Cloud	# Cervical Screening	Marital Status
Somali 1:	11	8	3	Married
Somali 2:	7	7	2	Married
Somali 3:	15	15	6	Divorced
Somali 4:	17	8	4	Married
Somali 5:	10	5	1	Single
Somali 6:	17	6	3	Divorced
Somali 7:	8	8	2	Married
Somali 8:	27	5	10	Married
Somali 9:	14	9	6	Married
Somali 10:	21	13	8	Married
Somali 11:	13	13	2	Single
Somali 12:	18	6	4	Married
Somali 13:	5	5	1	Single
Somali 14:	11	9	3	Widowed
Somali 15:	14	4	4	Married
Somali 16:	15	11	3	Married
Somali 17:	6	6	1	Single
Somali 18:	4	4	1	Single
Somali 19:	17	17	5	Divorce
Somali 20:	9	7	3	Common-law
Somali 21:	10	10	3	Common-law
Somali 22:	7	7	2	Single
Somali 23:	16	6	3	Widow/Remarried

**Data Collection**

Data collection for this study was completed in 21 days while interviewing a total of 23 participants. More than 30 interested women reached out; however, some of these women did not meet the inclusion criteria. For instance, some were 22 years old, 47 years old, have never had a cervical cancer screening, or did not have health insurance. The interviews lasted averagely 30 – 35 minutes except for one interview that was paused for

20 minutes break and later resumed and therefore lasted a total of an hour. Based on prior knowledge from the Somali culture and inquiring from cultural experts, it was suggested that financial tokens should not be offered. I was advised to sincerely thank people for their participation as they genuinely seek to improve healthcare services in their community and might feel offended if offered financial tokens. I scheduled a time that was convenient for the participants, sent a WebEx or Zoom link to their email and the interview was conducted. Two participants were interviewed face-to-face on different days in a large conference room while sitting more than six feet apart and wearing a face mask (Covid-19 distancing guidelines). All interviews utilized interview protocol outlined approved by Walden IRB, recorded, and transcribed (see Appendix C). At the end of the interviews, I offered all participants an opportunity to review the typed transcripts, and only two participants accepted while 21 declined. They were also offered a future opportunity to review an abbreviated summary finding of this study.

### **Data Analysis**

Participants responded to several questions stemming from three main research questions for this study and the data collected was audio recorded in an approved audio recorder and transcribed verbatim by the interviewer. The tape was played in short intervals, multiple times to ensure accurate transcription, and notepad handwritten recorded notes by the interviewer during the interview was used as a backup measure of checks and balances. I analyzed each question from participants to locate similarities in responses and emerging codes which were later put together to form themes. Here are some of the themes developed for the three main research questions.



Table 2

*Codes and Themes developed from the interview questions*

Codes	Themes
Ability to see a preferred provider	Availability of a female Provider
Schedule with a female doctor	
Want people we who look like us	(Subtheme: Need for more female/diverse healthcare Staff)
Nice to see someone I can relate with and trust	
Cervical cancer screening during pregnancy	Acceptability of Cervical Cancer
Screening	
They hurt me	(Subtheme: Emotional/Physical
discomfort)	
Just don't like it	
It made me bleed	
Uncomfortable	
It was traumatizing	
Will never do a pap smear again	
No co-pay	Affordability of Cervical Cancer
Screening	
Talked to my sister	
Talked to my mother and mother in law	Influence of mentors/Family role
models	
Hospital schedule screening	
I was pregnant	
Limited public media awareness	
ACS guidelines unknown	
Speculum causes cancer	Lack of Awareness
Married and faithful women do not need screening	
Cancer is punishment from Allah	
Cervical cancer screening during pregnancy	
Generational cultural knowledge of cervical cancer prevention	

*(table continues)*

Importance of cervical Cancer Screening Disease pathway understanding Speculum causes cancer Married and faithful women do not need screening	Enhance
Lack of trust between patient and healthcare provider Some doctors don't smile They are always rushing They told me I had no choice and I later found out that was a lie I don't trust them Healthcare providers seem to lack empathy	Lack of trust in healthcare system
Know I can call and schedule an appointment I know if I need a ride the clinic can assist There are free programs to help with payment	Availability of healthcare services
Lesser grip on religion Generational difference in understanding Different interpretation due repeated exposure to information	Importance of religion/faith

### **Evidence of Trustworthiness**

A digital recorder was used during the interview to maintain the credibility of this study. The interviews recorded were then transcribed word verbatim and participants were offered an opportunity to review the transcripts for edits and corrections as needed. As mentioned on the consent form signed, the reports coming out of this study does not share the identities of individual participants, and therefore participants' personal identifying information, such as the names, addresses, or date of birth will not be shared. The study uses code names such as Somali1, Somali2, Somali3, and so forth in place of participant's names. Transcribed data will be kept for at least 5 years, as required by the university, and then destroyed. The research questions had several sub cascading

questions. I also utilized several probing questions during the interviews to obtain clarity and best responses from participants. While transcribing the interviews, the audio recording was played multiple times for accuracy and once completed; the process was repeated at least twice.

A complete research protocol was furnished to Walden University during the IRB application. To ensure this study's transferability, the following is a complete overview with sections that include methodology, data collection, setting, demographic, and results. This study is a phenomenological qualitative research study that looked into understanding the lived experiences of female Somali Immigrants as it related to cervical cancer screening. The study transferability clearly defined inclusive criteria such as geographic location (St. Cloud, MN), the age range of participants (25-45 years), and level of education (noncollege graduate). The dependability of this study was established by continuing a spontaneous nature of journaling of all participants' body language and observable activities during the interviews. While the audio recorder captured the conversations, I was journaling and noting participants' nonverbal communication and body clues. These nonverbal clues were later added into transcribed interviews and provided a vivid understanding of some participants' emotions. Finally, I achieved confirmability in this qualitative study by sticking to the audio recording of the interview and carefully transcribing from the audio and notes taken during the interview.

## **Results**

After interviewing 23 participants for this study, each interview was transcribed, and color highlights were used during the coding phase. These codes were; Ability to see

a provider, Cervical cancer screening during pregnancy, Talked to my sister, Talked to my mother or mother in law, Hospital schedule screening, I was pregnant, Schedule with female doctor, Want people who look like me, They hurt me, Just don't like it, Uncomfortable, Speculum causes cancer, and Cancer is punishment from Allah. These codes were later analyzed to develop themes such as Accessibility to Provider, Accessibility to screening, influence of mentors, Family role models, Emotional and Physical discomfort, Lack of Awareness, Enhance understanding, Lack of trust in the Healthcare System and Importance of religious belief (see Table 2).

**RQ1: What are the lived experiences of Somali immigrant women without a four-year college degree accessing cervical cancer screening? (e.g., availability, accommodation, affordability, and accessibility).**

The themes of Availability of a Female Provider, Acceptability of Cervical Cancer Screening, and Affordability of Cervical Cancer Screening were the themes that arose from the data analysis to answer Research Question 1. Participants described the lack of female healthcare providers, the time they had to wait to obtain an appointment if they insisted on being attended to by a female, that they only received cervical cancer screening when they were pregnant as some of the issues with availability and accessibility of providers to services. However, participants also noted that they were able to obtain rides to appointments, to schedule an appointment, and to receive free services if they needed them, which were all positive aspects of accessibility and availability.

**Availability of female providers.** The availability of the provider relates to the demand of the participants to see a female provider and the lack of supply of female providers. Availability to see a female provider was said to result in a slightly longer waiting period, such as four weeks, but participants felt comfortable waiting. Somali12 expressed being ok with waiting for “about 3 weeks” to see a female provider. All participants had past experiences of waiting longer to see a female provider and typically the range was 2 - 4 weeks except Somali5 whose response was unique, and she waited for 3 months to see a female provider, but it was possibly due to a medical condition. Somali2 said, “I could always get an appointment, even on the same day sometimes but the problem was I wanted a female provider. The clinic had only two female providers and it took a long time to see her. Appointments were out 2-8 weeks to see a female provider.” Somali16 mentioned that what was most important to her was “having access to a provider and information about cervical cancer screening and other healthcare needs.” Somali4 who initially said, “I was able to get an appointment anywhere between within two weeks to a month depending on if I was willing to see a male doctor or far out if I wanted to wait for a female doctor” while discussing accessibility to screening, after reviewing the ACS screening guideline had this to say, “it will be a lot easier if they had more female doctors available, Somali women don’t like seeing men doctors for Pap smear.” Somali13 said, “my problem is the fact that I need a female doctor and someone who looks like me once in a while to explain what they are doing but there is nobody like that, sadly.”

**Subtheme: Need for more female/diverse healthcare staff.** – It isn't just female providers that the participants were looking for; it was more female and more diverse healthcare staff in general. Participant Somali10 stated during her interview,

I wish they had more diverse staff, I mean like the doctors and the nurse once in a while. I would like to go to the doctor and see people who look like me and who are not pressuring me to do stuff. Most often I get a female doctor but sometimes, I don't want to go through all the wait, and I book with a male doctor. I will say I had at least two screening with a male provider.

Somali23 said, "I had a Somali nurse, and it is always nice to see someone I can relate with and trust." These all indicate the need for more female/diverse healthcare staff.

**Acceptability of Cervical Cancer Screening: Emotional/physical discomfort.**

Acceptability relates to the services being good, or acceptable to those who received them. The data analysis revealed that all participants agreed that cervical cancer screenings are "uncomfortable", some used the words "I don't like them." While discussing her experience Somali7 said,

I would say my first experience was extremely invasive and painful and I literally cried and was in pain for several days after the exam. The second exam was better, and I had a different provider. A pap smear is still not something I look forward to doing but my doctor say I have to do it.

Somali5's description of her experience was a unique and stood out from the other participant's descriptions as being very traumatic. Somali5 said,

Frankly for some of us it is very painful. My doctor said I have a condition called ‘Vaginismus’ where my pelvic floor lies too close and the speculum makes it hurt. I am telling you, I will never do a pap smear again, that was the worst pain I ever experienced in my life. Many don’t understand, and they thought they knew too much and kept hurting me until one doctor figured it out. They just don’t care. I will never get Pap smear again”.

Somali23 was another participant who expressed her emotional and physical discomfort by saying, “I just don’t like doing the cervical exam, it is very painful, and it left me bleeding for a few days after. I was very scared that something bad may have happened inside me. I don’t think I will be doing one anytime soon.” Interestingly, Somali8 recounted how her negative experience evolved into a better one as follows

When I started getting cervical screening exam done, it was traumatizing and very uncomfortable. I believe it was on my third one, I had a great doctor who taught me how to relax my body and breathe and it’s been better tolerated since then. I have had a minimum of 10 screenings, I don’t enjoy doing it but it’s bearable.

**Acceptability to cervical cancer screening.** This theme was developed from listening to participants and analyzing the data related to different needs or challenges to obtaining screening due to location, distance, and ability to make appointments. Somali5 said, “I don’t like doing screening, but I have the ability to get cancer screening done like a physical or to schedule a doctor visit.” While participant Somali3 responded that access to screening means, “I think you need insurance and a doctor that you like”. Participant Somali5 had an outlier response when it came to availability and accommodation, she

stated, “Probably 3 months because I needed a special surgery. They said, I needed a pap smear while i was getting ‘de-infibulation (reversal of female genital mutilation)’, so they did surgery. The surgery was schedule in December and the Pap was done in October.”

The interviews also showed several opportunities of scheduling screening appointments quickly including same day and within 1-3 days. Somali16, Somali19 and Somali23 all had “same day Pap screening” which was offered to them while at the clinic for a different concern and they agreed. Location and transportation to the appointment was noted to be a limiting factor by some participants in the accessibility to cervical cancer screening. Somali1 stated, “I didn’t have trouble getting an appointment [for screening]. The trip to the clinic was not too far, I will say about 15-20 minutes although it always seems longer because I have to find parking.” Somali7 stated, “It took like a month to schedule an appointment [for screening] because I persisted on a female doctor. My sister in law took me once and my husband took me the other time.” Participant Somali20 said,

I know if I need a ride the clinic can assist me with scheduling a ride. The problem is my medical ride always comes late or they don’t come. On a few occasions, they didn’t come but lied that I was not home. This caused me to miss my appointment and it takes a long time to get a female provider or I simply give up and not reschedule it.

Somali22 said, “I stopped using a particular ride company because the driver was very rude and verbally insulted me at least on two different trips. I complained and nothing was done, and I ask my friends and family for a ride back then, now I have a car and I drive myself.” Needing an interpreter for their appointment presented challenges to



obtaining their cervical cancer screening services. Somali22 highlighted the interpreter challenge when she said,

I will ask for a female interpreter back when my English was not good, and they will send me a male interpreter. I don't care where he stands in the room; I cannot do a cervical screening exam with a male in the room who is not my husband.

**Affordability of cervical cancer screening.** This theme emerged in the data analysis as all participants had healthcare insurance and therefore agreed that the cervical cancer screening was available to everyone interviewed. All participants had health insurance and therefore affordability was not an issue as can be seen with the results. All participants had \$0 co-pay during cervical cancer screening although Somali8 added, "One time I didn't have insurance and I had to pay \$30 co-pay." Participant Somali11 stated, "I know I can call and schedule an appointment they tell me when I am at the clinic, but I don't like doing it." Participants were largely aware of cervical cancer screening services and other subsidiary services to assist such as assistance programs with co-payments as stated by Somali8 who went on to say, "after paying \$30 co-pay that one time to get a Pap smear, I was later told by another nurse that there is a state funded program call SAGE that could have paid for my screening."

**RQ2: How does awareness of services impact cervical cancer screening among Somali immigrant women without a four-year college degree?**

Themes such as the lack of awareness, enhance understanding, and lack of trust in healthcare system were the themes that arose from the data analysis to answer Research Question 2. Participants' responses described a lack of awareness in understanding the

full importance of cervical cancer screening as well as in understanding the causes of cervical cancer. Lack of awareness was apparent in limited understanding of ACS recommendations and guidelines on cervical screening. An enhancement in the understanding of the participants regarding the importance of screening as well as disease pathway is needed as reflected by the interviews. Throughout the interviews, trust between patients, the providers or healthcare systems seemed to be a crucial missing element. However, a few participants were willing to improve on their future screening after becoming aware of the ACS guideline which was a positive aspect of awareness.

**Lack of awareness.** From the data analysis it was clear that all participants understood what cervical cancer screening was and why it was done. Somali8 described cervical cancer screening as “It is a test that screen for cervical or vaginal cancer in women who are sexually active.” Somali15 said, “It is a test to check your cervix or your reproductive part so that there is no cancer.” This question explored awareness through public service campaign advertisements and only four participants admitted this modality of awareness having an impact on increasing their cervical cancer screening. Somali5 said, “I have seen many cervical cancer screening advertisements on TV, but I can’t remember names of the programs that aired them.” Most of the participants agreed that screening is important however, they defined it as being important when you are pregnant with examples such as, Somali1 said, “I don’t know. I think you are supposed to get pap smear ever year, but I do it only when I am pregnant”. Somali6 also responded that, “it is important when I am pregnant or when a woman is pregnant”, and Somali7 echoed the same theme, “I do it because my doctor says I need it for the baby.” When the ACS

guidelines were reviewed with Somali1, her response was “Oh, well, I can’t keep track and I prefer to do it only if I have too, such as when pregnant. I think if you do it too many times, they will start telling you, you have cancer, or something is wrong”. On the other hand, Somali4 said, “Yes, I do follow the recommended guidelines especially with a history of abnormal Pap smear. I am always scared, and I take screening seriously.” Although all participants understood that cervical cancer screening was to detect cell abnormalities in the cervix, providing awareness through public campaigns, advertisements, or simply more information about routine screening from ACS was not sufficient to increase participants’ future cervical cancer screening compliance. When participants were given the ACS cervical cancer screening guideline recommendation according to their ages and asked if this will affect their future screening habits, 5 participants said they might improve on their screening, Somali21, when she read the ACS guideline on cervical cancer screening said, “knowing this guideline will help me understand when to get the screening done in the future.” Somali3 said, “I will continue to follow the recommended ACS guidelines” while Somali13 and Somali21 both responded, “I will do my best to improve”. Fifteen participants were not sure they would change their screening habits based on having read the ACS guidelines, and 3 participants stated adamantly that they will never have a cervical cancer screening again.

**Enhance understanding.** An enhancement of understanding of the benefits of cervical cancer screening will be beneficial as responses such as from Somali21 demonstrate, “my mother in law and other older women in my family said, if you are married and faithful, you do not need to do the screening. I was told the cancer does not

go to good wives and if I must do it, I should only if I am pregnant.” On the other hand, Somali22 said,

Well, I think if you do too many screening especially if you are not marry and you let them put that thing inside you (you know – that metal thing), Allah will get mad at you and might punish you with cancer, (that thing referring to speculum). That is why I do not think I want to follow the ACS guideline you are showing me.

An enhanced understanding to include the disease pathway could be important in creating awareness and increasing cervical cancer screening participation.

**Lack of trust in healthcare system.** The theme of lack of trust in the healthcare system was echoed by participants firmly through examples such as, Somali1 said, “I think the main cultural difference between my Somali culture and U.S. culture when it comes to healthcare practice is the fact that, Americans like too many testing and screenings. Somali culture, we go to the doctor only when needed. Americans look for reasons to take medication, we don’t do that.” Later on, while probing Somali1, she added,

I love America, but I don’t trust them much. They did horrible things in Somalia and in Africa and it’s hard to accept everything they say. In my religion, I believe Allah takes care of me and if I am not sick, there is no need to go doing all these regular screening. In the past like in Somalia we didn’t know. Now I feel like I really can’t trust what Americans say about this screening. I chose to let Allah take care of me.

Participant Somali7 said, “I have not seen a provider I can trust, and they always seem to be rushing and don’t even smile with me. I feel like they don’t care about me and they want to get to their next patient fast.” Somali18 who has performed only one screening said,

Some healthcare providers seem to lack empathy and I can tell when they are performing the procedure. I have had only one cervical screening and it did not go well. I kept telling the provider I was in pain and she ignored me till she was finished. How do you expect me to trust someone like that? Maybe they are all like that? I might go back but not at this moment.

**RQ3: What is the role of acculturation in the experiences of Somali immigrant women without a four-year college degree in obtaining cervical cancer screening?**

The themes of Influence of mentors/family role models, and Importance of religion/faith emerged after analyzing the data to answer Research Question 3. Influence of mentors/family described that third-party individuals’ participants were more influential in their decisions when it came to cervical cancer screening. Participants described having conversations with trusted community or family members to guide them better than their professional healthcare providers/healthcare system’s guidelines such as the ACS screening recommendation when it came to deciding on cervical cancer screening. The data analysis also revealed a generational difference in how participants interpreted the Koran or religious guidelines. Religion/faith was shown to be an important part of the participants’ lives and the analysis of this question was able to indicate how much influence religion/faith exerts on cervical cancer screening decisions.

Further data analysis showed a relationship between acculturation and the experiences of Somali immigrant women without a four-year college degree. The participants who have completed the highest numbers of cervical cancer screenings happened to have lived in the United States for an average of 21 years. Participant Somali3 completed 6 screenings (lived in the United States for 15 years), Somali8 completed 10 screenings (lived in the United States for 27 years), and Somali10 completed 8 screenings (lived in the United States for 21 years). On the other hand, there were also participants like Somali6 who have completed only 3 screenings (lived in the United States for 17 years), and Somali23 completed 3 screenings (lived in the United States for 16 years). The results also indicated that marital status has a relationship with screening whereby the married women were more likely to be screened than the single women. During the interview, it was noted that the women who commented birthing many children, received more screening which goes back to some of the participants' self-redefined terms of screening "only when you are pregnant."

**Influence of mentors/family role models.** Participant Somali9 was a few of those happy to have developed a rapport with her provider, she said, "I am very comfortable with my gynecologist, he birth all 3 of my children and if he tells me I need a pap smear screening, I believe him and I get it done." Somali8 had a role model/mentor she referred to as "American godmother" and said, "When I was younger, maybe I had two conversations with my mom and my "American godmother." I call her that because she orientated me into American society upon arriving. She was very helpful, a lot of people from my country were not that lucky. Every time I did not understand something,

I will call her and ask her.” Participant Somali13 described, “My doctor influences some of my decisions when it comes to getting a cervical cancer screening and I do schedule whenever possible.” Somali17 said, “When it comes to cervical cancer screening and other things that I did not know back in Somalia, I look up to my American mentor friend. She is like a sister and I have known her for a longtime and I do what she does and that is my rule.” An influential aspect of acculturation was family members, for example, Somali10 who has completed 8 screening of cervical cancer screening said,

My mother in law is a physician and has been very educative to my understanding. I do not have frequent communications with my mother, but I have educated my mother and my two sisters, and they do get some degree of screening. I am not sure as regular as I do but, they tell me they do (married to a non-Muslim American).

The influence of family member was expressed by Somali1 when she said, “they told me to do it only when pregnant. They have birth children before me and therefore they are my role models and I take them very seriously,” when referring to her mother, her aunts, and elder sisters. Cervical cancer screening information is passed on via mentors such as role models, mothers and mother in laws and this was reflected in Somali2 stating, “my mom said if you are not pregnant you don’t need it,” while Somali19 said, “my mother in law said if you are a good wife (faithful) you don’t need it.” Somali21 also echoed similar family role model influence when she said, “my mother in law and other older women in my family said, if you are married and faithful, you do not need to do the screening. I was told the cancer does not go to good wives and if I must do it, I should

only if I am pregnant.” Somali23 said, “my sister is the healthcare family cop, she always calls everyone to remind them to get a complete physical schedule including things like cervical cancer screening, cholesterol check. Well, I do get the physical but not the cancer screening regularly.”

**Importance of religion/faith.** After completing an interview of 23 Somali women, 17 participants identified as Muslim practicing Islam, 5 participants identified as Muslim but non-practicing Islam, and one participant identified as Christian (converted by choice after she married a Christian). The participants’ religion and faith were clear themes in the data analysis. Participant Somali1 said, “I would say I am Muslim but some in my community will dispute that because I practice an evolved kind of Islam. I am opposed to certain things and I practice others.” Somali3 stated, “Older women reject testing, but I am a younger generation and I want to know stuff and take care of my body. The older women believe Allah will take care of you, but I don’t sit there and just wait for Allah to do that.” Somali7 said, “I am Muslim, and my religion does influence some medical practices. Most of my generation, we understand western medicine and decide to do preventive screening. We also believe Allah will take care of us, but we do cervical screenings.” Somali7 later added “some older women say they trust Allah to take care of them and that some American doctors create problems to fix and get money from insurance companies and therefore they refuse to screen for most cancers.” Somali8, “I identify as Muslim, but I am not a practicing Muslim, maybe that is why I do my own thing or whatever makes sense to me when it comes to my health. My religion has lesser grip on my health decision, and I believe that is true with many younger Somali women.”



Somali<sup>17</sup> lamented, “I have quite a few American friends and I believe my mom was right when she said, they will turn me against the Koran. I find myself, the more exposed I am to western friends my interpretation of the Koran is different from my mom’s version.”

### **Summary**

In this chapter, interviews of 23 Somali women were completed. The research criteria focused on Somali-born females ages 25 - 45 years old who did not have a four-year college degree and their experiences related to cervical cancer screening in St. Cloud, Minnesota (MN). After completing the interviews, it was transcribed, and the data analyzed. In chapter four, I reported on the findings of the data from the interviews. An investigation utilized three research questions and investigated access, awareness, and acculturation. Base on the interviews, data collected, and analyzed, the study did not show that increase access and awareness would result in an increase in screening. For instance, all participants had health insurance and were able to schedule a physician appointment within 2 – 4 weeks. All participants understood what cervical cancer screening was and when the ACS screening guideline was provided and explained to participants, it had little impact on increasing future desire to screen. On the other hand, the study showed that several participants felt comfortable receiving advice from family members such as sisters or mothers. Family members are looked upon as a trusted source of information and once one person in the family acquires the needed education, then they can influence their family and their circle to receive screening. The top three participants who had the highest screening also had the furthest number of years of

college but did not obtain their bachelor's degree. Therefore, the women who had more years of college education were more likely to screen for cervical cancer than the other women.

Finally, in chapter 5, I will cover in detail the interpretations of the findings, limitations of the study, recommendations, implications, and conclusion.

## Chapter 5: Discussion, Conclusions, and Recommendations

### **Introduction**

Cervical cancer screening is an important step in detecting abnormal cervical cells that could potentially cause cervical cancer when left untreated. The purpose of this research was to understand the lived experiences of Somali immigrant women ages 25 - 45 years who did not have a four-year college degree with obtaining cervical cancer screening services in St. Cloud, MN. Prior studies conducted in the Somali community of St. Cloud, MN included only women who were college graduates obtaining cervical cancer screening. This research also probed to understand why cervical cancer screening rates was lower among this selected demography of Somali women (Samuel et al. 2009). The research also attempted to understand if barriers to cervical screening in this group was similar to those of Ghebre et al. (2015) study that focused on Somali college graduates. The participants related their lived experiences in obtaining cervical cancer screenings and identified some barriers/hindrances to getting regular cervical cancer screenings. The Somali women who participated in this study freely and willingly discussed concerns and some of them offered suggestions that could potentially increase cervical cancer screening in the future in this population. Key findings from this study which interviewed 23 Somali females revealed several themes such as: (a) Accessibility to Provider: (b) Accessibility to Screening, (c) Influence of Mentors/Family Role Models, (d) Emotional and Physical discomfort, (e) Lack of Awareness, (f) Enhance Understanding, (g) Lack of Trust in the Healthcare System and (h) Importance of Religious Beliefs.

## **Interpretation of Findings**

There were several themes that emerged throughout the study and the interpretation of the findings of the research are based on the literature reviewed in Chapter 2, as well as the constructs of Panchansky and Thomas's theory of access (Saurman, 2015) and the Leininger's culture care model (2005) framework used to conduct the study.

### **Accessibility to Provider**

Accessibility to provider echoed the need for female providers to carry out cervical cancer screening as well as a need for diverse staff. Participants agreed that there were longer wait times to see a female provider. Participants felt more comfortable having a cervical cancer screening performed by a female provider than a male provider and some participants expressed a desire to have diverse racial and ethnic representation. Akinyemiju et al. (2015) used Panchansky and Thomas's theory of access in a South African study on cervical cancer screening and the findings showed that 1 in 4 women (25.3%, n = 65) who visited the health care center or facility within 12 months admitted to having cervical cancer screening (Akinyemiju et al., 2015). The patients who saw a medical doctor (73.1%) compared to a midwife or nurse (45.9%) had better screening rates. The availability and accessibility of medical doctors was an essential component of access to care and cervical cancer screening (Akinyemiju et al., 2015). In the study of Somali women without a four-year degree and understanding their lived experiences to cervical cancer screening, the findings confirmed the Akinyemiju et al., (2015) research that there is a need for more medical doctors or providers. Somali women expressed not only a need for doctors, but they would like an increase in access to female providers and

would like to see racial and ethnic diversity represented. Most participants believed some diversity in staff representation will increase trust. Participants mentioned requesting a female interpreter and being schedule with a male. The study responses from participants confirmed Odunukan et al. (2015) who concluded that Somali women prefer female providers and also prefer female interpreters for their gynecological examinations such as cervical cancer screening after studying fifty Somali women and their primary care providers.

### **Lack of Awareness**

Further data analysis of the interview and the themes showed that an improvement in Information Awareness will increase accurate knowledge in topics such as the importance of cervical cancer screening, and what causes cervical cancer will help dispel some common myths such as speculum causes cancer. An increase in accurate knowledge might increase the participants' motivation to adhere to the ACS guidelines and will help role model/family members to relate accurate information. Participants stated that the concept of cervical cancer screening was new to them. This confirms Qayad (2008) who indicated that the concept of preventive care is a new concept where in Somalia there was no preventive health practiced (Qayad, 2008). Findings from this research will enlighten the medical community of St. Cloud, MN, and beyond by allowing the healthcare community to see and understand the lived experiences of Somali women with cervical cancer screening. This will serve as feedback to healthcare services and how to improve those services in other to gain the trust of Somali women and increase future screening. Ackerson (2008) published that a lack of education among

African American women concerning the importance of routine screenings was a factor resulting in the low screening rate (Ackerson, 2008). This was demonstrated in this study as shown by two of the themes “lack of awareness” and “enhance understanding.”

Participants had the basic knowledge of what a cervical cancer screening was but showed a lack of awareness or lack of knowledge in understanding why it was important to screen regularly under the ACS guidelines. Participants also expressed inaccuracies when it came to an interpretation of what causes cervical cancer.

### **Enhance Understanding**

All participants received at least one cervical cancer screening in the United States and therefore they had lived experiences. They all expressed a basic understanding of what cervical cancer screening was; however, participants were not well advised/informed as to why it was important to keep a regular screening schedule. An analysis of collected data from the interview revealed that all participants understood why screening was necessary, but half of the participants had redefined when screening was important. A few examples expressed by participants was that they ‘get cervical cancer screening when I am pregnant’, and that ‘it’s important so that you can have healthy babies’. All participants affirmed in their understanding of cervical cancer screening that it was a screening test that “made sure you don’t have cancer.” Although they echoed proper knowledge of cervical cancer screening, the rate of screening continued to be low since some of the participants had wrongfully convinced themselves that “Allah” will protect them, good/faithful wives do not need to get routine screening and you need a cervical cancer screening only when you are pregnant. These expressed practices which

resulted in low and irregular screening confirm Ghebre et al. (2015) that cervical cancer has remained the second most common type of cancer among females of East African descent including Somali women and results in a high level of mortality. Collins et al. (2014) also pointed out that cervical cancer is a preventable disease although 275,000 women die annually worldwide from the disease, and nearly 90% of deaths occur in developing countries. Unfortunately, there are nearly 530,000 newly diagnosed cervical cancer cases each year across the world (Collins et al., 2014).

### **Emotional and Physical discomfort**

Participants in this study recounted lived experiences including; physical discomfort such as pain and emotional discomfort and some anxieties as well as one participant said her lived experience left her feeling traumatized. Although most participants had far less than the recommended numbers of screening, all participants were aware of why they needed cervical cancer screenings. All participants except one had more than one screening and this indicates that they did not let one bad or uncomfortable experience prevent them from going back at the next follow-up or routine exams. This finding was however underscored by the fact that three participants swore they will never perform a cervical cancer screening due to repeated negative lived experience. Two out of the three were currently practicing abstinence and therefore are not sexually active and they planned on maintaining that status for the time being.

### **Accessibility to Screening**

Data analysis from this study showed a variety of factors hindering accessibility to screening. Accessibility to screening was affected by a need for transportation to

obtain screening, lack of awareness regarding the importance of a routine screening, lack of female provider and distrust between the healthcare system/providers and the participants. However, a review of the WHO (2017) showed different factors that affected accessibility to cervical cancer screening in Africa (Somalia). WHO (2017) indicated that cervical cancer accounted for 22% of female cancer diagnoses in Africa. This puts the Africa burden at “34 out of every 100,000 women diagnosed with cervical cancer while 23 out of every 100,000 women die from cervical cancer every year” (WHO, 2017). The WHO’s approach to this issue of cervical cancer in Africa has been by promoting routine cervical cancer screening. Despite such efforts, the rate of screening has stayed unchanged or even decreased. My interview provided an extension to this WHO article, participants who immigrated while of age to obtain a cervical cancer screening in Somali all voiced the fact that screening was not a priority and it was important to survive. Several participants said they did not know what a cervical cancer screening was back in Somalia and they rarely went to a hospital as it was several hours away. It is important to note that participants also confirmed that preventive medicine is a foreign concept, and it was important to think of how to get out alive and where their next meal will come from and not cervical cancer screening. Participants confirmed Qayad (2008) that the concept of preventive care is a new concept contrary to the concept in Somalia where there was no preventive health. This finding is a possible enlightenment to the WHO article, the finding shows why the rate of screening in Africa has not improved. It also showed that Somalis like every human need conformed to “the physiological need and safety need” (Maslow, 1954). The physiological need was identified as food, water,



warmth, and rest while safety involved security needs for food and shelter. Tay and Diener (2011) researched Maslow's needs hierarchy established that physiological and safety needs are also known as basic needs. These are the needs that must be met before a human being can move on to satisfy other needs of the Maslow hierarchy pyramid. Throughout my interview, participants repeatedly said that cervical cancer screening was not a priority back in Somalia rather the basic needs were food, shelter, and safety. Until the WHO figures a way to satisfy the basic needs of women in Africa, the rate of cervical cancer screening might never improve.

All 23 participants in this study had insurance and therefore disconfirmed one aspect of Kangmennaang et al. (2018) when he wrote that among other reasons contributing to disparities in cervical cancer screening was lack of health insurance creating an inability to pay for needed screening, lack of gender equity programs, educational level influencing understanding, and cultural impact (Kangmennaang et al., 2018). My research did not find a lack of insurance among Somali women in St. Cloud, MN to account for low screening rates although the other reasons for lack of gender equity programs, educational level influencing understanding, and cultural impact were confirmed by participants' responses. Participants were aware of free screening or discounted programs that will cover screening services if they did not have insurance and this did not affect their willingness to comply with healthcare guidelines.

### **Influence of Mentors/Family Role Models**

Ghebre et al. (2015) in the Somali study with graduate women in St. Cloud, MN maintained the importance of shared family decision making within the Somali

community. An analysis of the responses in this study confirm family/mentor role in influencing the decision to obtain cervical cancer screening. Multiple participants mentioned asking their mother or a role model within the community if they should complete a cervical cancer screening as requested by their provider. A number of participants also mentioned that they were walking away from practices of family deciding their healthcare needs. These participants admitted that family and role models within the Somali community had played an important role in deciding their cervical cancer screening in the past but not as much now.

### **Importance of Religious Beliefs**

Kangmennaang et al. (2018) studied reasons contributing to disparities in cervical cancer screening and summed them as lack of health insurance, lack of gender equity programs, educational level influencing understanding, and cultural impact. In my interview of 23 Somali women, Kangmennaang et al. was partially confirmed as participants regularly referred to the cultural impact and religion. The Somali religion of Islam and culture intertwine and exert a strong hold to their degree of comfortability when it comes to cervical cancer screening. For instance, the Koran (bible) forbids undressing or being naked in front of a man who is not your husband. Participants mothers, mothers-in-law, and husbands who assist in decision making turn to discourage cervical cancer screening and re-define the screening guideline to be that screening is necessary only when a woman is pregnant though this inaccurate.

Participants' expressed the need to have diversity aligned with Leininger's cultural care model. Leininger (2015) was the second framework chosen to serve as part

of the conceptual framework for this study. Leininger's model looked at diversity in communities, clinics, and hospitals and the health needs of patients from different cultures (Leininger, 2015). Acculturation was one of the influencers used to support the framework for this study. The interview of 23 participants revealed a reliance on a family member and mentor rather than the participants' healthcare provider when it came to decisions on when to obtain cervical cancer screening and how often. The data collected and analyzed from my interview with Somali women confirms Leininger (2005) definition of acculturation as the degree to which an immigrant is traditionally or is non-traditionally attached to their culture, or the values and the general lifestyle of their new home. Another peer-reviewed literature that was confirmed and echoed multiple times throughout the interview by participants was Steefel (2018) who used Leininger's theory of cultural care in a cultural humility study to show its importance in nursing and healthcare. The study identified three areas of healthcare; "patient's culture, make accommodations for it, and/or repattern cultural ways that may be unhealthful" (Steefel, 2018). One of the findings confirmed that cultural humility may not always be visible, but without incorporating cultural humility in nursing and healthcare, there will be a deficit or no care. Participants stated that they felt their provider lacked empathy, did not care about them, and that they felt rushed. Two participants recounted that they had requested a female provider but ended up being scheduled with a male provider. Culturally and religiously, these participants did not feel comfortable undressing or being naked for a male provider. Incorporating cultural humility is an important part of showing respect for a patient and might improve future screening.

### **Limitations of the Study**

I interviewed 23 Somali women, although saturation was attained, the study carries a limitation in transferability. Trochim (2006) stated that the degree of transferability in a qualitative study can be hindered by the setting and therefore the results of one study should not be used as a generalizing tool across the world (Trochim, 2006). The report from this study is based on the lived experiences of 23 Somali women and the study was conducted in the city of St. Cloud, MN. This study could be generalized in the city of St. Cloud, MN among Somali women who fit the demography to enhance cervical cancer screening; however, this study should not be used to generalize all Somali women in other geographical regions of the United States or of the world.

This research was conducted in 2020 and the governor had sheltered in place order due to COVID-19. The shelter in place order generated a few limitations to this study. A major limitation was my inability to conduct a face-to-face interview for 21 out of the 23 participants. The IRB had considered this possibility and had me revise my application to include virtual interviews if needed before approving it. Two interviews were conducted face-to-face in a large conference room while observing COVID-19 precautions recommended by the CDC. Another limitation was the scheduling of Zoom and WebEx appointments due to participants' busy schedules and anxiety over rising COVID-19 cases in the community. It was challenging trying to synchronize our schedules for the interviews; luckily my schedule was very flexible enough to accommodate the participants' schedule. Once the interviews were scheduled, a

limitation arose in getting the consent forms signed and returned. The consent forms needed to be signed, scanned, and attached in an email back to me; however, none of the participants had a scanner, additionally, some participants had limited knowledge on completing an attachment. I decided to meet participants at the Mogadishu grocery store which is the same location I used to recruit participants. Once the consent form was signed, no other limitations were encountered. However, notwithstanding these mentioned limitations the results of this study and the lived experiences of these 23 participants provided an understanding of their experiences with cervical cancer screening.

### **Recommendations**

Future studies in this community should include women who need interpreters for an office visit. A future qualitative study on Somali women who do not have a four-year degree should include both women who are proficient in English as well as women who need interpreter services to better communicate. Future research should be conducted in another geographical location such as in Minneapolis, MN where there is an equally high population of Somali immigrants, and the results compared to St. Cloud, MN. The findings from this study revealed experiences that healthcare providers lacked empathy and also showed a lack of cultural sensitivity. For instance, when a patient requests a female provider and their appointment is scheduled with a male provider. This contributes to a lack of trust and accounts for low screening rates in cervical cancer. I recommend that future study should look at a group of patients' perceptions and experiences who recently received cervical cancer screening within the last three years

and another group should look at the perception of the healthcare providers. This would compare the patient's perception to the perception of the healthcare providers and the discrepancy in perception might be beneficial in developing a measure to impact future screening.

### **Implications**

The implications for potential positive change that stem from this study are changes that will impact the patient and the healthcare system. Somali immigrant women without a four-year degree could receive the needed evidence-based recommendation from the ACS and this will increase the accuracy of the information within the community. Awareness of information on cervical cancer could alter the behavior of Somali immigrant women and enhance their compliance in obtaining cervical cancer screening. An increase in cervical cancer screening could lead to early detection of abnormal cells and at the early stages of the abnormal cervical cell, there are proven medical interventions guided by the ACS that can prevent the development of cervical cancer (ACS, 2012). The implication to the patients will allow them to guide fellow family members since this is a community that relies on family shared decision making, as illustrated in this study.

The positive social implication for healthcare systems and providers regarding improving relationships with patients. The participants of this study had recommendations that might improve the relationship between patients and providers. These recommendations included increasing the number of female providers and the diversity of the staff. The healthcare system could benefit from using the

recommendations in this study to boost trust with immigrant Somali women by implementing these measures.

The study indicated that a lack of educational awareness, service awareness, a lack of trust between the patients and providers, and cultural/religious influences were all possible reasons for the irregular cervical screening practices. Ackerson (2008) demonstrated that a lack of incentives, patients' culture, and emotions are aspects affecting cervical cancer screening rates. These findings influencing cervical cancer screening are supported by the Penchansky and Thomas theory of access which was the first framework used in this study. Awareness of accurate educational material on cervical cancer can be enhanced by utilizing the places of worship such as mosques around St. Cloud and healthcare providers could take the awareness message to heavily dense regions of the city. Organizing information awareness in dense parts of St. Cloud will minimize the need for transportation and will go a long way in improving the trust relationship between the providers and their patients which could translate into a higher rate of cervical cancer screening. Improving cervical cancer screening would require improving accessibility to services such as providing accurate education and the most important aspects are providing access and availability to female providers to conduct cervical cancer screening.

Cervical cancer is a preventable disease and the most effective means for prevention is through routine cervical cancer screening (Ghebre et al., 2015). The high rate of cervical cancer diagnosis among women of East African descent including Somali women can be prevented by providing accurate information through awareness (Akinyemiju et al.,

2015). There currently exists a low rate of cervical cancer screening among Somali women according to studies by Morrison et al. which stated that, ‘cervical cancer screening prevalence and adherence among Somali women was below the state and national goals.’ The rate of cervical cancer screening is even lower among Somali immigrants who do not have a four-year college degree per the analysis of the data collected from the 23 participants from my study. This low screening rate can be boosted if healthcare systems will increase the availability of female providers and increase diversity in staffing to foster trust, as shown through this research. This research demonstrated that improving trust between the patients and the healthcare system or providers will lead to a rapport and the patient might implement the ACS guidelines readily. Ackerson (2011) explained that some women were reluctant to obtain cervical cancer screening when performed by a male provider and felt it would be more painful. This was partially confirmed in this study as a lack of empathy from some providers was verbalized by a few participants. It is recommended that more teaching or awareness materials such as flyers, brochures, and/or pamphlets should carry visuals of Somali women to foster relatability. The participants wanted to see a diverse staff as well as a representation of themselves in materials about cervical cancer screening. Awareness of virtual material that carries pictures of Somali women might come close to satisfying the need of having representation in healthcare educational material.



## Conclusion

The lived experiences of cervical cancer screening among Somali immigrant females who have not earned a four-year college degree appear to influence their willingness in completing a routine screening. Although participants demonstrated an understanding of what cervical cancer screening was; unfortunately, this understanding was not enough to encourage a regular screening. Participants overwhelmingly expressed a preference for having a female provider perform the cervical cancer screening because they felt more comfortable than having a male provider. The desire for a female provider was a personal preference, a cultural preference, and a religious preference. All participants except one had more than one cervical cancer screening in the United States although not performed at a routine schedule as recommended by the ACS guideline. Therefore, the expressed discomfort did not prevent them from returning for cervical cancer screening; unfortunately, it did affect how frequently they returned for screening. Cancer Prevention Research Institute of Texas (CPRIT, 2011) reported that diagnosis of cervical cancer happens most frequently in women who do not return for a routine of cervical cancer screening. The women who follow the ACS's recommendation on screening rarely progress to a diagnosis of cervical cancer (CPRIT, 2011). Sadly, the highest number of women who do not maintain a routine schedule is the immigrant population (CPRIT, 2011). In conclusion, taking measures to increase trust between the patients and their provider, creating awareness regarding the importance of routine cervical cancer screening will augment screening in the Somali population of St. Cloud, MN.

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### **Appendix A: Screening Questionnaire**

Thank you for agreeing to answer the questions on this questionnaire. The answers to these questions will be used to assist in assuring you meet the study criteria. Your answers will be strictly confidential. Your name will not be written on the questionnaire and no one else except me will have access to this information. Please read the question carefully and mark an X in the box next to the appropriate answer.

1. How old are you? \_\_\_\_\_
2. What is your marital status?     Single    Married    Common-law relationship  
 Divorced    Widowed
3. What is your highest level of educational attainment?    Primary school    High school  
 Some College/University    Completed University    Never attended school
4. Do you have health insurance?    yes    no
5. What is your religion? .....
6. Where were you born? .....
7. When did you move to the United States? .....
8. Have you had at least one cervical cancer screening in your life in the U.S? .....
9. What city do you live?    St. Cloud    Other .....

**THANK YOU FOR YOUR TIME AND PARTICIPATION!!**

**Appendix B: Interview Guide (Ackerson, 2008)**

1. Who or what has influenced you the most about Pap smear tests?
- 2. If you have to describe to a friend what a Pap smear test is, how would you describe it?**
3. We are all told to get pap smears, why do you think we are told to do that?
4. Some women don't get Pap smears, why do you think that is?
- 5. How would you describe how it is/was for you to have a Pap smear?**
6. It seems like for you it's been [okay, good, bad] to go through the visit to have a
7. Pap smear done. Tell me about what made that visit good/bad.
- 8. Do you think there's anything doctors or clinics do that makes it easier or harder for women to get this test?**
9. There is a kind of cancer called cervical cancer, what do you know about it?
10. Some people may have more risks for cervical cancer, what do you think your chances are for cervical cancer?

Questions in bold above will be incorporated in myself develop interview guide for this study. The questions are listed below:

1. If you have to describe to a friend what a Pap smear test is, how would you describe it?
2. How would you describe how it is/was for you to have a Pap smear?
3. Do you think there's anything doctors or clinics do that makes it easier or harder for women to get this test?

### **Appendix C: Interview Protocol**

*Welcome to the interview:*

My name is Rachel Anyu; I am a doctoral candidate at Walden University. I will like to thank you for volunteering to sit down with me for this interview. This interview will last up to about 60 minutes and it is in partial fulfillment of a required dissertation for my doctoral research course work.

*Explain the study purpose:*

The purpose of this study is to Understand Female Somali Non-College Graduate Immigrant's Experiences with Cervical Cancer Screening Services. This study seeks to understand the Somali female lived experience as related to obtaining a cervical cancer screening. This study will interview several immigrant women ages 25 – 45 years old.

*Sign the consent form:*

I have a hard copy of the consent form which I emailed a prior copy for your review. This is a voluntary interview and if at any time you need a break or need to stop the interview, please let me know. Your personal information will not be used in my final research. Do you have any questions? If not, I will have you sign here!

*Ice breaker questions:*

- You noted on your screening form that you've lived in the U.S. for xxxx years, have you lived in St. Cloud for the entire time?
  - Who from your family came from Somalia with you to the U.S.? Do you all live together here in St. Cloud? Probe: In the same apartment/house?
1. Somalia to the U.S. must have been quite a change, how has your cultural values been affected by the move? Probe based on above: ask about family at home. Ask about

- living together vs. living apart if they are not in the same apartment/house. 1. What is your understanding of healthcare in the U.S.?
2. Tell me about your experience with healthcare in Somalia? (Pap smear included if any).
3. If you have to explain to a friend what cervical cancer screening (Pap smear) is, what would you tell them?

*Research Questions:*

1. What are the lived experiences of Somali immigrant women without a four-year college degree accessing cervical cancer screening? (e.g., availability, accommodation, affordability, and accessibility).
- a) How many Pap smears have you had in your life and where did you get them?
  - b) What is your understanding of the phrase “access to healthcare/cervical cancer screening”?
  - c) When you went for your Pap smear here in St. Cloud how far away was the clinic?
  - d) When you called to schedule your Pap smear appointment how soon were you able to get in to see the healthcare provider?
  - e) How did you get to the clinic for your appointment?
  - f) How long did it take you to get to the clinic? Probe: did you feel that the clinic was easily accessible based on the distance?
  - g) Did you have to pay any deductible or fees upfront prior to getting your cervical cancer screening?

- h) Did you have any forms to complete while in the clinic? Did you fully understand the forms?
  - i) How would you sum up your experience regarding access to cervical screening? – Probe specifically about: availability, accommodation, affordability, and accessibility?
2. How does awareness of services impact cervical cancer screening among Somali immigrant women without a four-year college degree?
- a) Can you describe any advertisements/public service campaigns that you have seen since living in the U.S. about the importance of obtaining cervical cancer screening (Pap smear)?
  - b) Has seeing these advertisements/public service campaigns affected how you have had your cervical cancer screening (Pap smear) done? If so, how? If not, why not?
  - c) Can you describe the guidelines from the American Cancer Society (ACS) for getting a cervical cancer screening for your age?
    - i. Probing: If correct – Do you follow these recommended guidelines?
    - ii. Probing: If not correct – the interviewer will state ACS guidelines.
  - d) Has knowledge about the ACS cervical cancer screening guidelines affected how you have had your cervical cancer (Pap smear) screening done? Will it change your plans to screen in the future? If so, how?
3. What is the role of acculturation in the experiences of Somali immigrant women without a four-year college degree in obtaining cervical cancer screening?



- a) Tell me about the core differences between your cultural beliefs and those in the U.S. as they relate to routine disease prevention such as cervical cancer screening.
- b) Describe some conversations you have had with your family and friends from your culture regarding cervical cancer screening?
  - i. Possible probing: Tell me more about your family views regarding cervical cancer screening e.g. your husband's thoughts on cervical cancer screening?
  - ii. What are your mother/mother in law's thoughts on cervical cancer screening and how influential are they to your healthcare decision?
- c) How has your experience with your healthcare provider during your cervical cancer screening helped you integrate into performing routine screenings?  
Probe: Were you satisfied with your experience? Did you return to your healthcare provider?
- d) Has mastering the English language and listening to the American media changed you approach and tolerance for cervical cancer screening? Please, elaborate.
- e) We have come to the end of our interview, is there anything about your lived experience with cervical cancer screening that you would like to share with me?

Thank you for your time. I will transcribe this interview and have you review it for accuracy within one week. I can email it to you, mail it via the post office, or deliver it in

person to you, which would you prefer? Again, I would like to reassure you that your personal information will not be used for this study.

Thank you.

## Appendix D: Flyer

### **Volunteers needed for cervical cancer screening research - Female Somali Immigrants for interview.**



#### **Study on Cervical Cancer Screening “Pap Smear”**

My name is Rachel Anyu, a doctoral candidate at Walden University, conducting a research aimed at Understanding Female Somali Non-College Graduate Immigrant’s Experiences with Cervical Cancer Screening Services.

- ✚ Ages of 25 – 45 years who reside in St. Cloud, MN and has had at least one Pap smear in the United States
- ✚ Participants will be asked to participate in a one-on-one interview.

#### **Location**

All interview sessions will be at St. Cloud Public Library (about 60 minutes).

#### **Are you eligible?**

- ✓ Somali Female immigrant
- ✓ Born in Somalia
- ✓ Ages 25 – 45 years old
- ✓ Do not possess an undergraduate degree
- ✓ Reside in St. Cloud, MN
- ✓ History of at least one Pap smear in the United States

**Contact: Rachel Anyu**

**If you are unsure if you meet the requirements,  
and have any questions, please contact me at**

**[rachel.anyu-lainjo@waldenu.edu](mailto:rachel.anyu-lainjo@waldenu.edu)**

**Or call 612-423-0511**