

2018

## A Qualitative Grounded Theory Approach to Reducing Breast Cancer Disparities in the Latina Population

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Abstract

A Qualitative Grounded Theory Approach to Reducing Breast Cancer Disparities in the  
Latina Population

by

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Master of Business Administration, Walden University, 2009

Bachelor of Science, Palm Beach Atlantic University, 2005

Dissertation

for the Requirements for the Degree of

Doctor of Philosophy

Public Health and Policy

Johns Hopkins School of Medicine

and

Walden University (Issuer)

Summer 2018

## Abstract

Breast cancer is the leading cause of death among Latinas. Several barriers persist when accessing health care and utilization of healthcare services such as annual mammograms, leading to a late-stage diagnosis or death related to breast cancer illness. Consequently, this study was important to further examine potential risk factors such as beliefs, cultural context, health insurance, and socioeconomic status for this population. Further, gaps in research provide limited evidence of risk factors adversely influencing high morbidity and mortality incidence. The purpose was to focus on disparities in breast cancer experiences within Latina communities in the United States. A qualitative foundation used grounded theory with the Health Belief Model to guide the questions. The study research questions explored (i) access to breast care services that encourage early breast cancer detection; (ii) access to breast care diagnostics such as exams, mammograms, and biopsies; and (iii) views of availability to breast care exams, diagnostics and treatment options improving health outcomes. The method of data analysis used coding to analyze content and classify data for patterns and themes. A total of 12 Latina participants were recruited. The key results conclude the participants perceived the disease, as serious leading to death; and cultural context, insurance or socioeconomic status may or may not have assumed a level of susceptibility to the disease. In conclusion, this qualitative study demonstrates the need to further understand risk factors that influence high breast cancer morbidity and mortality outcomes among Latinas. These factors can then be translated into program interventions specific to the needs of Latinas. Future research is recommended to design effective interventions that reduce breast cancer incidence. Finally, the social change implication of this study demonstrated results that can contribute to the existing literature on health disparities, compliance motivations to diagnostic care, and long-term treatment of breast cancer among Latinas in the United

States. The social implication of the findings can also be useful to identify potential risk factors to be studied in women of other vulnerable populations.

**A Qualitative Grounded Theory Approach to Reducing Breast Cancer  
Disparities in the Latina Population**

By

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Bachelor of Science, Palm Beach Atlantic University, 2005

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Dissertation Submitted in Partial Fulfillment  
Of the Requirements for the Degree of  
Doctor of Philosophy  
Health Services  
Public Health and Policy

Johns Hopkins School of Medicine University  
Walden University (Issued)  
Summer 2018

Dedication

Always remember:

“Just when the caterpillar thought the world was over, it became a butterfly”

~Proverb~

Für immer in meinen Herzen

To my wonderful son, my proudest achievement...this journey was not just for me – but  
also for you!

Immer für den Weg des Lichts in deinem Herzen wird das Licht dich niemals in die  
falsche Richtung lenken!

## Acknowledgments

This acknowledgment is for Dr. Kourtney Nieves, my chair, my mentor, my friend; Dr. Magdeline Aagard, and Dr. James Zabora, ScD, MSW, Director, Education & Outreach Johns Hopkins Center to Reduce Cancer Disparities, Baltimore, MD, my Principal Investigator, co-chair and mentor and as long as we've been doing this – I think my dad (LOL!). For the countless guidance, and leadership of Dr. Zabora and the Johns Hopkins School of Medicine and the Johns Hopkins School of Medicine's Institutional Review Board, Debra H. Haynes, MPH, at Inova Healthcare - my sister and my friend! Thank you for the laughter and for being my travel companion and translator. Marcella Blinka, MSW, at the National Institutes of Health – the whip! Thanks for reminding us what could and couldn't be done. Also, the many participants you worked with to get qualified. The most awesome research leadership and support team!!

A very special “Thank You” to Sandra Villa de Leon at Nueva Vida of Washington, D.C.! Most of our participants were referred by Sandra at Nueva-Vida. Without your help, many of these women said that they would not be alive today! You deserve an award for the work of love that you do! The incomparable Jyl E. Pomeroy, RN, and staff at Behavioral Health Arlington Free Clinic for all her efforts to recruit, for use of private rooms to interview participants, and the presentation at a Hispanic female and Latina breast cancer support group! Also, to the Spanish interpreters who worked with me to translate English to Spanish for the group. All the team at John Hopkins School of Medicine, Inova Physicians and staff, and those who offered support at the Inova Life

With Cancer Center. \*To any and all volunteers, partners, and participants who have helped make this research possible – Thank you.

Last, but certainly never least to every woman who shared their breast cancer journey and their pain! #WE SEE YOU; #WE HEAR YOU; #YOU ARE THE BRAVE-ST!



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## Qualitative Demographics

TABLE 1.1 Demographics of Latina Breast Cancer Participants.

<b>Gender -</b>	Female
<b>Age Range) -</b>	42-72 years
<b>Stage of Cancer Range) –</b>	Stage Zero to Stage II

## Chapter1: Introduction to the Study

### **Introduction**

Breast cancer is the most common and leading form of cancer diagnosis among Latinas in the United States. According to Corcoron et al (2012) Latinas are surmised as the “second least likely ethnic group to obtain mammograms within two years” (p. 672). Corcoron et al (2012) further asserts breast cancer as a leading cause of death among this population., Moreover, Latinas’ are adversely influenced by several barriers to utilization of diagnostic exams including regular mammograms every two years, and perceived risks influencing motivation adherence (American Cancer Society, 2014). Another contributing factor to consider in the life cycle of breast cancer diagnosis is economic status. The World Health Organization suggest that the incidence of breast cancer as a major mortality risk in most high- income countries (WHO, 2014). For example, mammography screenings vary in accordance with wealth distribution and income (WHO, 2014). Conversely, limited evidence on this population exist examining causes of risks factors and barriers minimizing delays that could lead to early diagnosis of breast cancer morbidity and mortality rates. Research need to understand the Latina experience when confronted with the discovery of a breast tumor or breast cancer diagnosis or a requirement for biopsy. Results of such findings could provide improved awareness to providers as to effective prevention and treatment alternatives for these populations. This study was conducted to address the gaps in current literature that do not demonstrate understanding of the Latina experience in the United States healthcare system. This research study is necessary to provide detailed experiences of Latinas relative to access to care in the health delivery system when confronted with breast tumor, biopsy and finally breast cancer diagnosis. Consequently, potential social change implications of the study could improve outreach programs and initiatives failing to meet

the needs of Latinas (American Cancer Society, 2014). Subsequently, this research could inadvertently provide similar benchmark data useful to other minority populations as Black and African American females. The anticipated timeframe for data collection exceeded one-quarter term at Walden University. Individual interviews did not exceed more than 60 minutes as a whole for the first interview, and no second interview was required.

Chapter 1 provides an in depth view of the problem statement and purpose of study. Research questions were presented and the theoretical framework described the foundation for the study's structure. It further discusses the nature of the study, study assumptions, scope and delimitations. Chapter 2 detailed the gap in research regarding Latinas and their access to biopsy screening and experiences in the health delivery system when confronting tumor diagnosis. Furthermore, additional knowledge and education of this population in breast cancer care was addressed. Chapter 3 analyzed outcomes utilized to advance the understanding of the Latina experiences when seeking access to breast care services. It further discusses the data collection process and analysis approach that used a cross sectional sampling approach regarding predisposed psychosocial and cultural influence associations. A random selection of volunteer participants were recruited from various public health agencies. Participant recruitment utilized a series of flyers in English and Spanish. Recruitment announcements were made throughout public health agencies such as health departments, community clinics, breast-care physicians, cancer care centers; and related non-profit organizations targeting Latina breast cancer survivorship programs. Finally details of expanded recruitment approaches can be found in Chapter 3.

## Background

The World Health Organization asserts that on a global scale, breast cancer is the most pervasive type of cancer and a leading cause of death among women between 20-59 years of age (WHO, 2013). The World Health Organization suggested in a 2008 report (the latest data available, but updated in 2014) 33 per thousand among women suffer death related risk in their lifetime as a result of breast cancer most prevalent in wealthy countries compared to countries with fewer resources in lower/middle income countries (WHO, 2014). In the United States, it is estimated 220,000 or 1 in 8 women will be diagnosed with breast cancer annually (National Breast Cancer, 2012). The American Cancer Society (2013) estimates that the incidence rate of invasive breast cancer in women within the United States has increased to 232,340. In similar research, the National Cancer Institute (2014) surmises an overall incidence rate of invasive breast cancer of 127.8 out of every 100,000 women. Conversely, the death rate as a result of invasive breast cancer in women is 25.5 per every 100,000. This number equates to an average of 132.5 incidence rate and a 25.0 death rate for non Latinas. In comparison the Black American female incidence rate is 118.3 and mortality rate is 33.8, while Latinas estimated incidence rate is 89.3 with death occurrence at 16.1 between 2000-2004 (National Cancer Institute, 2014).

In a weekly report on Mortality and Morbidity cited in 2013 (CDC, 2013b), several studies on breast cancer statistics were analyzed regarding breast cancer incidence among disparaged female populations. The report stated for example, in 2009 211,731 cases of female breast cancer were diagnosed and were the most common among all female ethnic and racial groups. Black American females were cited as the highest in late stage diagnosis (CDC, 2013b). Further breast cancer is the primary cause of death among Latinas and health status may

contribute to the predisposition of this and some other illnesses (American Cancer Society, 2014; Corcoran et al, 2012). In addition, while slight decreases (1.6%) in breast cancer diagnosis have been noted between 2009-2012, most cases are determined at the late stage with socio-economic status (SES) and age with 54% at local stage in comparison to 64% of non Latinas (American Cancer Society, 2014). Further, higher incidence of diverse cancers and disparities are prevalent among certain underserved populations and racial/ethnic groups. Factors heavily influencing higher incidence of diverse cancers among underserved populations are being underinsured, lack of health insurance, and limited economic resources or low Socio-economic status (National Cancer Institute, 2014; Gonzales, et al., 2011; Maly, et al., 2011).

According to the American Cancer Society (2014) the US Census Bureau asserts the Hispanic females' population as the fastest growing population in the United States or are 16% of the American population. Survivorship among Latinas with breast cancer is currently five years or less (American Cancer Society, 2014). This study is critical in minimizing the percentage of late stage breast tumor diagnosis and increasing the survivorship of the Latina community in the United States. Existing literature suggests some "health system variables" such as socio-economic status and lower educational status as fundamental causes of delayed mammography screenings or higher percentage of late stage breast tumor diagnosis potentially correlated to socio-economic status (David & Rose, 2009; Corcoran, et al. 2012; American Cancer Society, 2014). This discovery could adversely affect such vulnerable populations as Black American and Hispanic females' American females with increased breast cancer incidence. According to the American Cancer Society (2014) effective communication techniques among Latinas' is required to increase beneficial knowledge of screening utilization, practices and the significance of early detection strategies to the Hispanic females' community

(American Cancer Society, 2014). Further, the Center for Disease Control and Prevention (CDC, 2012a) suggests Hispanic females' are less likely to participate in screenings compared to their non-Hispanic female counterparts varying per Hispanic female subgroups. Latina's are diagnosed at younger ages, is the leading cause of death, and are diagnosed at more advanced and harder to treat stages (Office of Women's Health, 2014). Sociologists continue to understand qualitative patterns or themes between health outcomes and individual disparities (Willson, 2009). Understanding the breast cancer experiences of Latinas will contribute to existing research and literature that expands beyond utilization of care services, but to the needs of the growing Latina population in the United States and their long-term survivorship. Additional analyses of related literature is examined below and in the Chapter 2 literature review.

This study demonstrates the need to address knowledge gap in literature in the discipline of breast cancer disparities with a progressive theoretical framework for cancer prevention programs and health promotion and education (Gehlert & Coleman, 2010; Kiddler, 2008). For example, in a similar study, Gehlert & Coleman (2010) utilized the Community Based Participatory Research (CBPR) application strategy to engage community leaders and participants in the process of evaluating questions and formulating answers for effective outcomes specific to Black American females and minimize the gap in breast cancer disparities. Focus groups were established as a methodological approach to provide a substantial amount of data collection within a short period of time (p. 4). The literature review constructs data on program intervention by analyzing the E2D2 model. In another study conducted in Alberta Canada, the E2D2 model four pillars of health prevention and intervention global best practices was utilized and merged to cover the broad spectrum of individual and population health challenges and chronic illness (Petermann & Petz, 2010). The methodological approach used in



the study was a comparative analysis of empirical theory and frameworks of various regional and provincial (health zones in Alberta Canada (two urban and three rural) physical activities and nutrition initiatives purporting to reduce cancer related risk factors achieving behavioral modification outcomes, that could be applied to helping physicians understand how to reduce late stage breast cancer diagnosis in Hispanic women (p. 562). According to Petermann and Petz (2010) the E2D2 model allows for the emergence of progressive evidence data, knowledge exchange, and revisions throughout a four- phase process (p. 562). Similarly, Kiddler (2008) developed Protect Our Women (P.O.W.) a breast- cancer intervention program in collaboration with community leaders and older black American females at risk for developing late stage breast cancer diagnosis. As such, breast cancer treatment outcomes for older African American females have proven unsuccessful potentially as a result of late stage breast diagnosis (Kiddler, 2008). Kiddler's discussion asserts a broad perspective of behaviors and cultural attitudes found in discussion.

This research study was necessary to address gaps in the literature giving insight to some knowledge of potential influences interfering with motivations to adherence of breast care compliance in effort to reduce breast cancer disparities in vulnerable populations. Further, the results of this research provided additional understanding of the experiences of Latinas' diagnosed with breast cancer that contribute to high incidence of the disease and related death. The qualitative study analyzed the impact of challenges and/or barriers vulnerable female populations realize when confronted with breast tumor findings, either from mammography procedures or self - examination, biopsy procedures, breast cancer diagnosis; and finally, breast cancer treatment decisions. The study used an approved one to one interview questions format per participants. Results of this study demonstrate the need for increased qualitative research

that contributes to the development of early prevention education, improved provider-patient relationships, early detection, equitable access to quality care, utilization of breast cancer diagnostics; and access to other related resources.

### **Problem Statement**

Breast cancer is the leading cause of death among Hispanic and Latinas (Corcoran, Crowley, Bell, Murray and Grindle, 2012). According to Corcoran et al (2012) Latinas are the “second least likely ethnic group to obtain mammograms within the past two years” (p. 672). As such, many Hispanic females are adversely influenced by several barriers to utilization of diagnostic exams including regular mammograms every two years and perceived risks influencing motivation adherence (American Cancer Society, 2014). Present literature reviews reveal gaps in the hypothetical voice or qualitative experiences of Latina American females and breast cancer diagnosis with findings primarily quantitative in nature (Erwin, Treviño, Saad-Harfouche, Rodriquez, Gage, and Jandorf, 2010). For example Erwin et al. (2010) asserts:

Although many studies use and report qualitative research Methods and findings to create and inform health education interventions, there is a dearth of methodological information about the interpretation and transformation of these qualitative analyses into intervention content and structure. (p. 694).

In accordance with the objectives of Healthy People 2020 to reduce the female breast cancer death rate, reduce late stage breast cancer, and increase the number of females counseled by health providers on mammography screening guidelines, the literature represents analysis of potential community based initiatives specific to this demographic population (healthypeople.gov, 2013). The research is necessary and was conducted to improve patient provider relationships, improve prevention programs, and improve resources and open equitable access specific to Latinas in the United States. In addition, the outcomes of this research may be

applied to Black and African American females and other minority and underserved populations, thus influencing the social implications aspect of existent literature. The research questions are as follows:

- i. How does perceived access to breast screenings such as mammography, influence biopsy decisions when a tumor is detected, contribute to delayed or late stage breast cancer diagnosis in Latinas?
- ii. How can breast cancer health providers, physicians, and professionals improve equitable access to care and breast care facilities that improve health outcomes related to breast cancer diagnosis, and increased survivorship among Latinas?
- iii. How can breast care health providers encourage early breast cancer detection and biopsy measures with tumor detection?

The articles included in this literature review are a combination of racial and ethnic demographics in breast cancer diagnosis, theories and models. Evidence from certain articles (Willson, 2009; Maly et al., 2011, Yearby, 2011 and Erwin, et al., 2010) suggests significant gaps in qualitative research methods understanding the experiences of disparaged or marginalized groups such as Black and Latinas to pursue mammography and diagnostic breast exams, and the quality of health care delivery system. For example, Willson (2009) suggests that in spite of large international databases minimal research exist documenting the individual link between socioeconomic status (SES) and health. Consequently, risk factors persist as a continued result of minimal and flexible resources for the advantage of improving health or warding off unfortunate preventable disease (Willson, 2009). African Americans and Latinas are more likely to have low wage jobs thereby lacking health insurance or by state/federal health programs. Further, 32% of 21% of Black Americans are uninsured compared to 13% of

Caucasians contributing to fewer physician visits and increased mortality (Yearby, 2011). Additionally, low income uninsured women are more likely to delay diagnostic care once BC is detected. According to Maly et al. (2011) diagnostic care is minimal in this group either self - detected or physician detected. Maly et al. (2011) contends that such studies have been generalized in scope regarding delays beyond detection of abnormally. These findings have included such independent variables as “self reporting socio demographic characteristics (age, marital status, education) or self efficacy (p. 1081).

To support the limitations in literature amongst vulnerable populations, evidence available as late as 2008, higher incidence of diverse cancers and disparities are prevalent among certain underserved populations, and racial and ethnic groups heavily influenced factors as underinsured, lack of health insurance, and limited economic resources or low Socioeconomic status (National Cancer Institute, 2014, para 1). Compounding the problem of higher incidence of diverse cancers and disparities are prevalent among certain underserved populations and racial and ethnic groups, the United States health care system rations services and upholds policies that exacerbate access based on capacity to pay contributes to the outcome of death related health effects (Yearby, 2011). Services are rationed favoring the wealthy and a bias structure overriding the majority common good toward minority and underserved populations, whom typically lack equitable resources for care (Yearby, 2011). In another example, according to Willson (2009), socioeconomic status is one factor strongly identified with persistent health disparities. Consequently, further studies of these contributory factors validate associations of breast cancer prevention and persistent health disparities. Further, according to the National Cancer Institute (NCI, 2014) and Wujcik et al. (2009) evidence demonstrates a higher incidence of breast cancer and late stage diagnosis potentially relative to insurance, barriers to early

detection and screening, treatment differences, compromised quality care and limited access to treatment among Latinas. In addition, the National Cancer Institute (NCI, 2014) suggest “more aggressive breast tumors persist in younger Black, and African, as well as, Latina in lower socio-economic (SES) areas potentially attributable to poorer survival rates (National Cancer Institute, 2014 and Maly et al., 2011).

Creswell (2007) asserts theories in current research are often inappropriate and ill suited for participants under study (p. 63). According to the Center for Disease Control and Prevention (CDC) Black and African American women have the highest incidence of death because of breast cancer (CDC, 2012). Various indicators throughout the literature reflect present research in breast cancer disparities, beliefs, social determinants and cultural behaviors potentially associated with delayed detection of breast cancer and promotion of mammography screenings (Clark, et al., 2009 and Maly, et al., 2011). For example, in a Boston Outreach case management study, African American women were utilized in a quantitative cohort study for promoting mammography screenings among Black and Latina American females ages 25-70 (Clark, et al. 2009). The goal of the study was to identify social obstacles correlating with BC screenings and abnormal results. Results concluded that while most women of the study continued BC intervention programs these programs could not be attributed to the timely follow-up of screenings. In other literature, Schootman, et al. (2009) discussed socioeconomic trends relative to breast cancer types, and potential social-psychological variables causing variance in incidence and mortality rates. As a result of the gaps in the current literature of qualitative studies and data collection amongst vulnerable female populations, more research is required to comprehend and examine the many complex factors specific to vulnerable female populations is necessary to minimize breast cancer disparities.

## **Purpose of the Study**

The purpose of the study is a qualitative grounded theory paradigm utilizing the Health Belief Model (HBM) as a guide to expand on a current theory or emergence of a new theory. This intent of study generated data recognizing emergent trends, categories and themes associated with barriers to access to care, quality of care and diagnostic utilization of services after a breast cancer diagnosis, biopsy of suspicious breast tissue or discovery of breast tumor through self detection. The study explored the lived experiences of Latinas diagnosed with breast cancer in the United States. The general definition of the central phenomenon is to understand the well woman needs of Latinas consequently minimizing late stage diagnosis, barriers, influencing early detection programs and improving the full scope of quality in healthcare delivery process for vulnerable populations. The results can contribute to significant reduction to breast cancer health disparities, access and utilization.

## **Research Questions**

As previously stated in this chapter, more research and data collection is required to comprehend and examine the many complex factors to minimize breast cancer disparities. Outcomes of this research can be applied to other vulnerable and underserved populations addressing the same following research questions: (i) How does perceived access to breast screenings such as mammography, influence biopsy decisions when a tumor is detected, contribute to delayed or late stage breast cancer diagnosis in Latinas; (ii) How can breast cancer health providers, physicians, and professionals improve equitable access to care and breast care facilities that improve health outcomes related to breast cancer diagnosis, and increased survivorship among Latinas; and (iii) How can breast care health providers encourage early breast cancer detection and biopsy measures with tumor detection.

## Theoretical Foundation

The theoretical framework selected is the grounded theory approach utilizing the Health Belief Model (HBM) as a guide for the interview questions to develop an innovative theory. A grounded theory does not require a hypothesis, but works best when the researcher is allowed to develop theory through coding metrics and inductive methods. For example, Creswell (2007) asserts grounded theory as an interpretive approach where substantive theory is developed via the researcher's view and participant experiences analyzed (p. 65). Additionally, the study's use of the Health Belief Model has been applied to the understanding of participant cues to action of health behavior compliance modification. Blearning (1998) asserts that individuals are most likely to alter health behaviors (control) when it is perceived to be serious. Further, the theory explains health behavior in a four-tiered construct: (1) perceived seriousness; (2) perceived susceptibility; (3) perceived benefits; and (4) perceived barriers including actions, motivating factors and self-efficacy (Blearning, 1998) and relates to cues to action when breast cancer tumors or cancer diagnosis is determined. It also provides a worldview of social constructivism allowing the researcher to expand subjective implications from participant experiences and relies heavily on the views of participants often based and negotiated socially and historically (Creswell, 2007, p. 20). For example, one potential participant may question perceptions of institutionalized racism as a constituent to quality care influencing delayed diagnostic exams and late stage diagnosis. Views are formed through interactions with others and historical and cultural norms operating in individual lives. Further details regarding the Health Belief Model will be discussed in chapter 2.

The study's theoretical approach relates to the research questions by providing perceptions of fatalistic health beliefs, available strategies and resources from participant

responses as strong predictors of behavioral influence. In a previous study, the Health Belief Model has been applied to the understanding of participants for smoking cessation successes, consumer shopping intentions, HIV and human behavioral research studies (Fishbein & Ajzen 1975 & 1980; Manstead, 2011). The construct relies on empirical evidence to determine or broadly predict attitudes, intentions, behavior controls, and expectations thereby providing some data on intentions, motivations, and perceptions interrelated to actions. As in the previous studies, it has supported previous studies in HIV by providing intention of behavior based on attitudes and “subjective norms.” Participant’s extent of belief ability and ability to control their behavior can assist with the emergence of new or expanded theory (Manstead, 2011). Previous research studies in predicting behaviors associated with sexual activity and HIV prevention have also demonstrated correlations between attitudes and expectation (Manstead, 2011).

As asserted by Blearning (1998) the Health Belief Model constructs demonstrate perceptions of disease and illness seriousness, susceptibility, benefits, and barriers examining behaviors of “cues to action, motivating factors, and self efficacy” (p. 1). These theories have provided the framework relative to the research questions by seeking connectors to behaviors associated with access to utilization of care and services, delay in screenings, barriers to biopsy, and non compliance to the process of health actions. This use of concepts from HBM informed the interview questionnaire and facilitated analysis of the data collected. The researcher, Senior Principle Investigator, and assisting staff of Johns Hopkins School of Medicine followed a Generic Inductive Qualitative Model (Maxwell, as cited in Hood, 2007) by noting and transcribing the themes that emerged from the participant interviews regarding their perceptions of access to breast biopsies and their motivations to comply with care. Transcribed interviews were analyzed through grounded theory’s “constant comparative analysis” approach to data



analysis (Charmaz, 2006; Glazer & Strauss, 1967) to understand participants' beliefs and attitudes. Wujcik et al. (2009) contend reasons for variations in delayed diagnostic exams and increased mortality among this population is unclear calling for expanded research of other contributory variables to divergent outcomes (p. 710). As such, the grounded theory and concepts of Health Belief Model relate to the present study of breast cancer in Latinas by combining variable concepts comparatively for analysis such as: socio psychological behaviors, income barriers, group or socio-cultural influence, and individual expectations. Further explanation can be found in chapter 2. Substantive norms and intentions impacting beliefs about mammograms, breast cancer seriousness or fears, access to the health care delivery system, and cultural beliefs surrounding breast cancer are also valuable in understanding barriers to available utilization of services.

Finally, the Health Belief Model could highlight additional beliefs, attitudes, intention, social norms and behaviors that identify the foundation links between attitudes and behavior under the individual's control (Manstead, 2011). For example, in a study targeting household recycling behaviors, results indicated that individual and personal identification with recycling behaviors were connected with social expectations or perceived social identities of intentions from the group (Manstead, 2011). Additionally, the study found an "individual's personal beliefs shaped intentions and behaviors" (Manstead, 2011, p. 368). This study explored the explanation of social group or cultural influence, and individual beliefs consistent with perception of seriousness of breast cancer, and self imposed beliefs of access to services. Consequently, the Health Belief Model construct is most commonly used for health education and promotion aligned with the grounded theory to analyze and suggest recommendations to reduce breast cancer disparities.

### **Nature of the study**

Contributions to the study Latinas that are breast cancer patients and provides rationale of the design by demonstrating approaches that improve comprehensive quality of care before breast cancer develops, through stages of recovery and onto survivorship. In the Health Belief Model, supportive data analyzed perceived risks associated with motivation behavior in health disease specific to biopsy exams, follow up of compliance motivations, and other early detection measures. The Health Belief Model construct can identify the participant's perceived severity, seriousness, or susceptibility to the disease (Rosenberg, 1974). Perception influences a range of interpersonal factors and self-efficacy to health behavior (Blearing, 1998). For example, the Behavioral Model for Vulnerable Populations by Gelberg-Anderson, a framework designed to examine utilization of health services, characterizes associations with need based healthcare, need based factors, predisposed conditions, such as cancers in Latina populations, or other vulnerable groups (Gonzales, et al., 2011). The central phenomenon of the study explored the lived experiences of Latina breast cancer survivors. The general definition of the central phenomenon was to understand the needs of Latinas related to their experience of breast cancer diagnosis. In a study by Bazargan, Bazargan-Hejazi, and Baker (2005) on Hispanic females' and African Americans and depression and self-reporting, results assert correlations between depression and chronic illness. Further, the research study contends minorities are more likely to confront barriers to care considering health issues as depression a stigma, more than non-minority groups (p. 329). This perception impedes healthcare utilization services available to both minority groups increasing risk to overall short and long-term health (Bazargan, et al., 2005). These barriers asserted by Bazargan, et al. (2005) contend the "under delivery of health services, higher disability, and greater frequency of medical illness (such as hypertension and

diabetes) among African Americans increase their risk of ill health multifold” (p. 329). The study is important to disparaged (vulnerable) health populations as Black and African American and Latinas, as well as other minority female groups as potential variables contributing to higher incidence of late stage breast cancer reporting and the motivation adherence to biopsy exam. Consequently, assess utilization of health care services, beyond mammography, such as biopsy affordability and access, at the onset of tumor diagnosis, or self- reporting with health care providers can contribute to breast cancer prevention and intervention programs.

The methodology of the study will consisted of a small sample size of twelve Latinas and in the United States. These participants were recruited in the Northern Virginia and immediate surrounding areas such as Maryland and Washington, District of Columbia areas with the assistance of various participating partnerships and public health government and non- profit agencies. Participants completed one- time individual interviews with the assistance of a language interpreter. Creswell (1998) suggest a sample size of 20-30 is sufficient for saturation in a grounded theory (p. 64). Charmaz asserts, “a study of 25 interviews may suffice for certain small projects” (p. 114). Saturation or Theoretical Saturation is defined as “the point at which gathering more data about a theoretical category reveals no new properties nor yields any further theoretical insights about the emerging grounded theory” (Charmaz, 2006, p. 189). A qualitative expert associated with the Life With Cancer Center in Northern Virginia and immediate surrounding areas such as Maryland and Washington, District of Columbia was consulted to confirm the required number of participants required for a qualitative study. The Life With Cancer Center has tested sample sizes of 25 in past studies and their results were sufficient. Additionally, other qualitative studies related to chronic illness studies such as other cancers or breast cancer demonstrate sample sizes of women 25 or less participants with sufficient results in

themes from category saturation (Banning & Tanzeem, 2013, p. 254; Lee, Wakefield, Foy, Howell, Wardley, and Armstrong, 2011, p. 1044). Participants were kept in anonymity and interviews conducted in confidence. Each set of interview materials were placed in individual envelopes and sealed for review by Senior Principle Investigator, Dr. James Zabora, ScD, Director, Education & Outreach Johns Hopkins Center to Reduce Cancer Disparities, Baltimore, MD,,the student researcher, and approved staff of Johns Hopkins School of Medicine. The data collected was analyzed with the Atlas.ti database software. As such, the study provided a voice to the Latina population for qualitative studies of breast cancer survivors or patients and their experiences regarding biopsy and mammogram exams. It pursued the objective to discover a deeper personal view of perceived risk barriers, as well as motivation to compliance. Further detail is provided in chapter 3.

### **Definitions**

**Breast Cancer** – malignant tumors that begin in breast cells and may increase or metastasize to other parts of the body. (American Cancer Society, 2013, p 2., para 1).

**Service Utilization** – improved access to equitable care influencing health outcomes, minimizing disparities and costs. This includes utilization of evidence- based services, and clinical preventative measures (HealthyPeople, 2020 Overview, 2013, p. 1).

**Access to Care** – Timely utilization of personal health services in the areas of 1) uncomplicated entry into health care system; 2) location access where needed services are required; 3) a trustworthy healthcare provider for patient connection. It involves quality care, utilization, timeliness, and workforce. (HealthyPeople, 2020 Overview, 2013, p. 1).

**Cultural Competency** – Cultural and linguistic competence is a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations. (Jenks, 2011, p. 210).

**Cancer Disparities** – as adverse differences in cancer incidence (new cases), cancer prevalence (all existing cases), cancer death (mortality), cancer survivorship, and burden of cancer or related health conditions that exist among specific population groups in the United States. (NCI, 2008, para. 1).

**Hispanic female and Latina population** – A person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin regardless of race (U.S. Census Bureau, 2012, p. 2).

**Mortality rates** - A measure of the frequency of occurrence of death in a defined population during a specified interval of time. (CDC, 2013, para. 11).

### **Assumptions**

Assumptions are many throughout the breast health and breast cancer outcomes among Latina's living in the United States; as well as Black and African American females, and other vulnerable populations. For example, current health care models are built on the assumption of the following factors, 1) health decisions are determined by societal and socio economic conditions, 2) diverse perspectives to planning and implementation of prevention programs, and 3) interpersonal beliefs (Petermann & Petz, 2011). Based on these findings, first, it is assumed the majority of Latina populations have regular mammograms, that language barriers delay exams, poverty, and diverse cultural backgrounds compound the already complex scenarios (Medina-Shepherd & Kleier, 2012). Secondly, in contrast, it has been asserted that other contributable factors that contribute to delays in exams and increased morbidity and mortality rates include, 1) access to equitable & quality care, 2) patient to provider relation perception, 3) knowledge of Behavioral Model of Vulnerable Populations sought to analyze determinates or factors limiting breast cancer development. In a quantitative study demonstrated by Gonzales, et al. (2011) the healthcare utilization by minority females (422-423). A category of third

assumptions asserts that predisposed characteristics such as age, marital status, health beliefs, or education may impede the use of healthcare services. The study's predisposed outcomes assumed that age and language contributed to impede, as well as the need for care or previous utilization of preventative services (Gonzales, et al., 2011).

Creswell (2007) asserts that qualitative research differs from quantitative by analyzing the perceptions, and experiences of participants and how they attribute to their lived lives, and the understanding of how or why they occur (p. 195). As such, methods of analysis of data collected and referred to as contributable factors, will be coded, analyzing content, categorizing and classifying data for patterns and themes assessment. Since a previous observation of Latina cancer group had been assessed prior to data collection, a small sample pool of one to one interview format per participant for this research, was completed and open coding applied providing more detail in the process (Huberman & Miles, 1994; Creswell, 2007, p. 156).

### **Scope and Delimitations**

The research study focused on the lived experiences of diverse Latinas and their journey through the United States healthcare system upon breast tumor findings. Participants recruited were diagnosed either by mammography or self-examination, or a long-term observation of the breast tumor for further development; and finally, the study focused on the decision making process for diagnosis confirmation and treatment options. The appropriate methodology for this study was qualitative utilizing the grounded theory approach, where theories are often developed and presented at the end of study shaped by the foundation of research questions. Grounded Theory consistently utilized the data collection generating theories from trends refined through the coding and data collection process. In contrast, phenomenological approach has no theoretical orientation building from the experiences of participants from a central phenomenon

and was not chosen as the approach (Creswell, 2007). A qualitative grounded theory study employs:

It may also be a theoretical lens or perspective that raises questions related to gender, class, race, or some combination of these. Theory also appears as an end point of a qualitative study, a generated theory, a pattern, or a generalization that emerges inductively from data collection and analysis. Grounded theorists, for example, generate a theory grounded in the views of participants and place it as the conclusion of their studies. Some qualitative studies do not include an explicit theory and present descriptive research of the central phenomenon” (Creswell, 2007, p. 70).

Researchers must seek to understand the experiences of the Latina population’s reasons for delays in breast cancer screenings in efforts to reduce breast cancer morbidity and mortality incidence. Gonzales et. al (2011) suggests one possibility is the influence of stigmatization or fear based beliefs. For example, if one gets an exam it is an indication of immoral behavior, or perceived curse. There may be the fear of a procedure actually finding something (cancer) or that the process of screening may be painful or unpleasant. These findings therefore supported the requirement to investigate the psychosocial and cultural structure of influence in this community, as well as perceived risk and comprehension of risk as motivation to compliance. Finally, the potential for transferability of the study was not an issue. As asserted by Creswell (2007, p. 200) descriptive and detailed collection of participant experiences will provide ongoing transferability (external validity) providing reliability to study. For example, participants of this study completed a onme time interview process. They did not require a follow up interview to verify description of researcher’s findings; analysis of ensuring their perspective is legitimate, and minimizing researcher bias or reflexivity.

## Limitations

Grounded Theory will not provide quantitative descriptions as earlier research studies regarding Latina have prescribed. Grounded Theory in a qualitative study provides a perspective lens of participant beliefs, and attitudes. In contrast, a quantitative approach deductively seeks to verify or test a theory already established (Creswell, 2007, p. 29). For example, previous research studies assert statistical data for demographic and variables for quantitative analysis (Medina-Shepherd & Kleier, 2012). Creswell (2007) asserts a hypothesis is developed as a foundation for research questions forming a theoretical foundation and organized model for data collection. An instrument is then selected to measure attitudes and behaviors for the study with scoring outcomes that validate the original theory or support the hypothesis (p. 29).

Limitation results of this study demonstrated a qualitative assessment of interpreted experiences provided by the participant population from data analysis, coding, and interpretation. For example, Creswell (2007) purports the qualitative approach to develop theory through a perspective lens of culture, class, gender, and race (p. 62). In addition, Patton (2002) asserts this approach would evaluate “why do individuals behave as they do, how do human beings behave, think, feel, and know, what is normal and abnormal in human development and behavior?” (p. 216). Moreover, the strengths of this study highlights influences on late stage diagnosis relative to equitable quality of care or access to services. Additionally, the study built data collection results by illuminating the experiences or expressed perceptions of participants as they sought health care assistance at various breast cancer stages, while simultaneously considering the impacts interconnecting socio economic status, societal systems or both.

A quantitative approach would have challenged the theory development in literature review. Explanation of past theory must be ascribed inductively and built upon broad themes



collected throughout the process (Creswell, 2007, p. 58-59; Creswell, 2007, p. 63). Conversely, the study focused qualitatively on possible causes of mammography delay, access to diagnostic services, and self-identification of suspicious breast tissue. It further, considered themes related to ethnic/racial population differences, language barriers, cultural conceptualization, or other reasons for delays in diagnostic screenings disparities, such as minimal health care insurance or lack of coverage in decisions to seek confirmed diagnosis, gain increased education of breast health, utilization of available resources. As such, a quantitative approach would limit the perceptions or cultural evaluation or trust to seek care within the healthcare delivery system. If the study, were quantitative, it would require focus on documents with median ranges and variances.

Although the study demonstrates disparities are present; indicators are limited and are not specific to race and ethnicity disparities or inequities; demonstrating internal threats to cause and effect validity outcomes of various breast cancer stages and types. Creswell, (2009) asserts the sample populations' purpose for identifying specific characteristics and psychosocial inferences within the research while providing reasonable turnaround of results (p. 146). An Internal threat to validity within this research study could be the behaviors, beliefs, cultural conceptualization and attitudes of participants with regard to perceptions of care, equitable equipment, or services. Internal validity threats within this study can interfere with true/correct inferences within a population study when attempting to establish design (Creswell, p. 162, 2009).

### **Significance**

This study demonstrates the significance of addressing gaps in present literature. The problem addresses potential contributions advancing the knowledge discipline of breast cancer disparities research with a progressive theoretical framework for cancer prevention programs and

health promotion and education (Gehlert & Coleman, 2010; Kiddler, 2008). Contributions of this study can advance the practice of healthcare disparities among Latinas in the United States. Understanding the breast cancer experiences of Latinas expands beyond the quantitative outcomes of utilization of care services based on socio economic influence alone, but to the qualitative needs of the growing Latina population in the United States and their long-term survivorship. For example, current research asserts that socio-economic deprivation contributes to advanced risk of breast cancer in Black and African American women and Latinas posing increased risk of breast cancer mortality (Vona-Davis & Rose, 2009). As of 2012, it is estimated that 29% or 17,100 females were diagnosed with breast cancer (American Cancer Society, 2014). The American Cancer Society contends that factors contributing to increased breast cancer risk include (a) age, (b) onset of menses, (b) family history and (c) genetics, (d) late menopause, (e) alcohol consumption, and (f) physical inactivity (American Cancer Society, 2014, p. 6). As previously stated, breast cancer is the leading cause of death in Latinas. While slight decreases (1.6%) in breast cancer diagnosis have been noted between 2009-2012 with limited reasons as to the cause, most cases are determined at the late stage with socio-economic status (SES) and age with 54% at local stage in comparison to 64% of non Latinas (American Cancer Society, 2014).

Furthermore, the American Cancer Society (2014) suggests increased breast cancer in Latinas could be a result of lower utilization of mammography screenings, and delayed followed up exams upon abnormalities discovery (p. 6). Consequently, Latinas incur difficult tumors with limited response to treatments. This may be a result of disparities in difference access to quality care and treatment in a timely manner compared to non Hispanic females' populations (American Cancer Society, 2014) tumor result outcome differences associated with lower survival rates. An analysis of research study could increase understanding and communication

between providers and improved intervention programs. Other contributory factors to high incidence of breast cancer in Latinas and survivor rates for consideration include (a) beliefs, attitudes, and culture (American Cancer, Society, 2014).The American Cancer Society (2014) asserts that to care as a leading cause of socio-economic status. Latinas' are less likely to have financial resources or health care insurance or income to assist with access to care making diagnostic screenings and treatment a challenge. Such variables as high poverty rates, discrimination and "provider bias" contribute to the influence of diminished access to care and preventative services (American Cancer Society, 2014). Contributions from this study, however, can add to current research on Latina breast cancer survivors and how health care professionals can improve comprehensive access to quality of care before breast cancer or late stage diagnosis develops.

Finally, the social change implication of this study demonstrated results that are able to contribute to the existing literature on health disparities, compliance motivations to diagnostic care and long- term treatment of breast cancer among Latinas in the United States. The study is significant as these results lay a foundational framework for the design of healthcare models specific to disparaged populations as Black and African American and other vulnerable female groups where minimal research exist on the topic. This research can be shared and compared when addressing other ethnic and non-white female populations.

### **Summary**

The American Cancer Society (2014) suggests the Hispanic females' community as the fastest growing population in the United States. It further asserts breast cancer as the most common form of cancer among Latinas in the United States (American Cancer Society, 2014). The Center for Disease Control and Prevention (CDC, 2013a) asserts that "while Black Women

have a 40% higher incidence of breast cancer related deaths (morbidity) and mortality rates in American than women of any other ethnic group, Hispanic females' are less likely to be screened and varies among Hispanic females' subgroups" (CDC, 2013b). These subgroups consist of Puerto Rican, Mexican, Cuban, Mexican American, and other Hispanic females' subgroups. Consequently, limited data exist on Latina culture and breast cancer incidence (Miranda, Tarraf, & Gonzalez, 2011). The Center for Disease Control and Prevention suggest "Incidence rates of late-stage breast cancer were highest among women aged 70–79 years and black women" (CDC, 2013c). Conversely, breast cancer among diverse racial and ethnic categories and subgroups exist primarily in quantitative research, with minimal research in current or qualitative numbers of breast cancer screenings or accurate assessment. Current research among Black females and Latinas in breast cancer screenings, diagnosis, and experiences of patient provider relations are impacted for various reasons not understood. For example, limited research persist regarding socio economics, social status, health behaviors, beliefs, and cultural competency influence on experiences among Black American females in breast cancer outcomes.

Chapter 1 has provided background information on some breast cancer statistics and incidence among African and black American females, and Latinas in the United States. It has further identified breast cancer as the most common cancer diagnosed amongst Latinas. Supporting evidence by the World Health Organization and American Cancer Society for example has provided some statistical data related to mammograms, racial and ethnic comparison between Latinas and Black and African American females. Demonstrated studies on breast-cancer among vulnerable female populations have been discussed. The qualitative study focused on barriers to diagnostic exams as mammography, biopsy decision –making; and their impact on discovery of breast tumor and late stage diagnosis contributing factors.

Chapter 1 further identifies the problem statement to reduce breast cancer disparities among Latinas in the United States according to the literature. As asserted, in 2009, 211, 731 cases of breast cancer diagnosis were highest among female ethnic and racial populations with Black females with highest of all population groups (CDC, 2012; CDC, 2013b). Yet, the disease is the primary cause of death among Latinas contributing to other types of cancers (American Cancer Society, 2014). Further, the chapter addressed the theoretical framework of a qualitative grounded theory approach to identify the expressed experiences of Latinas' with a breast cancer diagnosis. Chapter 1 reviewed the E2D2 model by Petermann and Petz (2010) and a collaborative community program by Kidder (2008) utilized to identify emerging evidence with the goal to answer questions that could assist physicians in building effective intervention programs preventing late stage BC diagnosis. In contrast, the Health Belief Model addressed in earlier in chapter 1, was utilized in correlation with the research questions for this study. The results of these tools contribute to the overall social change implications and current theories in breast cancer research among vulnerable female populations seeking breast health care in the United States. Further, these contributions provide reflective insight applicable to early prevention initiatives and required revisions to current policies impacting vulnerable female populations in the United States seeking access to care and utilization of services. Chapter 3 outlines the method of research from a qualitative perspective.

Finally, the proposal nature of the study will contribute to existent research on continuing gaps between minority populations in the United States and non -white groups. Chapter 1 addresses primary definitions of the study, assumptions to the barriers of Hispanic females' Latinas regarding mammography and delayed exams, and other cultural backgrounds impeding study outcomes (Gonzales et al., 2011). Limitations, delimitations, and significance of the study

are addressed in chapter 1. Subsequent to Chapter 1, Chapter 2 reviews pertinent literature to demonstrate current gaps in the research field regarding this population class and disparities in breast cancer. Chapter 3 of this proposal will describe the study's design: participants, assessment of data, data collection, and procedures of information obtained.

## Chapter 2: Literature Review

Chapter 1 identifies the problem statement as the need to reduce breast cancer disparities among Latinas in the United States. The purpose of this study explored the lived experiences of Latinas in the healthcare delivery system when a breast tumor was found or a confirmation of breast had been diagnosed. Present research concerning the relevance of the problem suggest, Latinas' in the United States and Black and African American women have a higher incidence of late stage breast cancer diagnosis, and breast cancer related death (NCI, 2014; CDC, 2012). Latina women in the United States include "Mexican origin (63%), followed by Puerto Rican (9%), Central American (8%), South American (6%), and Cuban (4%) and other descent" (American Cancer Society, 2014, p. 1).

To date, research has been limited in understanding the deficits of breast cancer diagnosis and staging among Black and African American and Latinas. This limited has been primarily designed in a quantitative method providing minimal qualitative approaches. "Thus, there is limited research with respect to these markers, as well as the relationship between breast cancer risk factors and breast tumor subtypes" (Hines et al., 2011, p. 1548). For example, in a study on socio economic disparity influences, Davis and Rose (2009) assert a correlation between high breast cancer risk and mortality among minority groups as African American and Hispanic females' individuals in the United States and socioeconomic deprivation and poverty (Davis & Rose, 2009). Davis & Rose (2009) contend this increased breast cancer risk is correlated to advanced incidence risk than white patients. Conversely, reasons or understanding of why or how these markers contribute to the incidence of increased breast cancer or advanced stages of the disease are assumed to socioeconomic deprivation and poverty as asserted above. Further, according to the Center for Disease Control and Prevention (2012c), black women in the United

States are more likely to die of breast cancer than any other ethnic/racial group followed by Latinas. These two population (Black and African Americans and Latinas) demographics are also diagnosed at more advanced stages of the disease (CDC, 2012c). In comparison with another minority group, a study of American Indian/Alaska Native women over the age of 40 findings' asserted by Center for Disease Control and Prevention (2012c) utilized variables such as income, health insurance, and education certain minority populations and mammography exams. Findings suggested lower compliance to mammography or access to mammography screenings contributing to increased breast cancer incidence and late stage prognosis or size of tumors (CDC, 2012c). For example, Davis and Rose (2009) contend in a quantitative study of socioeconomic influence on African American and Latinas:

Hispanic females' breast cancer patients were reported to have a higher frequency of ER-negative tumors than non-Hispanic females' white patients, but the difference was not as great as that seen for African American patients (p. 885).

Further, the study by Davis & Rose (2009) found:

...confirmed the significantly higher proportion of ER-negative breast cancers in Hispanic females' white women (OR 1.4, 95% CI 1.3-1.5,  $p < 0.05$ ) and, particularly, African American women (OR 2.1, 95% CI 1.9-2.2,  $p < 0.05$ ) women compared with non-Hispanic females' white women (p. 3).

This study considered such health disparaged themes as the influence of socioeconomic status, poverty, education, health care insurance and cultural health beliefs or values potentially influencing systematic trust (American Cancer Society, 2014). Other considerations included spiritual or religious influence and perception of prognosis severity. Conversely, variables of the study focused on a) compliance and adherence to biopsy diagnostic exam and b) health outcomes of Latinas in the United States.



Because this population group varies in diversity types, identifying barriers to health education of breast cancer, family genetics, and knowledge of breast cancer health would prove beneficial to understanding similar behavior variables or trends impacting each demographic group (Corcoran, et al, 2012; American Cancer Society, 2014). For example, Latina immigrants, South American or Mexican women may have cultural and behavioral differences in approach to chronic disease, prevention, and health care importance than American born Latinas. Therefore, further qualitative studies, focused on the populations groups varying diversity types, would contribute significantly to community support programs; prevention methods influence quality of care, health care access, and insurance programs (American Cancer Society, 2014). While not indicative of race or ethnicity, some research results among Black and African (those of direct African descent) Americans and Latina are compared (American Cancer Society, 2014). Chapter 2 reviewed relevant literature of the theoretical Health Belief Model and themes of culture, access to care or biopsy, equitable care. Variables of the study considered a) compliance and adherence to biopsy diagnostic exam and b) health outcomes of Latinas in the United States.

### **Literature Search Strategy**

Presentation of research inquires and methodologies established a location strategy for future article reviews. The review strategy of literature emphasized research outcomes present in the location of articles for analysis, comparison, and contrast of data collected. Search engines utilized for literature review include government agencies such as Center for Disease Control and Prevention and National Cancer Institute. Databases researched were Pubmed, CINAL and Medline. For example, CINAL and Medline key terms utilized throughout the research process include access to care, Latinas, biopsy, mammogram, health disparities, breast cancer, and socioeconomic factors. Many current studies included quantitative studies regarding this

population demographic in combined studies such as breast cancer, cervical cancer, and colorectal cancers. Limited research literature on Latinas in the United States focused on breast cancer and disparities alone persist. It was determined that a comparative association of the Black and African American female demographic and breast cancer could be utilized. As cited throughout the dissertation, Black and African American and Latinas are dis-proportionately impacted by a higher incidence of late stage breast cancer diagnosis, and breast cancer related death (NCI, 2014; CDC, 2012, Hines et al., 2011). Additionally, these two minority groups have lower rates of mammography exams.

### **Theoretical Foundation**

The theoretical framework selection for this grounded theory qualitative approach is the Health Belief Model (HBM) with potential to develop an innovative theory or contribute to current theory literature review. Glasser and Strauss established the origin of grounded theory in 1967. The theory is a systematic process of collecting and analyzing qualitative data “grounded in the data themselves” (Charmaz, 2006, p. 2). Data is collected at the onset of the research project with the outcome of generating concepts from analysis that demonstrate and reflect the lives of participants in their environment. Data is then separated, sorted, and synthesized utilizing qualitative coding. This data is categorized and compared giving researcher a “scene” of what is happening within the data (p. 2-3). The worldview is the social constructivism approach. Through this lens the researcher expands subjective implication from participant experiences and relies heavily on the views of participants often based and negotiated socially and historically (Creswell, 2007, p. 20). For example, one potential participant may question perceptions of institutionalized racism as a constituent to quality care influencing delayed diagnostic exams and late stage diagnosis. Views are formed through interactions with others

and historical and cultural norms operating in individual lives. The Health Belief Model examines health behavior in a four tiered construct: (1) perceived seriousness; (2) perceived susceptibility; (3) perceived benefits; and (4) perceived barriers including actions, motivating factors and self-efficacy (Blearning, 1998) and can provide insight as it relates to breast cancer tumors or diagnosis in Latinas in the United States. In addition, the grounded theory approach will support this study. Creswell (2007) contends:

Grounded theorists, for example, generate a theory grounded in the views of participants and place it as the conclusion of their studies. Some qualitative studies do not include an explicit theory and present descriptive research of the central phenomenon. (p. 70).

### **Literature Review**

Latinas in the United States face an increased mortality risk associated with breast cancer diagnosis. It is also the most commonly diagnosed cancer among Latinas (Hines, et al., 2011; ACS, 2014). A qualitative study of access to biopsy exams, and perceived severity of illness analyzed the following: a) compliance and adherence to biopsy diagnostic exam and b) health outcomes of Latinas in the United States. The construct of the Health Belief Model guided the foundation: (1) perceived seriousness; (2) perceived susceptibility; (3) perceived benefits; and (4) perceived barriers including actions, motivating factors and self-efficacy (Blearning, 1998). The literature review addressed the potential relationship between patient health disparities, provider influence, insurance, access to care or ability to pay, and autonomy.

Related studies of health disparities in breast cancer research approach are posited. For example, according to article published by the Institute for Health Research and Policy (LaVeist, Gaskins & Richard, 2009) on what influences minority women to follow the doctor's advice about breast cancer approximately 1 quarter of American women are faced with greater risk of developing breast cancer and beyond interventions of a mammogram and at age 40 and above.

The risk increase with age and are less treatable due to advanced staging of tumors and other at risk factors as recent physician visits. This would also depend on individuals risk associated with frequency of breast exams, and mammogram screenings before the woman turned 40, MRI scans mammograms or other medications associated with breast cancer (LaVeist, et al., 2009). Additionally, a quantitative study conducted by Medina-Shepherd & Kleier (2012) predicting mammography results utilizing the Champions Health Belief Model sought to understand behaviors of Latinas in Florida. The criteria were for 200 Spanish -speaking women between the ages of 45-75 with no history of breast cancer in effort to identify barriers. Though similar questions were asked results did not align with the Champions Health Belief Model outcomes (Medina-Shepherd & Kleier, 2012).

## **Culture**

Diverse Latino and Hispanic females' cultures present a range of barriers to care access, quality, and services received. As such, these "cultural variations" have influenced the process of inequities in initiatives and prevention programs in the United States (ACS, 2014; Willson, 2009). Further, in a study by Erwin, et al. (2010) these cultural complexities have presented ongoing challenges within the Latino cultures when addressing health control intervention programs such as cancer or the development of breast cancer. In this study, the authors attempted to develop a theoretical framework based on a larger intervention development program for the diverse Latino and Hispanic females' cultures/groups and influence of culture, ethnicity and intervention. Participants were of Puerto Rican, Dominican Republican, and Mexican descent in New York and its surrounding areas and Mexican immigrants from Arkansas (Erwin, et al., 2010). In addition, the authors sought to research the associations' or variations

of barriers based on culture with variables as religious affiliations, gender relations, and experiences within the Latino and Hispanic females' sub-communities and their connection to social political structures within the community. Results from the study conversely, determined that multi-locations of these subcultures are impacted by different systems or environmental factors. Each rural or urban location and subculture produced variations of traditional beliefs. These facts are critical to the research in providing insight to varying perceptions of illness severity, or access to biopsy exams and resources available for treatment.

### **Equitable Care**

In the twenty first century, the dynamics of health care and health care utilization is changing dramatically. Though the United States has been one of the most resourceful countries in the world, it ranks 37<sup>th</sup> in equitable health care delivery, providing compromised health care coverage, as well as leadership in national and global health challenges (World Health Organization, 2013). While technology is advancing, the cause of health care delivery policy and research measures, equitable access should be a priority predicated upon the explicit requirements of United States emerging societal framework. For example, small steps in economic rectification contribute significantly in aligning today's health care delivery system to meet the requirements of the Latinas, Black and African American females and other population citizens, as well as non citizen immigrants. Consequently, a manageable affordable plan encompassing quality and utilization of services, provider education, and quality of care aligned to meet minority and vulnerable populations, such as those of Hispanic and Latin, and Black and African American descent is recommended. The Center for Disease Control and Prevention (2014) has identified such groups as "Multiracial, American Indian or Alaska Native, Asian

American, Black or African American, Hispanic or Latino, and Native Hawaiian or Other Pacific Islander” (para. 1).

### **Access to Care**

According to Courtwright (2008) individual health outcome status can be directly compared to individual social status or socioeconomic status. Conversely, the literature argues differences in health disparities based upon various patient capabilities in justice approach, rather than socioeconomic status. It is argued that education, income, social stigmatism, and resources facilitate balance in the inequities of health disparities. However, economist, Amartya Sen, asserts correlation between inequities of health disparities and individual accesses to quality functioning capabilities determine patient opportunity to create well-being.

Courtwright (2008) posited the connection between social status or autonomy, patient capabilities, and health disparities. Perceptions of health equity play a vital role in concepts of treatment, severity of illness, and quality of care received. The author addresses the formative theory of injustice proposed by the economist, Amartya Sen approach of relationship between health disparities and autonomy. Sen’s approach suggests a collection of an individual’s life activities dictate “functions” or labels of functioning in society based on freedom of alternative choice. For example, individual happiness, adequate nutrition, community involvement and view of mortality and morbidity affirm a person’s overall well-being. Sen’s asserts restrictions or limitations to access these freedoms of function limit opportunity to obtain well-being (Courtwright, 2008, p. 6). In contrast, Marmot (Courtwright, 2008) implies autonomy and well-being are products of socioeconomic status or syndrome, not freedom of function limitations.

Such variables are attributable to the level of control and autonomy perceptions by minority and ethnic groups and improved health outcomes.

The Maly et al. (2011) analysis reviews relationship of delayed diagnosis of breast cancer incidence and survival rates among disparaged populations (Wujcik, et al., 2009). In this quantitative study (Maly et al., 2011) utilized established indicators aligned to demonstrate increased abnormalities and correlation of diagnosis among low-income women. Analysis of a time lapsed study utilized patients diagnosed with Breast Cancer (BC) abnormalities who were low income, with health insurance, health system utilization and those self detected abnormalities. Outcomes of the study demonstrated women of the self -detected group incident with higher occurrence of increased delay of diagnosis. For example, African American females demonstrated longer intervals seeking resolution than females of Caucasian population (Maly, et al. 2011).

According to Maly, et al. (2011) research low income uninsured women (15%) present higher incident of late stage breast cancer diagnosis. The cross sectional quantitative study which consisted of 921 women of low income status asserted variable characteristics associated with delayed BC and BC abnormalities are fewer mammograms, low income status, as well as beliefs, attitudes, and experiences within access to the healthcare system and resources. Inconsistencies persist in accordance with race and ethnicity. Conversely, research is limited associating delay in care, low income among populations self detected and healthcare system detection of abnormalities (Maly, et al., 2011). In addition, communication outcomes between physician and patient upon diagnosis and delay in follow up care has not been significantly investigated. In a study assessed between 2003 – 2005 in association with the California Breast and Cervical Cancer Treatment Program utilizing underinsured and uninsured participants,

participants with language barriers in English or Spanish were excluded from the study (Maly, et al., 2011)

Finally, the study only involved patients in California. Further studies are required to make full assessment of similar outcomes associated around the country. In another study, according to Gonzalez, Mills, Calavera, Elder, and Gallo (2011) as of 2011 it is anticipated over 230, 000 American women will be diagnosed with breast cancer. Early detection increases survival and morbidity rates to 5 years after diagnosis. Conversely, ethnic disparities have a higher incidence of breast cancer mortality and morbidity due to later diagnosis. A quantitative analysis was conducted with an objective to examine validity of multiple cancer prevention programs in contrast to individual cancer screenings for effective outcomes of program adherence. Nonetheless, Hines, et al (2011) argues Latinas have fewer breast cancer diagnoses but, higher mortality incidence of breast cancer latent stage diagnosis. Analysis of cancer risk associations and tumor features were investigated in peri-menopausal and menopausal participants to determine relationship between alcohol ingestion and quantity of children, obesity, or staging of tumor type or subtype as possible causes of breast cancer.

The author (Willson, 2009) utilized a quantitative statistical methodological approach that examined pathological reports, breast cancer tissue samples for tumor assessment, and microarrays acquired from the 4 Corners Breast Cancer Study and the NHW generalized population-controlled case study demographic. The goal was to understand or identify why patterns of health disparities persist, and a potential connection between health and socioeconomic status. Results of the study were sufficient and proved data from participants based on such contributing factors as “diet, lifestyle, and genetic disposition” (Willson, 2009). Willson (2009) argued the following:



...persons of higher SES have at their disposal a broad range of flexible and multi-purpose resources that can be used to the advantage of their health, including knowledge, money, power and social connections. These resources are used in a purposeful way to influence health, which allows the strong relationship between SES and health to persist despite particular social factors that exist at a given time. (p. 94).

Results of such a quantitative study are appropriate to the qualitative study of Latinas and breast cancer potentially as additional variables to health and economic status. The research examined these variables of socioeconomic status and is appropriate to this study.

In a quantitative study by Bynum et al. (2012) of HPV health beliefs and cancer 575 African American college students (male and female) between ages 20-24 attending historically black colleges/universities. Similar variable measures of socio-demographics, health care system distrust, results yielding outcomes of HPV vaccine acceptability in the prevention of HPV virus were included in the method approach (Bynum, et al., 2012). The study utilized the Health Belief Model and included variables of perceived susceptibility and severity, perceived risk of illness/virus and would prove useful in developing health programs specific to the population. Further, findings concluded that health beliefs and history or past behavior was not indicative of vaccination acceptability. This would provide culturally appropriate knowledge based initiatives.

In a study by Nelson, Zakher, and Miglioretti (2011) the literature systematically reviews factors attributable to breast cancer in women over 40 years of age. Criteria were established in a quantitative study design, and outcomes were analyzed in follow up. Compilation was established through quality of sample size, and applicable assertions utilized from observation, randomized and controlled trials, and Meta – analysis data collection effort. For example, the study demonstrated women with dense breast tissue are at increased risk of breast cancer over

the age 40. This information is significant in the development of community breast cancer awareness programs, initiatives, and promotional campaigns directed explicitly to minority female populations at risk. The Center for Disease Control and Prevention (2014) has identified such groups as “Multiracial, American Indian or Alaska Native, Asian American, Black or African American, Hispanic or Latino, and Native Hawaiian or Other Pacific Islander” (para. 1).

Further, according to Nelson, et al. (2011) previous results from over sixty- six other studies examined associated personal health risks, reproductive factors, family history, practices and procedures. Results from the study indicated a 2 fold increase of breast cancer among women with dense breast tissue, one or more relatives of breast cancer diagnosis, and are over the age of 40. Though the clinical trials associated with the study produced useful tools and suggested modifications with potential to reduce breast cancer incidence among women 40 years of age and older, data has been insufficient and untested. Consequently, the article recommends improved models of potential risk factors, strategies with higher incidence of prediction rates, and increase relevant and recent research in effort to provide increased future application outcomes.

Gonzales et al. (2012) contends the U.S. Prevention Services Task Force recommend appropriate mammograms for at risk women age 40 and over. Conversely, benchmarks have yet to establish criteria and recommendations sufficient to minority female populations. Further, the authors assert research indicators have been unambiguous in a broad epidemiologic analysis and afford minimal reliability.

In review of access to care, Yearby (2011) discuss the seriousness of rationed healthcare services and access to care in the United States. For example, while access to care may be widely available, income disparities may halt treatment at minimal cost verses the high cost of

blocked access to services with exorbitant cost. Yearby (2011) contends this is in large part due to the higher number of minorities receiving government healthcare assistance with diminished ability to pay for health care services, and lack of physician participation in such government funded programs. The system of health care services and access to care rationing began as a way of managing and allocating limited resource based on scarcity of available services. This set the stage for services based on ability to pay or income, and required health care insurance.

Consequently, privatized health insurance and high income provides access to care and quality services, while limiting the access to care and quality of services to those with government funded insurance (Medicaid, Medicare, Management Care) and limited income resources. Minorities that are uninsured or underinsured are less likely to have access to health care, receive quality care, or to receive preventative care. In addition, cost of medical bills and required prescription are not affordable. In the United States, minorities disproportionately receive lower wages than Caucasian counterparts making it difficult to obtain health coverage and higher incidence of receiving government health rationed resources as Medicaid (Yearby, 2011).

According to Yearby (2011) the Census Bureau (2007) suggests minority groups suffer disproportionately higher levels of poverty. For example, the 2007 report asserts 24.5% Black and African Americans, and 21.5% Hispanic females' Americans were in poverty compared to 8.2% Caucasian Americans thus increasing chance of racial inequities and a 25% increase of mortality within the United States. These numbers do not include Asian Americans, though classified a minority population. Further, Yearby (2011) research indicates African American's have higher incidence of trauma related mortality associated with lack of insurance or insurance status than their Caucasian counterparts (Yearby, 2011; Gonzales, et al., 2012).

It is concluded that the United States system of health care is irrational and favors wealth over need, thereby increasing inequitable allocation of supposed scarce resources. This assertion assumes minorities as disproportionately impacted on the basis of limited wealth and resources, thereby having limited means of equitable access to services and care. Because the minority groups of reference are Black and African American and Latina American, the policy of rationing of health resources characteristics specific to these populations should be addressed in understanding social factors and economics relative to these populations.

In a review study by Wujcik, et al. (2009), statistics and data collection information was presented relative to delayed mammography testing after diagnosis and procedures among disparaged and vulnerable female populations. Predictors for behaviors associated with delayed interventions are examined and relevant to breast cancer research dissertation. Variables of the study consist of females in underserved populations, minority women, and low-income women. The authors, Wujcik, et al. (2009), endeavored to illustrate results of free statewide mammography program for females run between 2000 through 2006 to determine associated delays of diagnostic testing or follow up after diagnosis of breast cancer. Participants of post breast cancer diagnosis, and abnormal mammography outcomes were observed. A combination of quantitative methods of research was utilized in a regressive bi-variant and multivariate controlled case design with objective to identify factors contributing to delays in breast cancer treatments. Variables established in the statewide mammography screening program study included zero fees for screening, race, ethnicity, marital status, age, and breast health history; however, income was eliminated as participant requirements were for low-income females. The authors, Wujcik, et al, (2009), assert severe consequences confront females who delay mammography screenings or treatments after diagnosis. The study determined that low-income

minority women demonstrated three variables associate with delay in diagnostic screenings and follow up after diagnosis. Those variables include marital status, age, and history of breast health.

### **Quality of Care**

The overall objective of research is to provide a comparative précis of relationship in socio-economic status or social deprivation, and (ACS, 2014; Nelson et al., 2012) breast cancer mortality between European white women and diverse racial and economic female groups in the United States. In contrast, the author's research and comparative synopsis include links between obesity, genetics, and increased breast cancer prevalence (ACS, 2014; Nelson et al., 2012). In addition, higher incidence and rates of breast cancer diagnosis are reported among white American and European females of upper income or socio-economic status, whereas increased adverse breast cancer prognosis is associated with low income or diverse socio-economic females both European and racial and ethnic class Americans.

Vona-Davis & Rose (2009), contend assessment methods utilized were based on SES indicators as education, income, environmental consequence such as smoking, or other neighborhood factors influencing increased breast cancer diagnosis, stress related factors, and poor health assessment. Participants were acquired from therapeutic clinical settings; conversely considerations for neither socio-economic influences, nor age of participants at time of prognosis were factored in to study results (Vona-Davis & Rose, 2009). In contrast, Willson (2009) purported the fundamental cause's theory is utilized to demonstrate or validate improved health status based on economic resources; in contrast to compromised economic influence and universal health coverage as a predicator to health inequity and delayed treatment and care of

preventable disease. Asserted results suggest higher incidence of preventable disease in the United States in contrast to Canada due to inequitable social policies and economic resources.

Willson (2009) suggests socioeconomic inequities have contributed to health disparities both nationally and internationally. The author sought to identify or determine causes of persistence of health disparities, risk attributable and preventable disease. Minimal comparisons in literature exist with developmental frameworks for impact of inequities and disparities in the United States. Those in higher economic class status maintain broader flexibility within societal measures of acquired access.

### **Summary and Conclusions**

In conclusion, Latinas', as well as Black and African American females are disproportionately impacted by disparities in the healthcare delivery system. According to The National Cancer Institute (NCI, 2014) "more aggressive breast tumors persist in younger Black/African and Latina American females in lower socio-economic (SES) areas potentially attributable to poorer survival rates." While some literature exists demonstrating relationships between health status and disparities, Willson (2009) asserts minimal comparative literature exist to understand the connection between health disparities and SES or socio-economic status and the individual thought process. Further, in the fundamental cause theory comparatively conducted between the United States and Canada demonstrates that individuals of higher socio-economic status utilize more multi purpose and flexible resources that ensure stronger health and wellness outcomes. Conversely, improvements in risk factors have not minimized health disparities (Willson, 2009, p. 94).

Research has demonstrated intent to fill one gap in present literature. For example, according to Gonzales, et al. (2011) research has focused on understanding and utilization of

specific preventative interventions through increased educational knowledge of screenings proving less threatening; asserting this advanced knowledge could contribute to decrease in disparities among minority populations. Also asserted by Gonzales, et al (2011), breast cancer is the primary cause of death among Latinas and health status may contribute to the predisposition of this and some other illnesses. Characteristics of predisposed illness may include ethnicity, health beliefs, and marital status. In addition, an individual's ability to utilize healthcare services such as insurance or usual source of care is determinants in breast cancer. It is considerable that generalized health promotion campaigns focused on all major cancers are preferred over individualized breast screening campaigns and increased adherence to cancer screenings (Gonzales, et al., 2011, p. 431). Chapter 2 has explored current literature focused on socioeconomic status, in health analysis of health disparities, characteristics of cultural health beliefs, both predisposed and cultural, and ability to pay for access to service and utilization of available resources. Other factors cited in Chapter 2 for consideration included stress factors, behavioral patterns or intention of behavior change, perceived attitudes of physicians to target demographic, associated with delayed screenings, biopsy, and intervention programs.

The remainder of the dissertation's organization is as follows: Chapter 3 focused on research design and rationale, including the role of the researcher, and procedures of data collection. A social constructive philosophy of research demonstrates the research topic approach. Interview questions specific to access to care and utilization of services was utilized to examine associations to breast cancer screenings, access to biopsy, and related diagnostic services; including patient to provider relationship. Data collection procedures employed in compliance with the Johns Hopkins School of Medicine. The sample population of Latinas in the Northern Virginia, Maryland and District of Columbia areas consisted of twelve participants.

The collection of the data used gained from a one to one interview format per participant in English or Spanish in accordance with the participant's language preference. Understanding the expressed journey of Latinas' when diagnosed with breast cancer provides awareness of the physiological and psychological reflective perception of breast cancer morbidity and mortality incidence, improved community program initiatives, and contribute to the needs of this population's demographic; as well as other minority groups. This study was appropriate to the research questions posited in that it illustrates barriers to access to quality care, perceptions of biopsy exam access; and other accessible medical resources in the Northern Virginia and immediate surrounding areas such as Maryland and Washington, District of Columbia. The results are comparative between Black and African American and Latinas, contributing to other emerging research data collected from shared experiences of other minority females facing breast cancer in the United States in the future. The Center for Disease Control and Prevention (2014) has identified such groups as "Multiracial, American Indian or Alaska Native, Asian American, Black or African American, Hispanic females' or Latino, and Native Hawaiian or Other Pacific Islander" (para. 1).

Chapter 4 addresses the findings of how the research data was collected, gathered, and recorded. Understanding of recording keeping, cataloging system is identified. Further, Chapter 4 analyzed the data and presentation materials, problem exploration and research design; while Chapter 5 discusses the final interpretation of the results, conclusions, and research recommendations from data collection process.



## Chapter 3: Research Method

### **Introduction**

Chapter 3 discusses the qualitative research methodology focusing on the lived experiences of Latinas' and their access to breast care services, including biopsy exams. It discusses the method of research from a qualitative perspective. The study employed the grounded theory design utilizing the Health Belief Model (HBM) as a guide to expand on the theory or emergence of a new theory. This generalized grounded theory approach applied the conceptual framework of the Health Belief Model (HBM) to investigate progressive trends relative to this population demographic approach generated data recognizing any emergent trends, categories and themes.. Chapter 3 addresses the present gaps in literature for Latinas associated with barriers to access to care, quality of care and diagnostic utilization of services; after a confirmed breast cancer diagnosis, a biopsy of suspicious breast tissue, or discovery of breast tumor through self-detection. The chapter, further, addresses the necessity to advance the specific knowledge of their experiences in efforts to improve breast health wellness care for vulnerable female populations. It can benefit current literature pursuing the understanding of breast cancer experiences and access to care among Latinas' in the United States. The results of these tools will contribute to the overall social change implications and current theories in breast cancer research among minority females in the United States. Further contribution provides reflective insight applicable to early prevention initiatives and policies impacting minority females in the United States access to care and utilization of services.

## Research Design and Rationale

This study endeavored to answer the following research questions asserted in Chapter 1:

(i) How does perceived access to breast screenings, such as mammography, influence biopsy decisions when a tumor is detected, contribute to delayed or late stage breast cancer diagnosis in Latinas; (ii) How can breast cancer health providers, physicians, and professionals improve equitable access to care and breast care facilities that improve health outcomes related to breast cancer diagnosis, and increased survivorship among Latinas; and (iii) How can breast care health providers encourage early breast cancer detection and biopsy measures with tumor detection. This includes utilization of evidence-based services, and clinical preventative measures in breast cancer exams and diagnostics influence delayed exams and late stage breast cancer diagnosis.

The central phenomenon of the study explored the lived experiences of Latina breast cancer survivors by exploring their perceptions of access to care when confronted with the discovery of a breast tumor or breast cancer diagnosis and requirement for biopsy. The general definition of the central phenomenon was to understand the needs of Latinas related to their experience of breast cancer diagnosis and care. Current research literature traditionally examines the potential connections between beliefs, cultural context, and socio-economic status contributing to delay breast screenings by quantifying or measuring these outcomes. Conversely, this study implored a qualitative method allowing the participants to give voice or opinions to their experiences. Creswell (2007) asserts that qualitative research differs from quantitative by analyzing the perceptions, and experiences of participants and how they attribute to their lived lives, and the understanding of how or why they occur (p. 195). As such, analysis of the data collected referred to as contributable factors, was coded, categorizing and classified for patterns and themes assessment.

The traditional research method for a grounded theory utilizing the construct of Health Belief Model relates to the present study of breast cancer in Latinas by combining variable concepts comparatively for analysis such as: socio psychological behaviors, income barriers, group or socio-cultural influence, and individual expectations. Further, substantive norms and intentions impacting beliefs about mammograms, breast cancer seriousness or fears, access to the health care delivery system, and cultural beliefs surrounding breast cancer are also valuable in understanding barriers to available utilization of services. The grounded theory approach does not require a hypothesis but works best when the researcher is allowed to develop theory through coding metrics and inductive methods. For example, Creswell (2007) asserts grounded theory as an interpretive approach where substantive theory is developed via the researcher's view and participant experiences analyzed (p. 65). Grounded theory is most appropriate rationale tradition for this qualitative study, as the design provides data for the research questions based on the views of participants to develop inductive ideas in the study and the researcher as the observer developing a potential new theory or contributing to current theories in similar research studies (Creswell, 2007, p. 50). The grounded theorist researcher gathers abstract analytical data from interview data that explains theory action, interaction, or process. Theoretical sampling provides the development of interrelated categories for new theory trends associated with the phenomena of study (NSU, 2003). Though a new theory was not demonstrated from data collected; however, unexpected data trends were generated toward the end of study results, such as the impact of stricter immigration policies for undocumented Hispanic and Latino populations residing in the United States. As a result of these unprecedented immigration policy changes many potential volunteers were hesitant to share their experiences or add their voice for the research. Latinas may endure increased limitations to access to care and equitable quality care

challenges as a result of stricter immigration policies, economic and psychosocial insurance status, knowledge or education, cultural beliefs, income, religious affiliations, and language barriers.

### **Role of the Researcher**

Bias of the researcher, DBora Schrett, in this study is minimal and functioned as that of the observer and student only. There are no personal or power relationships, supervisory or mentorship roles with any participants as volunteers will be recruited anonymously in collaboration with Johns Hopkins School of Medicine and supporting area government and non-profit agencies. Consequently, no biases exist. Conversely, the researcher has experience as an uninsured minority female in the Northern Virginia and immediate surrounding areas such as Maryland and Washington, District of Columbia area seeking mammography screenings based on ability to pay and access to care. In addition, the researcher of this study has acted as caregiver to a minority female parent facing non Hodgkin Lymphoma and brain tumor removal (meningioma) with supportive care required at the Johns Hopkins School of Medicine and supporting area government and non profit agencies. As a caregiver, the researcher student has been involved in the process of care for patients of cancer from initial diagnosis, lifetime treatments, receiving emotional and spiritual support, physician and oncologist specialist affiliated with Inova Hospital Cancer Service and Johns Hopkins School of Medicine and supporting area government and non- profit agencies.

Additionally, the student researcher has completed a comparative analysis of health insurance markets in the United States, Germany, and Canada. Further, the researcher in this study has worked in the health insurance industry and has experience with the protocols of health insurance compliance, patient provider relations, and ability to pay options as well as alternatives

among minority females in the Northern Virginia and immediate surrounding areas such as Maryland and Washington, District of Columbia area. As such, the researcher is aware of these experiences potential impact on the study and will safeguard knowledge accordingly. Finally, there were no ethical issues or conflicts of interest that interfere with this study. Participants were not interviewed in researcher work environment therefore no power differentials existed.

### **Methodology**

The demographic population identified for this study is Latinas, with a confirmed diagnosis of breast cancer. The constructive sampling strategy is purposive or based on what is known about the participants. The sampling strategy required 17-25 Latinas as required by the Johns Hopkins School of Medicine and supporting area government and non- profit agencies for sufficient saturation of data for collection. Twelve Latinas were recruited and participated in this study. Creswell (1998) suggest a sample size of 20-30 is sufficient for saturation in a grounded theory (p. 64) . Charmaz asserts, “A study of 25 interviews may suffice for certain small projects” (p. 114) providing evidence to support the sample strategy. Saturation or Theoretical Saturation is defined as “the point at which gathering more data about a theoretical category reveals no new properties nor yields any further theoretical insights about the emerging grounded theory” (Charmaz, 2006, p. 189).

A qualitative expert associated with the Johns Hopkins School of Medicine, Life With Cancer Center and other supporting area government and non- profit agencies were consulted for sample strategy justification. The Johns Hopkins School of Medicine and Life With Cancer Center have tested sample sizes of 25 in past studies and their results were sufficient. Additionally, other qualitative studies related to chronic illness studies such as other cancers or breast cancer demonstrate sample sizes of women 25 or less participants with sufficient results in

themes from category saturation (Banning & Tanzeem, 2013, p. 254; Lee, Wakefield, Foy, Howell, Wardley, and Armstrong, 2011, p. 1044). The small sample size of participants does not pose a problem in grounded theory. For example, according to Charmaz (2006) “small samples and limited data do not pose problems because grounded theory methods aim to develop conceptual categories and thus data collection is directed to illuminate properties of a category and relations between categories (p. 18).

The criterion selection required participants to live in the United States specific to Northern Virginia, Maryland and Washington, D.C. Participants were also required to be female, self-identified as Hispanic heritage, and 19 years of age or older. The inclusion criteria for each participant of the study were individuals who discovered a breast tumor and engaged in the decision making process to seek biopsy, breast cancer diagnosis, and treatment alternatives. It was preferable that participants received diagnosis, treatment, and care within the Northern Virginia and immediate surrounding areas such as Maryland and Washington, District of Columbia. Recruitment inclusion recognized by all participants to meet qualification preferences was: female, self-identified as Hispanic heritage, and 19 years of age or older, breast cancer survivor or patient with a breast cancer diagnosis; and, have had a mammogram within the last three years. Participants could be English, Spanish or bilingual speaking.

As previously stated, participants were recruited utilizing flyers approved and developed in collaboration with the Johns Hopkins School of Medicine Institutional Review Board (IRB). Flyers were placed throughout Oncology and Radiology departments at the Breast Center of Johns Hopkins Medicine in Baltimore, Maryland, Department of Health locations throughout Loudoun County, Virginia, participating physician office’s with Inova Hospital Breast Care center, Floris United Methodist Church in Northern Virginia, Nueva-Vida of Washington, D.C.,

Life With Cancer Center in Fairfax, Virginia distribution lists and the Arlington Free Clinic. Flyers were designed in English and Spanish as required by Johns Hopkins School of Medicine IRB. The flyers included the contact information of Marcela Blinka, MSW. Ms. Blinka, who is bilingual in English and Spanish, was able to explain the selection criterion and required qualifications to participate in the callers preferred language. In addition, potential prospective subjects were identified within the several local participating public health partnerships serving the Hispanics and Latina healthcare communities where recruitment flyers were displayed. The Office of Community Health assisted as required. Participants were identified in partnership with Johns Hopkins Medicine Breast Center, local partnerships and government and non- profit agencies and contacted via approved marketing materials established with the Johns Hopkins School of Medicine IRB and the Office of Community Health as required. The sampling strategy required 17-25 Latinas as required by the Johns Hopkins School of Medicine and supporting area government and non- profit agencies for sufficient saturation of data for collection. Conversely, twelve volunteer participants qualified according to the inclusion criteria and agreed to join the study. Charmaz asserts, “A study of 25 interviews may suffice for certain small projects” (p. 114) providing evidence to support the sample strategy. Saturation or Theoretical Saturation is defined as “the point at which gathering more data about a theoretical category reveals no new properties nor yields any further theoretical insights about the emerging grounded theory” (Charmaz, 2006, p. 189).

## **Participants of the Study**

Latina women in the United States are disproportionately impacted by high incidence of breast cancer, increased mortality rates, and challenges to breast cancer treatment (American Cancer Society, 2014). The study utilized purposive and convenience sampling methods from the participants. Other qualitative studies related to chronic illness studies such as other cancers or breast cancer demonstrate sample sizes of women 25 or less participants with sufficient results in themes from category saturation (Banning & Tanzeem, 2013, p. 254; Lee, Wakefield, Foy, Howell, Wardley, and Armstrong, 2011, p. 1044). Purposive is defined as a method of sampling “according to categories that one develops from ones analysis and these categories are not based on quotas; they’re based on theoretical concerns” (Charmaz, 2006, p. 101). Convenience sampling is defined a “no probability sample in which respondents are chosen based on their convenience or availability” (Creswell, 2009, p. 148). Purposive sampling is selected based upon participants appropriate for the study, while convenience sampling is based upon those participants available (convenient) for the study through assertive recruitment methods.

The main research question of this study is: (i) How does perceived access to breast screenings such as mammography, influence biopsy decisions when a tumor is detected, contribute to delayed or late stage breast cancer diagnosis in Latinas; (ii) How can breast cancer health providers, physicians, and professionals improve equitable access to care and breast care facilities that improve health outcomes related to breast cancer diagnosis, and increased survivorship among Latinas; and (iii) How can breast care health providers encourage early breast cancer detection and biopsy measures with tumor detection. Conversely, the gap in breast cancer literature research minimally addresses influences to Latinas at increased risk attitudes, beliefs, and actions to access to care and quality of services utilization. The purpose of this



exploratory study was endeavored to minimize that gap by attempting to understand perceptions of breast care, breast cancer and the biopsy decision making process for Latinas at risk. The participant age requirement consisted of Latinas 19 years of age or older. The study pursued a sample size of 17-25 participants for recruitment. Saturation or Theoretical Saturation is defined as “the point at which gathering more data about a theoretical category reveals no new properties nor yields any further theoretical insights about the emerging grounded theory” (Charmaz, 2006, p. 189). Recruitment flyers for participants were selected from the Oncology and Radiology departments at the Breast Center of Johns Hopkins Medicine in Baltimore, Maryland, Department of Health locations throughout Loudoun County, Virginia, participating Physician office’s with Inova Hospital Breast Care centers, Floris United Methodist Church in Northern Virginia, Nueva-Vida of Washington, D.C., Life With Cancer Center in Fairfax, Virginia distribution lists and Arlington Free Clinic in Arlington, Virginia and by word of mouth from community public healthcare leadership associated with this target population.

Upon completion of data collection results may be utilized by the Johns Hopkins School of Medicine with consent from the student researcher, DBora Schrett, for future research pertaining to Latinas. The study required 17-25 Latinas as required by the Johns Hopkins School of Medicine IRB and the Walden University Institutional Review Board for sufficient saturation of data for collection. Creswell (1998) suggest a sample size of 20-30 is sufficient for saturation in a grounded theory (p. 64). Charmaz asserts, “a study of 25 interviews may suffice for certain small projects” (p. 114). Saturation or Theoretical Saturation is defined as “the point at which gathering more data about a theoretical category reveals no new properties nor yields any further theoretical insights about the emerging grounded theory” (Charmaz, 2006, p. 189).

Conversely, only twelve Latinas participants were recruited for the study. The recruitment outcome was negatively influenced by current uncertain changes in immigration policy by the Trump Administration, ICE, and the Department of Homeland Security. A qualitative expert associated with the Life With Cancer Center and other supporting area government and non profit agencies was consulted, as well, Senior Principle Investigator, Dr. Zabora, for validity and credibility of the sample size and alignment with the research questions . The Life With Cancer qualitative expert and supporting area government and non profit agencies tested sample sizes of 25 in past studies and their results were sufficient.

### **Instrumentation**

The method for collecting data was through individual interviews of Latina participants. The instrument for interviewing participants was a series of qualitative questions utilizing the grounded theory method produced by the researcher, DBora Schrett and pre-approved by the Johns Hopkins School of Medicine Institutional Review Board and supporting area government and non-profit agencies staff to ensure alignment with research questions of the study. The interview protocol questions can be found in Appendix B. The study sought 17 -25 Latinas as required by the Johns Hopkins School of Medicine and supporting area government and non-profit agencies for sufficient saturation of data for collection. As previously stated, a small sample of twelve Latinas participated in the study potentially creating a threat to validity. A small sample pool of one to one interview questions per participants was completed and open coding applied providing more detail in the process (Huberman & Miles, 1994; Creswell, 2007, p. 156).

The basis for instrument development asserted by Creswell (2007; 2009) delineates characteristics of significance in qualitative research. A quantitative approach is inappropriate

for this study as quantitative operates within a deductive model of fixed objectives for research, exhaustive definitions prior to research proposal and precisely defined (Creswell, 2009). In comparison, qualitative methods provide for diverse philosophical examples, assumptions, data collection methods, interpretation, analysis, ethical considerations, and strategic inquiries define validation of treatment implications of unique steps in analysis, and diversification of strategic inquiries. Further, instruments of collection are inductive with meaning implications from the individual, emergent, and employs theoretical lens, is holistic, and interpretive (Creswell, 2009). In addition, Patton (2002) contends limited investigated data persist on this demographic population, and provides understandings, concepts, and theme depth within data collection process.

Charmaz (2006) asserts qualitative research in grounded theory, originally established by Glaser and Strauss in 1967 providing further explanation of theoretical frameworks, abstract meanings of phenomenon researched, employs different philosophical assumptions; and systematically provides consistent guidelines for data collection and analysis based in a grounded approach of emergent trends and concepts throughout the interview process (p. 2-6). According to Charmaz (2006) interview questions should be a minimal set of open-ended questions to allow for further detail of topic discussion. Conversely, in theoretical sampling selection initial sampling is a guide point rather than a theoretical elaboration proposing to know in advance of sampling criteria. Instead, categories are constructed as emergent themes throughout the procedure in grounded theory (Charmaz, 2006, p. 100). The sufficiency of the one to one interview protocol questions aligned with research questions were approved by Johns Hopkins School of Medicine Institutional Review Board and supporting area government and non-profit agencies and Walden IRB.

Conversely, data was collected and reached saturation for the three research question posed as follows: (i) How does perceived access to breast screenings such as mammography, influence biopsy decisions when a tumor is detected, contribute to delayed or late stage breast cancer diagnosis in Latinas; (ii) How can breast cancer health providers, physicians, and professionals improve equitable access to care and breast care facilities that improve health outcomes related to breast cancer diagnosis, and increased survivorship among Latinas; and (iii) How can breast care health providers encourage early breast cancer detection and biopsy measures with tumor detection. The recruitment outcome was negatively influenced by current uncertain changes in immigration policy by the Trump Administration, ICE, and the Department of Homeland Security. Charmaz (2006) asserted that validity must be established early in the study context; 1) credibility, 2) originality, 3) resonance, and 4) usefulness in data collection and evaluation are required. However, the number of participants was approved by Johns Hopkins School of Medicine's IRB, the research staff, and the Walden chair and committee as a sufficient number to provide validation of the data collection instrument. Saturation or Theoretical Saturation is defined as "the point at which gathering more data about a theoretical category reveals no new properties nor yields any further theoretical insights about the emerging grounded theory" (Charmaz, 2006, p. 189). A qualitative expert associated with the Life With Cancer center and other supporting area government and non profit agencies was consulted, as well, Senior Principle Investigator, Dr. Zabora, ScD., for validity and credibility of the sample size and alignment with the research questions.

## **Recruitment**

The study sought to recruit a sample size of 17-25 Hispanic females and Latina's diagnosed with breast cancer within the last three years. Twelve Latinas were recruited and participated the study. The demographic participant information data collected is stated as demonstrated on the demographic sheet in Appendix D. The demographic sheet was recommended and designed by the Johns Hopkins School of Medicine's IRB; their staff and my Senior Principle Investigator, Dr. James Zabora, ScD, Director, Education & Outreach Johns Hopkins Center to Reduce Cancer Disparities, Baltimore, Maryland in order to secure participant identity privacy.

Participants were required to live in the United States specific to Northern Virginia, Maryland and Washington, D.C. Participants were also required to be female, self-identified as Hispanic and 19 years of age or older. The inclusion criteria for participant of the study are those individuals that discovered a breast tumor and engaged in the decision making process to seek biopsy, breast cancer diagnosis, and treatment alternatives. It was preferable that participants have sought diagnosis, treatment, and care within the Northern Virginia and immediate surrounding areas such as Maryland and Washington, District of Columbia. Recruitment inclusion required all participants to meet preferences.

Participants were recruited utilizing flyers posted throughout the Johns Hopkins Medicine Radiology department and Breast Care Center for recruitment purposes in addition to word of mouth by Latina healthcare coordinators and leadership staff. The recruitment flyer was posted in English and Spanish explaining the purpose of the study, the inclusion and exclusion criteria and an explanation of participant commitment. The participant level of commitment was a maximum 60- minute one- time interview. The researcher, DBora Schrett, conducted the

interviews in conjunction with the Spanish interpreter, Debra Haynes, MPH, who translated the interview questions and answers as needed for Spanish speaking participants. Debra Haynes, MPH, was certified for translation prior to the recruitment and interview process as required by Johns Hopkins School of Medicine:

“Protecting “Subjects Who Do Not Speak English” Translation

According to JH-IRB Policy: Pages: 6, 7, 10 & 16, as required by The Department of Health and Human Services (DHHS) regulations (45 CFR 46.116 and 45 CFR 46.117) and FDA regulations (21 CFR 50.25 and 21 CFR 50.27) for “Obtaining and Documenting Informed Consent of Subjects Who Do Not Speak English” participants who do not speak English will be provided a written consent document in Spanish to them and a translator in both English and Spanish will be provided to the participants (Hopkins Medicine, 2016a).

Certification of Translation:

In accordance with Johns Hopkins Office of Human Research Subjects Research – Institutional Review Board policy a certificate of translation provided by the Office of Human Research Subjects Research – Institutional Review Board forms was signed by each study participant, the Senior Principle Investigator, Dr. James Zabora, ScD, and the Spanish translator, Marcela Blinka, MSW. The document was written in the language understandable to the study participant and for the translator in both English and Spanish versions (Hopkins Medicine, 2016a).”

- a. Marcela Blinka, MSW, assisted with participant identification meeting the inclusion criteria and Spanish interpretation if needed to ensure potential volunteers met the inclusion criteria for the study. Participants must be 19 years or older, self-identified as Hispanic heritage, breast cancer survivor or patient with a breast cancer diagnosis; speaking English, Spanish or bilingual and, have had a mammogram within the last three years. The study sought 17 -25 Latinas as required by the Johns Hopkins School of Medicine and supporting area government and non-profit agencies for sufficient

saturation of data for collection. Creswell (1998) suggest a sample size of 20-30 is sufficient for saturation in a grounded theory (p. 64). Charmaz asserts, “A study of 25 interviews may suffice for certain small projects” (p. 114). Saturation or Theoretical Saturation is defined as “the point at which gathering more data about a theoretical category reveals no new properties nor yields any further theoretical insights about the emerging grounded theory” (Charmaz, 2006, p. 189). "Yin (2009) suggests this kind of exploratory study is "justifiable rationale with the goal being to develop pertinent hypotheses and propositions for further inquiry" (p.10).

Participants were recruited utilizing flyers approved and developed in collaboration with the Johns Hopkins School of Medicine IRB. Flyers were placed throughout Oncology and Radiology departments at the Breast Center of Johns Hopkins Medicine in Baltimore, Maryland, Department of Health locations throughout Loudoun County, Virginia, participating physician office's with Inova Hospital Breast Care center, Floris United Methodist Church in Northern Virginia, Nueva-Vida of Washington, D.C., Life With Cancer Center in Fairfax, Virginia distribution lists and the Arlington Free Clinic. Flyers were in both English and Spanish.

### **Data Collection**

The Data collection was presented in a one to one interview format per participant. Recruitment procedures are addressed above. Each interview did not exceed 60 minutes maximum. Responses from individual interviews were recorded using memo (field notes) transcription, which is required. Participants were debriefed at the end of each interview session. No further follow up interviews were required in order to develop themes from the pre-approved research questions. According to Charmaz (2006) “memo-writing leads to theoretical sampling” which leads to theory development defined from expansion of categories (p. 103).

Consequently, the participate or sample size is the starting place while the theory is formed from the categories refining theory sampling of data to answer research questions. This process may also illuminate new open- ended questions from participants not yet covered (Charmaz, 2006, p. 103). Field notes of record log utilized itemized organization of data collected relative to personal experiences, widespread experiences, and background. The researcher student delivered the interview questions to each individual participant with the oversight of a Spanish Language interpreter. The interview process was a one time event. No follow up procedures will be required. According to Yin (2009) "Even though your data collection may have to rely heavily on information from individual interviewees, your conclusions cannot be based entirely on the interviews as a source of information" (p. 2532). Yin (2009) suggests this kind of exploratory study is a "justifiable rationale with the goal being to develop pertinent hypotheses and propositions for further inquiry" (p. 10).

Upon completion of the interview process each individual interview data was enclosed within separate envelopes and sealed. The sealed envelopes were handed to the student researcher, DBora Schrett, and prepared for individual analysis. Copies of the original memo field notes and all documents associated with the research and participant information was turned over to Senior Principle Investigator,, Dr. James , ScD, Director, Education & Outreach Johns Hopkins Center to Reduce Cancer Disparities, Baltimore, MD to keep confidential within an office of Johns Hopkins School of Medicine in a secured place. This dissertation has been submitted for final approval through Walden University's expert panel review by Chair, Dr. Kourtney Nieves and Committee, Dr. Magdeline Aagard. In addition, the Johns Hopkins School of Medicine IRB and Senior Principle Investigator, Dr. James Zabora, ScD, Director, Education & Outreach Johns Hopkins Center to Reduce Cancer Disparities, Baltimore, MD, approved the



Johns Hopkins School of Medicine IRB research application, participant questions for interview purpose, e-Form proposal protocol request and all required documents, signed consent forms and submitted through JHED research protocol submission account for expert panel review for clarity of structure to participant pool.

### **Data Analysis Plan**

The grounded theory analysis of the data collection involved organizational techniques that sort data from categories of unit themes, trends and concepts based upon the experiences of participant interviews connected to the research questions. For example, participants were asked research question, (i) how does perceived access to breast screenings such as mammography, influence biopsy decisions when a tumor is detected, contribute to delayed or late stage breast cancer diagnosis in Latinas (Appendix B). Data analyzed from their responses demonstrated the participants of the study had no challenges receiving access to diagnostic services, such as mammograms or biopsy. Therefore, late stage breast cancer outcomes were not influenced by access to those services. Open coding from the data collection developed categories from the one to one interview format with questions in Appendix B that characterized events, and experiences relative to annual breast screenings, biopsies, diagnosis, treatments, and follow up for long- term care and future health outcomes. These coded themes were analyzed utilizing the Atlas.ti qualitative software system. Creswell contends data analysis allows the researcher to peel back layers of data preparation, conducting analysis, representing the data and interpreting larger significance (2009, p. 183). The procedure involves reflective methods of data gathering and interpretive analysis. Due to the nature of grounded theory approach it is expected that several themes and categories will emerge. Grounded theory relies primarily on contribution to existing theory or development of a new theory from themes and categorical data collected

providing significant aspects to proposal (Maxwell, 2005) use of existing theory can clarify justification for study, inform decisions for methodology, and generate and test data for modification of theories (pp. 55-56). Conversely, the analytical tools as cited by Creswell (2009, p. 184) Corbin and Strauss assert are a blend of systematic steps validating information include generating categories of information (open coding) positioning it in a theoretical model (axial coding) and emerging a story around these categories (selective coding). No discrepant cases were discovered.

Participants of the study were Latinas in the United States participating by choice. Upon approval by Walden University IRB and the Johns Hopkins School of Medicine IRB and supporting area government and non profit agencies' process consent form and confidentiality statement agreements were included for each participants. Consent form and Confidentiality Statement can be found in Appendix D. Vulnerable populations must be protected and risk minimized (Creswell, 2009, p. 89). Further, prospective subjects were approached with regard to ethical considerations and treatment defined in the Belmont report (USDHHS, 2013) involving human subjects. The Belmont report asserts ethical principles of respect, beneficence, and justice. First, respect refers to autonomy and entitlement protection for those of diminished autonomy. Second, beneficence implies the obligation to "do no harm" to human subjects and to maximize possible benefits, while minimizing harmful outcomes. Third, refers to justice or the ability to ensure equality to individuals according to need, individual effort, contribution by society, and merit in research practice (USDHHS, 2013).

Consequently, an informed consent form in concurrence with proposition was submitted and approved from the Johns Hopkins School of Medicine IRB prior to recruitment of participants. Moreover, the signed informed consent and confidentiality statements will be

obtained proceeding one on one interviews', congruently with individual interviews.

Recruitment processes and materials will include an audit in compliance with the Johns Hopkins School of Medicine IRB and supporting area government and non -profit agencies.

Confidentiality of data collected from the interview process with participants will be limited to the Johns Hopkins School of Medicine IRB leadership and Senior Principle Investigator, Dr. James Zabora, ScD, Education & Outreach Johns Hopkins Center to Reduce Cancer Disparities, Baltimore, MD. These findings intention is to influence social change in the Latina breast cancer survivors and breast care community for future research to change practice approach to vulnerable populations regarding access to care and service utilization and development of program initiatives in the United States.

The individual interview sessions with each of the twelve participants did not exceed 60 minutes each and will be accompanied by an interpreter to minimize English to Spanish to English language barrier limitation. Furthermore, the interview session questions will include knowledge of breast cancer exams and mammography benefits, biopsy access to care upon abnormal mammography results, quality of care throughout the process, related health beliefs, healthcare distrust, socio-demographic characteristics, and cultural pride. A qualitative study implores consistent checks for accuracy of findings (Creswell, 2009). Necessary protocols, informed consent, will be in place to ensure privacy and consent, validity and credibility, and procedural explanation for protection of participants' rights.

Procedures documented for validity verification as asserted by Creswell (2009). Further, upon approval by Walden University IRB and the Johns Hopkins School of Medicine IRB process consent form and confidentiality statement agreements were included for participants. Codes identified from data collected will be checked and cross checked by Chair,

Dr. Kourtney Nieves, Senior Principle Investigator, Dr. James Zabora, ScD, Director, Education & Outreach Johns Hopkins Center to Reduce Cancer Disparities, Baltimore, MD, and student researcher, DBora Schrett, to insure credibility and by comparison of data with codes and memos throughout the data gathering process (Creswell, 2009, p. 190). Female participants were recruited from a breast cancer support agencies such as physicians offices, clinics, Johns Hopkins School of Medicine and supporting area government and non profit agencies in Northern Virginia and immediate surrounding areas such as Maryland and Washington, District of Columbia serving Hispanic female's and Latina breast cancer patients within the last three years. Although access to participant data will be limited to the leadership, the director or senior investigator may share findings with the Johns Hopkins School of Medicine research department for further studies. Conversely, interview findings will be collected in a confidential manner and filed in secure location with the Johns Hopkins School of Medicine's filing system to protect participant responses. All data collected for this research, as well as back up data, may be destroyed after five years via shredding methods approved by the cancer center and the selected computer software program, potentially Atlas.ti recommended by the cancer Center's leadership. Further participant confidentiality, assurance that participants can withdraw at any time, and respect of participant trust will be stated within the consent form (Creswell, 2009, p. 89-90). When checking data with providers of care, the student researcher will identify possible provider bias prior to interviewing participants to ensure collaborative findings of results. Provider bias can be clarified at the outset of study and reviewed frequently against researcher codes to confirm validity or threats to validity (Creswell, 2009, p. 190)

Finally, the research recruiting team, Senior Principle Investigator, Dr. James Zabora, ScD, Director, Education & Outreach Johns Hopkins Center to Reduce Cancer Disparities,

Baltimore, MD, Debra Haynes, MPH, Marcela Blinka, MSW and student researcher, DBora Schrett, approached prospective subjects. The Johns Hopkins School of Medicine IRB; Senior Principle Investigator, Dr. James Zabora, ScD, Director, Education & Outreach Johns Hopkins Center to Reduce Cancer Disparities, Baltimore, MD, leadership staff, in alignment with the approved interview questions, will provided a script for recruiting volunteer participants. The researcher student will continue to consult with Senior Principle Investigator, Dr. Zabora, Dr. Kourtney Nieves, and the Johns Hopkins School of Medicine IRB leadership team and dissertation committee to insulate against participant or data abuse and maintain researcher objectivity.

### **Issues of Trustworthiness**

Some criteria for building credibility of trustworthiness in Grounded Theory and qualitative research asserted by Charmaz (2006) must establish early in the study 4 primary context; 1) credibility, 2) originality, 3) resonance, and 4) usefulness in data collection and evaluation. First, credibility (internal validity) is recognized as truth in findings or implications of sufficient evidence that substantiates claims or empirical data's worth ensuring trustworthiness (p. 182). Additionally, as asserted by Creswell (2007, p. 200) descriptive and detailed collection of participant experiences will provide ongoing transferability (external validity) providing reliability to study. Consequently, participants of this study completed did not require a follow up interview to verify description of researcher's findings; analysis of ensuring their perspective is legitimate, and minimizing researcher bias or reflexivity. Secondly, tenants of originality refer to new conceptual analysis or insights to data or theoretical work that contribute to the populations health outcomes; this includes the ability of findings to challenge current theories and conceptual frameworks, or practices within the research discipline. Third, originality

can contribute to transferability or connecting concepts that are applicable to other contexts (Lincoln & Guba, 1985). For example, the research could potentially be applicable to understand correlations of socio-economics, income, spiritual beliefs, and cultural structure to other areas of quality care services, or diagnostic services minimizing inequities in the healthcare system to minority populations. The data collection specific to the Latina population associated with the breast cancer treatment and support centers and included recruitment from other local government, physician offices, and non-profit agencies as well as breast care centers. An audit trail of the student researcher data collection and analysis will take place throughout entire process.

Third, resonance or dependability is the ability to make data collected makes sense to participants and appropriately represents their experiences or applicability to other findings or context and can be repeated with reliability (Charmaz, 2006, p. 182; Lincoln & Guba, 1985, p. 120). The study was overseen (audit trail) by the Johns Hopkins School of Medicine IRB, Senior Principle Investigator, Dr. James Zabora, ScD, Director, Education & Outreach Johns Hopkins Center to Reduce Cancer Disparities, Baltimore, MD; Walden University Chair, Dr. Kourtney Nieves; and Qualitative Committee, Dr. Magdeline Aagard, and the leadership staff. This practice would also ensure conformability corroborated by the leadership teams. Results can become part of future research added to understanding the population and strategies for servicing effectively. Further, participants completed approved interview questions with student researcher directly related to their access to care and healthcare utilization services. This can minimize the researcher bias, and assumptions of findings and interpretation of data. According to Creswell (2007), interviews play a fundamental role in the data compendium within grounded theory. Procedures for data collection include participant observation during one on one

interview's and researcher journaling or memo writing to develop theory within the conceptual framework of sampling approach. Review of existing literature comparison, adding data from participants and individual interview methodology is ongoing throughout the process of data collection (2007, p 181).

Fourth, usefulness of the study must answer the question of contribution to the knowledge of literature and social change (Charmaz, 2006). For example, the research question (i) How does perceived access to breast screenings such as mammography, influence biopsy decisions when a tumor is detected, contribute to delayed or late stage breast cancer diagnosis in Latinas in the United States?" will provide valuable insight to the Johns Hopkins School of Medicine IRB and research team members, Senior Principle Investigator, Dr. James Zabora, ScD., Director, Education & Outreach Johns Hopkins Center to Reduce Cancer Disparities, Baltimore, MD, and research student, DBora Schrett.

Participant observation throughout one on one interview created a limitation due to the nature and sensitivity of the topic during the breast cancer stage experiences. Conversely, participants were breast cancer survivors having already experienced the varying stages of breast cancer diagnosis, treatments, are in remission or survivorship within the last three years, and/or potentially receiving lifetime hormone therapy treatments is included. Creswell (2007) suggest synthesis and agreement of validation for perspective or interpretive lens and developing questions of the researcher applicable throughout the qualitative process. Current literature can provide consistency of data as well as measures utilized for analysis that yield changed or unchanged results drawing accurate conclusions (Leedy & Ormrod, 2005, p 31). As such, an interview with an oncologist for recommended questions not yet considered are provided if required. Another limitation to study is overcoming bias and reliance on personal judgment for

justification. The process of inter-coder reliability can be applied. Inter-coder reliability is ability of two or more independent coders categorizing content similarly without prior knowledge of the others findings (Leedy & Ormond, 2005).

Finally, intra-coder reliability is performed by the researcher utilizing coding for a qualitative grounded theory method of one on one interview questions regarding “access to care” or diagnostic services related to breast cancer screening and diagnosis. Questions will explore the participant’s experience, but fit the researcher’s topic (Charmaz, 2006, p. 29). The leadership team of Walden University, comprising of Dr. Kourtney Nieves, Chair, Dr. Magdeline Aagard, Committee and Qualitative expert familiar with all aspects of qualitative methods will potentially provide assistance with coding and scoring. Additionally, the Atlas software program can help with defining coding and thematic trends relative to findings. This step ensures and validates the “inter-coder” reliability of data collected by imploring the insight and judgment and expertise of two or more coder experts.

Miles and Huberman (1994) suggest “consistent assessment and drawn conclusions that confirm meaning from patterns, and contrast of themes building relationship and coherent understanding and validity” (p. 286). Validity in qualitative research is an opportunity to “rule out plausible alternatives, threats to interpretation and explanation in presentation of strong supporting argument of intention for proposal” (p. 107). Explanation lens to eliminate bias associated with expectations, beliefs, and perceptions as a standard of integrity is required to ensure trustworthiness in the research outcomes (p. 108).

The participant pool was a semi structured interview approach consisting of twelve participant females. Participants were recruited in partnership with the Oncology and Radiology departments at the Breast Center of Johns Hopkins Medicine in Baltimore, Maryland,



Department of Health locations throughout Loudoun County, Virginia, participating Physician office's with Inova Hospital Breast Care centers, Floris United Methodist Church in Northern Virginia, Nueva-Vida of Washington, D.C., Life With Cancer in Fairfax, Virginia distribution lists and Arlington Free Clinic in Arlington, Virginia and by word of mouth from community public healthcare leadership associated with this target population. Creswell (1998) suggest a sample size of 20-30 is sufficient for saturation in a grounded theory (p. 64). Charmaz asserts, "A study of 25 interviews may suffice for certain small projects" (p. 114). Saturation or Theoretical Saturation is defined as "the point at which gathering more data about a theoretical category reveals no new properties nor yields any further theoretical insights about the emerging grounded theory" (Charmaz, 2006, p. 189). Interview procedures engaged participants of the Latina female participants in the United States demographic personal experiences utilizing open-ended questions in one on one interviews inclusive of a Latina support group facilitator for interpretation. Each interview did not exceed 60 minutes maximum. Responses from individual interviews were recorded using memo (field notes) transcription. The interview framework was designed around topics specific to access to care and ability to pay, and quality of care within supportive facility with recommended questions from an area oncologist treating minority females of breast cancer survival. Additional sample literature or Virginia Breast Cancer data base review was not considered from the same or similar demographic for comparison (Patton 2002).

The National Cancer Institute (NCI, 2014, p. 6) purports "more aggressive breast tumors in younger Black and African American and Latina American women in lower Socioeconomic Status (SES) areas are attributable to poorer survival rates." The data collection instrument was an interview approach for a qualitative grounded theory design. The population group was a

self-identified mix of Latina American females diagnosed with breast cancer prior to treatment, survivors of breast cancer and/or receiving lifetime hormonal treatment, or participating in annual comprehensive diagnostic breast exams and biopsy after diagnosis of breast cancer. Data collection validated further findings of concepts, themes, trends, insights, and understandings attributable to delays in breast cancer screenings and increased incidence of breast cancer mortality and morbidity among minority women in the United States and Northern Virginia and immediate surrounding areas such as Maryland and Washington, District of Columbia and surrounding area for population demographic (Patton, 2002). Finally, the researcher student scholar was required to complete standardized training to increase knowledge of study protocols and interview.

### **Ethical Procedures**

Prospective subjects were approached with regard to ethical considerations defined in the Belmont report (USDHHS, 2013) involving human subjects. Participants were provided with the following: **1.** explanation of the study; **2.** informed consent; **3.** one demographic questionnaire, which was completed prior to their interview for this study; **4.** an individual interview with the student researcher and an approved staff member of who was fluent in English and Spanish. **5.** permission forms were obtained from each site location in accordance with Johns Hopkins Office of Human Research Subjects Institutional Study Review Board policies. The Belmont report asserts ethical principles of respect, beneficence, and justice. First, respect refers to autonomy and entitlement protection for those of diminished autonomy. Second, beneficence implies the obligation to “do no harm” to human subjects and to maximize possible benefits, while minimizing harmful outcomes. Third, refers to justice or the ability to ensure equality to individuals according to need, individual effort, contribution by society, and merit in research

practice (USDHHS, 2013). Finally, the IRB application approval process from both the Johns Hopkins School of Medicine and Walden University are required in order to ensure the process of this research study and its participants are protected according to guidelines.

The data was recorded with handwritten memo notes for data analysis by DBora Schrett, student researcher and Debra Haynes, MPH, Spanish Interpreter. This information was provided in the participant consent form. Data collection is as follows:

1. Communication of interview questions with Spanish only speaking participants was delivered and interpreted with the assistance of Debra Haynes, MPH, in collaboration with Marcela Blinka, MSW, a Spanish interpreter and other interpreter coordinators as needed. The student researcher, DBora Schrett, was present for each interview using the primary interpreter, Debra Haynes, MPH. Ms. Marcela Blinka, MSW, collected consent form signatures upon qualifying participant volunteer for the study as needed. The student researcher, DBora Schrett, Senior Principle Investigator, Dr. James Zabora, ScD, Director, Education & Outreach Johns Hopkins Center to Reduce Cancer Disparities, Baltimore, MD, and Marcela Blinka, MSW, facilitated in person distribution and oversight of the signage of consent form by participants. Further, Dr. Zabora and Ms. Blinka distributed remaining \$25.00 thank you gift cards for participation to volunteers upon completion of research interview.
2. Flyers were designed by DBora Schrett in collaboration with Debra Haynes, MPH, , Marcela Blinka, MSW, and Senior Principle Investigator, Dr. James Zabora, ScD, Director, Education & Outreach Johns Hopkins Center to Reduce Cancer Disparities, Baltimore, MD, with the Johns Hopkins School of Medicine IRB for recruitment of participants regarding how they perceived their experiences with a breast cancer

- diagnosis. Flyers were printed in English and Spanish versions and written at a 3<sup>rd</sup> or 4<sup>th</sup> grade level. Participants were recruited by the leadership staff by utilizing flyers posted at the Oncology and Radiology departments at the Breast Center of Johns Hopkins Medicine in Baltimore, Maryland, Department of Health locations throughout Loudoun County, Virginia, participating physician office's with Inova Hospital Breast Care centers, Floris United Methodist Church in Northern Virginia, Nueva-Vida of Washington, D.C., Life With Cancer in Fairfax, Virginia distribution lists and Arlington Free Clinic in Arlington, Virginia and by word of mouth from community public healthcare leadership associated with this target population.
3. As required by the leadership team, the researcher sought to conduct 17 – 25 interviews with the voluntary participants. Upon completion of data collection, the results would be utilized by the Johns Hopkins School of Medicine for future research pertaining to Latinas and publication. Participants were recruited by utilizing flyers in Spanish and English; and in collaboration with the Latina research team in association with Johns Hopkins School of Medicine. These flyers were posted throughout the Oncology and Radiology departments at the Breast Center of Johns Hopkins Medicine in Baltimore, Maryland, Department of Health locations throughout Loudoun County, Virginia, participating physician office's with Inova Hospital Breast Care centers, Floris United Methodist Church in Northern Virginia, Nueva-Vida of Washington, D.C., Life With Cancer in Fairfax, Virginia distribution lists and Arlington Free Clinic in Arlington, Virginia and by word of mouth from community public healthcare leadership associated with this target population.

4. Per compliance with Walden Institutional Review Board and Johns Hopkins School of Medicine Institutional Review Board, the researcher confirmed and requested interest in participation of potential Latina subjects. The interview protocol questions are provided in Appendix B. The student researcher, DBora Schrett, was present for most consent form signage, confirmation of consent from each participant at the time of scheduled interview, including confirmation of consent of all participant interviews was required. Participants were advised of the nature of the study for understanding and confirmation of participation at the time of the study in Spanish by Debra Haynes, MPH and Marcela Blinka, MSW and Senior Principle Investigator, Dr James Zabora, ScD. Upon approval by the Johns Hopkins School of Medicine IRB, participant interviews occurred within an estimated one week timeframe and were conducted by the student researcher with the assistance of Debra Haynes, MPH, the Spanish Interpreter. The interview questions provided by student researcher were approved and the recruitment process begun in collaboration with the leadership staff team of Johns Hopkins. This team included, Senior Principle Investigator, Dr. James Zabora, ScD., Debra Haynes, MPH and Marcela Blinka, MSW and DBora Schrett, student researcher. For example, questions addressed (a) cultural family context, (b) cultural perceptions of breast cancer, (c) insurance status or ability to pay, or patient provider relationships.
5. The interview questions were also approved by student researcher, DBora Schrett, Senior Principle Investigator, Dr. James Zabora, ScD, Director, Education & Outreach Johns Hopkins Center to Reduce Cancer Disparities, Baltimore, MD, and Walden University Chair, Dr. Kourtney Nieves, Committee, Dr. Magdeline Aagard,

and URR, Dr. Raymon Thron. Approved interview questions were then administered to participants in a one to one interview format, with the Spanish interpreter present, after the consent form signage process was complete. Transcription of interview question feedback was collected verbatim and analyzed in accordance with outlined steps proceeding end of Chapter 3. Interviews were not recorded with an audio tape recorder. Handwritten memo notes were taken for each interview and written in both English and Spanish.

6. Themes from transcripts were derived from data collection provided from participant interviews.
7. Ethical considerations for prospective subjects were approached with regard to ethical considerations and treatment defined in the Belmont report (USDHHS, 2013) involving human subjects.
8. Protection of participants is in respect to beneficence which implies the obligation to “do no harm” to human subjects and to maximize possible benefits, while minimizing harmful outcomes. (USDHHS, 2013).

All materials is securely stored at locked in a confidential file in the Principal Investigator’s office within the Center to Reduce Cancer Disparities. Participants were kept in anonymity and interviews were conducted in confidence. The file will be encrypted and secured to eliminate any identifying criteria of volunteers. For example, only county of residence and the numbers from each address will identify patient #1. So, in this way patient #1 could be Baltimore/7006, and patient #2 might be Baltimore/409. Each set of interview materials have been placed in individual envelopes and sealed for review by Dr. James Zabora of The Johns

Hopkins University School of Medicine. Data collected was translated for interpretation of the final study results.

### **Summary**

Breast cancer is considered the main cancer cause among Latinas with outcome resulting in increased incidence of mortality (survival rates) and morbidity. Further, it is assumed this is in part due to lower mammography screening rates. Contributory factors assumed are low income and education levels, lack of health insurance coverage, body mass, language barriers, poor physician recommendations, and sources of care. Other factors to consider are health status or wellness, disparities in health care, and access to utilization of cancer screenings (Gonzales, et al, 2011, p. 422). A qualitative research study focuses on the participants based on their reality of lived experiences (Creswell, 2007, p. 195). The central question and phenomena of this study was “How can breast care healthcare providers, physicians, and professionals meet the needs of Latina American females in reducing late stage breast cancer diagnosis? “ Research analysis and outcomes reported may contribute to understanding of express experiences of underserved and minority populations’ initiatives to provide education, prevention, and treatment options for vulnerable populations.

Chapter 3 has provided limitations of the researcher role to participants and the study. The recommended methodology utilized a participant pool that would have included 20-25 volunteers of the Latina female demographic in the United States. However, only twelve Latina women volunteered for the study due to recent immigration challenges in the United States. These individuals were located within the Northern Virginia and immediate surrounding areas such as Maryland and Washington, District of Columbia. As previously stated in chapter 3 participants were recruited with the assistance of the Johns Hopkins School of Medicine and

supporting area government and non- profit agencies in Northern Virginia and immediate surrounding areas such as Maryland and Washington, District of Columbia. These partnerships serve the Hispanic female and Latina breast cancer demographic. Senior Principle Investigator, Dr. Zabora, Dr. Nieves and Dr. Aagard supervised the audit trail and issues of trustworthiness and ethics compliance engaged with the data analysis of data collection material. Finally, the participants were protected in conjunction with the Belmont Report as discussed in chapter 3.



## Chapter 4: Results

### **Introduction**

The purpose of this research study was to examine among Hispanic females and Latina's the quality of their healthcare experience when diagnosed with breast cancer. The approach to obtain the data began from either the annual mammography or from the moment in time when a breast tumor was discovered. Phenomena examined socio-economic, cultural, psychosocial influences on motivation to seek medical attention upon discovery of breast tumor, as well as influences upon decisions about immediate follow up, treatments and long-term care. The chapter will detail the recruitment process and each participant profile; how the data was collected and stored at Johns Hopkins School of Medicine, how the data was analyzed, and identification of main themes, as well as and protocols in place to ensure validity and credibility.

### **Settings**

Participant interviews took place at one of the following locations either face-to-face or over the phone: Floris United Methodist Church, Herndon, Virginia, the Arlington Free Clinic, Arlington, Virginia, Chantilly Regional Library, Chantilly, Virginia, the home office of Debra H. Haynes, MPH, Centreville, VA, and the home office of DBora Schrett, Aldie, Virginia. In compliance with Johns Hopkins School of Medicine and the IRB protocol prior to each interview, participants were pre-qualified with Marcela Blinka, MSW to ensure they met the research study requirements before being interviewed. As stated above, specific identifying data, such as income, age, number of children, of the participants as seen on the demographic sheet (Appendix D) is display in ranges. Finally, participants are not identified by their full name, but as letter and letter code for the records of Johns Hopkins School of Medicine. For example, using my name DBora Schrett, the code would be P #1-DB-SC.

The researcher, DBora Schrett and interpreter, Debra H. Haynes, MPH, were present at each interview except one, where no interpreter was required as the participant spoke English only. This participant interview was by phone at the home office of the researcher, DBora Schrett. The home office was located in Aldie, VA. The offices were quiet, private and there were no distractions. The remaining interview locations for participants were at Arlington Free Clinic in Arlington, VA, where three in person interviews were conducted. The researcher and interpreter were given a small private office within the clinic to meet with each participant in person and to conduct the interview process. Chantilly Regional Library in Chantilly, VA, was also used where 7- interviews were conducted over the phone. The researcher and interpreter were given a small private room within the library to conduct by phone each interview. Finally, one participant interview was conducted by phone at the home office of Debra H. Haynes, MPH with the researcher in Centreville, VA. The Centreville, VA office was quiet, private and without distractions. At each location, the researcher and interpreter were given a small private office within the clinic to meet with each participant in person and to proceed with the interview process. Arlington Free Clinic - the office was quiet and private with no distractions.

The study was explained again to participants prior to beginning their individual interview. Participants were also given detailed information regarding the study with Marcela Blinka, MSW as part of the pre-qualification process, as previously mentioned. Each interview office was quiet, private and without distractions throughout the entire process. Each participant prior to the interview questions beginning completed a demographic form. The demographic sheet required by Johns Hopkins School of Medicine included ranges of age, income, number of children, marital status, primary household provider, family history of cancer and education. Participants were not required to answer any question if they did not wish to do so.

## Demographics

The study sought to recruit a sample size of 17-25 Latinas diagnosed with breast cancer within the last three years. Twelve Latinas participated in the study. The demographic participant information data collected is stated as ranges in each category as demonstrated in Appendix D. The range approach was recommended by the Johns Hopkins School of Medicine's IRB and Senior Principle Investigator, Dr. James Zabora ScD, Director, Education & Outreach Johns Hopkins Center to Reduce Cancer Disparities, Baltimore, Maryland in order to secure participant identity privacy.

Participants were required to live in the United States specific to Northern Virginia, Maryland and Washington, D.C. Participants were also required to be female, Spanish and 19 years of age or older. The inclusion criteria for participant volunteers of the study are those individuals that discovered a breast tumor and engaged in the decision making process to seek biopsy, breast cancer diagnosis, and treatment alternatives. It was preferable that participants have sought diagnosis, treatment, and care within the Northern Virginia and immediate surrounding areas such as Maryland and Washington, District of Columbia. Recruitment inclusion required all volunteer participants met preferences. Participants must be 19 years or older Latinas breast cancer survivors or patient with a breast cancer diagnosis; self- identified female have had a mammogram within the last three years.

The study sought 17 -25 Latinas as required by the Johns Hopkins School of Medicine and supporting area government and non-profit agencies for sufficient saturation of data for collection. Creswell (1998) suggest a sample size of 20-30 is sufficient for saturation in a grounded theory (p. 64). Charmaz asserts, "A study of 25 interviews may suffice for certain small projects" (p. 114). Saturation or Theoretical Saturation is defined as "the point at which

gathering more data about a theoretical category reveals no new properties nor yields any further theoretical insights about the emerging grounded theory” (Charmaz, 2006, p. 189).

Volunteer participants were recruited utilizing flyers approved and developed in collaboration with the Johns Hopkins School of Medicine IRB. Flyers were placed throughout Oncology and Radiology departments at the Breast Center of Johns Hopkins Medicine in Baltimore, Maryland, Department of Health locations throughout Loudoun County, Virginia, participating physician office’s with Inova Hospital Breast Care center, Floris United Methodist Church in Northern Virginia, Nueva-Vida of Washington, D.C., Life With Cancer in Fairfax, Virginia distribution lists and the Arlington Free Clinic. Flyers were in both English and Spanish.

### **Participant Profiles**

Participant Number 1, Sy-M-Ri, is a 55-year old and self-identified Hispanic female from Nicaragua. She currently resides in Virginia. She was recruited for this study at Floris United Methodist Church in Northern Virginia. The participant was interviewed at Floris United Methodist Church in Northern Virginia. Her primary language is Spanish. She is married and has four children, a 21-year old daughter, a 13-year old son and an older son, whose age was not revealed. Conversely, the older son resides in Maryland. The participant regarding her 4th child provided no further information.

Participant Number 2, Ja-de-l-Ri, is between the ages of 45-54 years old and self-identified as Latina from Bolivia. She was recruited from Floris United Methodist Church in Northern Virginia. Participant was interviewed at Floris United Methodist Church in Northern Virginia. She speaks English and Spanish, however her primary language is Spanish. She currently resides in Virginia. She is married with no children. She and her husband share in

household responsibilities. The participant works as a director in a church ministry office in Northern Virginia.

Participant Number 3, An-Mc, is between the ages of 55-64 years of age and self-identifies as a Hispanic female from Bolivia. She was recruited from Arlington Free Clinic in Arlington, Virginia. Her primary language is Spanish. She was also interviewed at Arlington Free Clinic in Arlington, Virginia. She currently resides in Virginia. She has a 15-year old daughter and an older son, whose age was not revealed. She describes her family upbringing as a typical close-knit family. She is the principle provider of the household. She has had family members with cancer.

Participant Number 4, No-Me, is between the ages of 45-54 years old and self-identified as Hispanic female from Honduras. She was recruited from Nueva Vida in Washington, D.C. She was interviewed in Herndon, Virginia. Her primary language is Spanish. She currently resides in Virginia. She has two daughters, ages 22 and 29 years old and one son age 17 years old. She is divorced and is the principle provider of her household. There is no history of cancer in her family. The participant works as a housekeeper.

Participant Number 5, Iv-De, is between the ages of 55-64 years old and self-identified as Latina from Guatemala bordering Nicaragua. She is a doctor and holds a professional graduate degree. The participant speaks English and Spanish, however her primary language is Spanish. She was recruited from Nueva Vida in Washington, D.C. She was interviewed at Arlington Free Clinic in Northern Virginia. She currently resides in Virginia. She is married. She is not the principle provider of the household. The participant has daughters' ages 12, 26 and 27 years old.

Participant Number 6, So-Ca, is between the ages of 45-54 years old and self-identifies as Hispanic female from Mexico. She was recruited from Nueva Vida in Washington, D.C. She is

married. She was interviewed over the telephone with a Spanish interpreter. The telephone interview was completed at Chantilly Regional Library, 4000 String fellow Road, Chantilly, Virginia in a private room. She currently resides with her son in the United States. She also has a daughter. Participant states she has between 3 to 4 children, however no further information was revealed. Participant stated her mother had a cancer. She is the principle provider of her household. Her primary language is Spanish.

Participant Number 7, Gr-Mo, is over the age of 65 years old and self-identifies as a Hispanic female. She is originally from Mexico. She was recruited from Nueva Vida in Washington, D.C. She was interviewed over the telephone with a Spanish Interpreter and her daughter present to assist with language barrier. She is not married. Her primary language is Spanish. The telephone interview was completed at Chantilly Regional Library, 4000 String fellow Road, Chantilly, Virginia in a private room. She is unemployed. She is the principle provider for the household. There is no history of cancer in her family.

Participant Number 8, D-Mor, is between the ages of 45-54 years old and self-identifies as Latina from Honduras. She was recruited from Nueva Vida in Washington, D.C. She was interviewed over the telephone with a Spanish Interpreter to assist with language barrier. She is not married. Her primary language is Spanish. The telephone interview was completed in Centreville, Virginia in a private room. Participant has a daughter that resides in Chicago and two sons' ages 15 years old and 25 years old. Her 25-year old son resides in Honduras. She currently resides in Maryland. There is a history of cancer in her family.

Participant Number 9, El-Gi, is between the ages of 55-64 years of age and self-identifies as Spanish. She was recruited from Nueva Vida in Washington, D.C. Her primary language is Spanish. She currently resides in Maryland. The telephone interview was completed at

Chantilly Regional Library, 4000 String fellow Road, Chantilly, Virginia in a private room. She was interviewed over the telephone with a Spanish Interpreter to assist with language barrier. She is a housewife and is not the principle provider of the household. However, she is a widow. Her family does have a history of cancer. Participant has an older son and a daughter, whose ages were not provided, resides in Honduras.

Participant Number 10, Th- Mo is between the ages of 45-54 years old and self-identifies as Hispanic female from Brazil. She currently resides in Maryland. She was interviewed over the telephone in Aldie, Virginia. No interpreter was required. She is a Scientist. The participant holds a professional and doctorate degree. She is married and has a 16-year old son. Participant was recruited from Nueva Vida of Washington, D.C. Her primary language is English. She and her husband are shared principle providers of the household. There is a history of cancer in her family.

Participant Number 11, Al-Po, is over the age of 65 years and self-identifies as Hispanic female from Dominican Republic. She currently resides in Maryland with her daughter. She was recruited from Nueva Vida in Washington, D.C. She was interviewed over the telephone with a Spanish Interpreter to assist with language barrier. The telephone interview was completed at Chantilly Regional Library, 4000 String fellow Road, Chantilly, Virginia in a private room. She is not married and is retired as a result of the cancer diagnosis. She has five children. Their ages were not revealed. Participant has a history of cancer in her family.

Participant Number 12, Ma- Am, is between the ages of 55-64 years old and self-identifies as Hispanic female from El Salvador. She was recruited from Nueva Vida in Washington, D.C. She was interviewed over the telephone with a Spanish Interpreter to assist with language barrier. The telephone interview was completed at Chantilly Regional Library,

4000 String fellow Road, Chantilly, Virginia in a private room. She currently resides in Maryland. She is employed at a restaurant cleaning tables and rolling silverware. She is married. Her husband is the principle provider of the household. Participant does have a family history of cancer.

### **Data Collection**

Field notes of record log were utilized for itemized organization of data collected relative to personal experiences, widespread experiences, and background. The researcher student delivered the interview questions to each individual participant with the oversight of a Spanish Language interpreter. The interview process was a one- time event. No follow up procedures were required. As previously stated in Chapter 3, all materials was securely stored at locked in a confidential file in the Principal Investigator's office within the Center to Reduce Cancer Disparities. Participants were kept in anonymity and interviews were conducted in confidence. The file has been encrypted and secured to eliminate any identifying criteria of volunteers. For example, only county of residence and the numbers from each address will identify patient #1. So, in this way patient #1 could be Baltimore/7006, and patient #2 might be Baltimore/409. Each set of interview materials have been placed in individual envelopes and sealed for review by Dr. James Zabora of The Johns Hopkins University School of Medicine. Data collected was translated for interpretation of the final study results.

Upon completion of each interview process each individual interview data was enclosed within separate envelopes and sealed. The sealed envelopes was handed to the student researcher, DBora Schrett, and prepared for individual analysis. Copies of the original memo field notes and all documents associated with the research and participant information were



turned over to Senior Principle Investigator, Dr. James Zabora, ScD, to keep confidential within an office of Johns Hopkins School of Medicine in a secured place.

Plan for Protecting “Audio-Tapes” (Records Retention) According to JH-IRB Policy: Pages: 5, 6, 7, 11, 12 & 13

*Data Gathering Section III, Storage and Records Retention:*

As required by Johns Hopkins School of Medicine the Principle Investigator “of the study, Dr. James Zabora, will retain research records for participants associated with this study in accordance with federal and Organization requirements. The research records will be kept in a secure, protected manner in accordance with JHM IRB guidance on Record Retention and in accordance with Johns Hopkins policies for data gathering, storage and record retention. For example, interview notes and interview recordings will be stored in a safe place accessible to Dr. James Zabora and authorized personnel to protect research participants in accordance with Johns Hopkins institutional policy (Hopkins Medicine, 2016b). National Institutes of Health recommend data be “retained for three years following the submission of the final report.

Further, interview findings were collected in a confidential manner and filed in secure location with the Johns Hopkins School of Medicine’s filing system to protect participant responses. All data collected for this research, as well as back up data, may be destroyed after five years via shredding methods approved by the cancer center and the selected computer software program, potentially Atlas.ti recommended by the cancer Center’s leadership.

This study encountered an unusual circumstance during recruitment, in spite of this, there were no unusual circumstances encountered during data collection. As previously stated, the study sought to recruit and interview 17-25 Latinas for the study, however twelve Latinas agreed to participate in the research. The data collection for this study consisted of twelve Latina’s diagnosed with breast cancer within the last three years. Each woman participated in a one- time 45-60 minute interview relating to the study to answer a set of pre-approved qualitative or Grounded Theory style questions. Interviews with each volunteer were either in person at a

secured and private location that included the participant, student interviewer and a Spanish interpreter for language barriers; or over the telephone in a private and secured location. The interview process began with gentle rapport building and introductions between the student researcher and the interpreter. For example, each participant was asked if they were comfortable providing information of their personal journey with breast cancer diagnosis, though they were pre-qualified and consented prior to the interview process. If a participant indicated any discomfort or had any questions they were allowed to ask them before the interview began. A few participants requested confirmation of length of time needed to complete the interview. They were then asked if it were still a good time for them to interview or if another time would be best. Each participant's need for time constraints, if any, was respected per their request. If any distractions were noticed on the end of the participant during phone interviews, researcher asked if it were a good time to interview. Participants were also asked if they had any additional questions or concerns before the interview began. Participants who provided in person interviews were given water to drink, asked if they were comfortable with the room, location, interpreter, room temperature, and if there was anything of concern before we began.

In the case of in person interviews the Consent Form was signed, and a demographic questionnaire gathering basic information such as "place of birth, marital status, education level, occupation, ethnicity/race, principle financial provider, residence, age range, children, income range, and history of cancer (of any type) in the family. Women who participated in the study over the telephone signed Consent Form with Senior Principle Investigator, Dr. James Zabora or Marcela Blinka in the Baltimore, Maryland location.

Methods of analysis of data collected and referred to as contributable factors, were coded, analyzing content, categorizing and classifying data for patterns and themes assessment. Since a

previous observation of Latina cancer group had been assessed and a small sample pool in a one to one interview format per participants were completed and open coding applied providing more detail in the process (Creswell, 2007, p. 156; Miles & Huberman, 1994).

### **Data Analysis**

The research study examined the qualitative experiences, using the ground theory approach, of Latinas confronting breast tumor or the biopsy decision- making process and finally breast cancer. The research considered access to care or ability to pay outcomes in the Northern Virginia and immediate surrounding areas such as Maryland and Washington, District of Columbia and surrounding communities' demographics. Maxwell (2005) asserts theory as a simplified model of "why the world is the way it is." It provides a statement about the prescribed phenomena the researcher seeks to explore in research population. Consequently, in application, the grounded theory approaches data inductively developed from the actual data derived from the study. Conversely, the intent of this research was to interject phenomena of relationship themes of late stage breast cancer diagnosis and access to care or ability to pay in the U.S. or Northern Virginia and immediate surrounding areas such as Maryland and Washington, District of Columbia and surrounding area health delivery system. The study's findings, presented in themes below, demonstrate some similarities or connectors to their experiences relative to the construct of the Health Beliefs Model. These themes were analyzed and defined as they associated to the study and initial research questions previously stated. The results of the study's findings are stated below.

### **Detection Outcomes**

The 1st research question, asked (i) how does perceived access to breast screenings such as mammography, influence biopsy decisions when a tumor is detected, contribute to delayed or

late stage breast cancer diagnosis in Latinas . This question sought to discover if any influences contributed to delays in breast cancer detection or late stage diagnosis of the disease. Though 9 of the 12 participants found with questionable breast tumors or cancers either through self-reporting or a non-trusted physician in their country of origin, their official breast cancer diagnosis was not confirmed as until their arrival in the United States. Participant number 9, diagnosed in the United States, stated,

Before coming to the United States, physicians in Honduras only care about charging the patient. They do not care about the patient or their health; but I received very good care in the United States. There are not a lot of facilities. Further, they (community) do not speak about it, especially since it's so expensive. The culture's view of women regarding breast cancer is fear of what would be known. Women are afraid to get exams. Usually when they go for an exam it's found an advanced cancer tumor. This is due in part because there is limited access to mammograms, exams and diagnostics. Honduras does not have very good diagnostic measures or facilities.

The remaining 3 of the 12 participants have resided in the United States since early childhood. These 3 participants are gainfully employed, married, financial stable with health insurance coverage, had no issues obtaining access to biopsy or breast care. As previously stated, participant number 2 reported, "Yes, I had insurance. Insurance helps, working helps pay on any bills. Without insurance I wouldn't have been able to pay. I can't imagine the fear and stress of how to pay." Each or the twelve participants stated, the lack of knowledge, education, healthcare facilities, and supplies, equipment such as mammography machines, women's wellness programs, and the cultural perception of all cancers. For example, participant number 9 stated, "they (community) do not speak about it, especially since it's so expensive. The culture's view of women regarding breast cancer is fear of what would be known. Women are afraid to get exams. Usually when they go for an exam it's found an advanced cancer tumor". This is due in

part because there is limited access to mammograms, exams and diagnostics. Honduras does not have very good diagnostic measures or facilities. Breast cancer is perceived as a taboo or not spoken of within their home countries and community; therefore they would have died from the breast cancer. Participant number 9 shared,

There are no cases of cancer in the area of the county where I lived. There is a perception that Cancer only existed in the city because they had more access to care. They hide or stayed inside and didn't want anyone to know in Honduras for many years.

The participants reported breast cancer stages between zero- to stage two. Each participant sought medical care in the United States within Hispanic communities. They did not seek medical care or assistance outside of their culture.

The first research question, (i) How does perceived access to breast screenings such as mammography, influence biopsy decisions when a tumor is detected, contribute to delayed or late stage breast cancer diagnosis in Latinas further sought to discover strategies and recommendation about how breast care healthcare physicians, staff, caregivers, and nurses can improve survival outcomes, quality of life, outreach resources and education of breast care and breast cancer. Each participant reported cultural shock related to the differences between care in their countries of origin and the United States. Participants stated while healthcare was much better than their countries of origin they did, unfortunately, experience unkindness, a lack of sensitivity of a woman's diagnosis as well as the state of their mental health upon learning of the disease, lack of privacy or care about medical information shared with strangers in public settings with no regard or sensitivity to the participate or the diagnosis, and the participants need to know what to do next; in addition to cultural and racial bias within the United States healthcare system throughout their breast cancer journey. For example, participant 4 reported, "...the staff was not sensitive or compassionate" during her biopsy procedures. Participant 11

reported, “the worse care she received was from a female Latina physician. She states, “there are bias’ based on ethnicities even within your own community. Minority women have a higher pain tolerance level so fewer anesthesia’s are given during procedures. But, Caucasian women are made more comfortable during the same procedures and treatments.” These phenomena seemed to exist even among healthcare providers and staff of Hispanic origin. In contrast, in their countries of origin individuals were kind to one another in most situations. Participants reported this phenomenon of lack of sensitivity and kindness as part of their cultural shock.

### **Access to biopsy services**

The 2nd research question asked (ii) how can breast cancer health providers, physicians, and professionals improve equitable access to care and breast care facilities that improve health outcomes related to breast cancer diagnosis, and increased survivorship among Latinas. Each participant was asked during her interview process questions related to the second research question. One question posed related to the second research question, “how did you decide to obtain a biopsy” or “how did finances influence decisions for care.” The participants reported there were no challenges obtaining biopsy services. Each participant had access to various financial resources assisting with financial decisions for care. Three of the 12 participants diagnosed with breast cancer were employed in professional careers, educated with at least a bachelor’s degree, married and had health insurance through her employer or spouse insurance. For example, when participant number 2 was asked if she had healthcare insurance at the time of her diagnosis she stated,

“Yes, I had insurance. Insurance helps, working helps pay on any bills. Without insurance I wouldn’t have been able to pay. I can’t imagine the fear and stress of how to pay.”

Participant number 5 stated, “I was not working at the time, but I had insurance through my husband.” Participant number 11 had insurance through her employer and spouse. The remaining nine participants were provided with community financial support services from free clinics, cancer programs through non-profit organizations or local hospitals such as Johns Hopkins Hospital and Virginia Hospital, family members, friends, insurance from a spouse’s employment or their own, the Affordable Care Act, Hispanic physicians, Hispanic physician associated to the family and Medicare and Medicaid. Participant number 1 stated,

“I didn’t have insurance. My son is in a church in Maryland. His church gives medicines every two weeks. The next day, Monday after diagnosis, I was sent to the clinic and my son’s church paid for everything. Also, my children got me “Anthem” off the health marketplace exchange Obama care.”

Participant number 3 stated,

“I had no insurance. The Arlington Free Clinic took care of all my treatments. I had no separate bills. Had Arlington Free Clinic not taken care of everything If they hadn’t I would not have received care and would have died.”

Participant number 12 responded to the question similarly, health insurance was not an issue at the time. However, Sandra at Nueva-Vida University of Baltimore was very instrumental in helping. Participant number 12 stated,

“I had no insurance. The University of Baltimore program helped like Sandra at Nueva-Vida. They paid everything.”

Some financial and health insurance assistance varied depending on the individual state of residence. For example, participant number 7 reported,

I received a discount resident card from the state of New York where I resided at the time. The card helped with all services and physician expenses. I was concerned at first because I was not certain the card would be accepted or what it paid for. But, the surgeon said not to worry and that the finances would be taken care of.

Participants without access to healthcare insurance when cancer was initially discovered only needed to prove residency based on a 6- month to 12-month period. Their citizenship at the time of diagnosis was not required. Consequently, the participants reported minimal challenges with their ability to pay for biopsy and related services to their cancer diagnosis. Conversely, a small number of participants did experience some economic or financial impact if they were not married or were single parents. Participant number 8 is a single parent diagnosed with breast cancer. When asked how finances and healthcare insurance influenced receiving a biopsy, she stated, “I do not work however; I need lots of financial support. My husband and parents are deceased.” While 9 of the 12 participants initially questioned how they would pay for diagnostic services such as biopsy and treatment, the services and care were provided and paid in full as a result of the above community resources and Obama care health insurance as a result of the Affordable Care Act. Participant number one stated,

“I didn’t have insurance. My son is in a church in Maryland. His church gives medicines every two weeks. The next day, Monday after diagnosis, I was sent to the clinic and my son’s church paid for everything. Also, my children got me “Anthem” off the health marketplace exchange Obama care.”

Though citizenship questions were not asked or a part this research, participants that are non-citizens and diagnosed most recently in the U.S., reported they are challenged additionally with the current immigration challenges now faced in the United States under the current administration. As such, each participant who has arrived in the United States within the last 5 years or less stated they have fear of being returned to their home country of origin. Though length of time residing in the United States was not an interview question, participants were asked if she



were diagnosed in her country of origin or the United States. Additionally, the inclusion criteria stated participants were required to be diagnosed within the past three years. Participant Number 8, a single parent of a 15-year old son, stated,

“I wish no one had to go through this journey of breast cancer or what I am going through. I am asking for letters from doctors so I can stay in the United States. I am getting paperwork to a lawyer so I don’t have to return to Honduras. There’s no way I will be able to get care there in Honduras. Especially, not the care I receive in the United States. In Honduras, I would die. Right now I only hold a green card.”

### **Emotions and Feelings**

Each participant, as would be expected reported the same vast array of emotions and feelings upon learning of the disease or suspecting the possibility of the disease prior to official diagnosis of breast cancer. While most individuals universally or instinctually respond emotionally in the same or similar ways based upon a cancer diagnosis the two themes are different. Emotions though universal to all individuals, are based on reactions to events outside of our being and are experience first. Some emotions can be considered as the following: fear, grief, anger, love or happiness. Each participant reported such emotional states as shock, fear, anger, sadness, disbelief, getting the cancer as a punishment for a wrong committed, determination of the disease as God’s Will for them, disregard for their feelings or pain. For example, participant “I was in shock and began crying a lot.” Participant 2 shared that in her culture, “Christians from Central America believe cancer is a “curse.” They believe there must be something wrong with your life and the cancer is a punishment from God.”

In contrast to emotions, feelings are internal learned behaviors not based on circumstances associated or trigger by an outside event such as joy. Each participant reported

feelings of worry, faith or belief in a higher power, resentment or bitterness, joy or pain as part of their feelings paradigm. For example, participant 9, diagnosed with stage 2-breast cancer in the United States reported that she had lots of pain in her right arm. However, once diagnosed, she says,

“I could not believe the diagnosis when I heard it and was prepared to die. Both my mother and grandmother died of it. But, the doctor said “don’t worry we will fight it together. We caught in time.” “I cried and cried lots and asked – why me?” Elda progressed quickly. I trusted the Physicians in the United States and took them at their word. The Physicians provided lots of emotional support and it helped raise my confidence.

Participant number 11 was diagnosed with stage zero. She stated, “the physicians in the United States took very good care of me. I felt very tranquil because I had faith in God and the doctors. However, I felt bad because it isn’t easy going through this journey.” Participant number 12, who has lived in the United States since 2005, learned of her breast cancer diagnosis through her annual mammogram. A ball was found in 2014 but was non-cancerous. It was recommended she have a mammogram every six months. In 2015, the ball had grown larger and a biopsy revealed it to be non- invasive cancer.

### **Cultural perception of breast cancer**

Finally, the 3<sup>rd</sup> research question (iii) how can breast care health providers encourage early breast cancer detection and biopsy measures with tumor detection is related to culture. This may be challenging due to the broad and diverse structures of each Hispanic or Spanish country. For example, the participants shared that in their country of origin breast cancer. Other types of cancer are rarely, if ever, recognized or discussed within their communities. Consequently, understanding and training of breast care physicians and staff caring for this diverse cultural, perceptions, limited knowledge, and education of the disease is imperative. Most of the participants reported they were born and lived in small communities with very limited medical resources. For example, participant number 1 stated that in “their country was not as advanced as the United States. They were not educated about related health issues. Many assumptions were made when someone within the community became ill and would die, that it was most likely cancer. When the breast cancer diagnosis was given she stated,

“I thought maybe it was as a result of resentment toward my husband. I blamed him, but forgave him. He was a womanizer – but, I forgave him. I was angry because I held the resentment so long inside and thought I’d gotten rid of it. My uterus had polyps and her husband would joke she would get cancer. He would also joke that women with small breasts didn’t get cancer.”

Participant number 2, a breast cancer survivor, stated in her home country, “People don’t talk about it. They keep it secret. So they travel to other areas such as Chile and Argentina for example for exam, diagnosis and treatment. In Central America cancer is considered a curse. People believe cancer is a punishment from God for something you did wrong. She shared her diagnosis on Facebook, however some did not agree. She reported,

“I put on Facebook that I had breast cancer. But, my mom was upset that I announced it on Facebook. But, I received many private messages for prayer and others began sharing their

experiences. Many shared only because I shared my diagnosis on Facebook. They became better. Now others can help others.”

Participant number 3 indicated, “There, in Bolivia, is little breast cancer diagnosis as in the United States. In the Latin culture, breast cancer, is taboo or not spoken of until the end or rather death. It’s also not spoken of because of the economic impact. It’s considered “taboo” because of the fear, not so much taboo. The reason for the fear is because they believe there is no cure, they have no resources and because of the fear of death.” Participant number 4, stated in her country of Honduras, cancer only exists in the city because there is more access to care; therefore you don’t go to the doctor regularly. It’s also perceived that those living in the city are more educated and have knowledge of breast. In her community no one went to the doctor for cancer. There are no medical exams or tests done, therefore, people die from cancer without knowing they had it. Participant number 4 indicated that in her home country, people are becoming more open to discuss breast cancer depending on the type.

“They don’t speak of breast cancer. Even if someone is ill on one asks questions. There are two different types of people in Guatemala: one is the indigenous and they don’t have access to facilities or medical care or quality diagnosis. The second group is the middle class people and they don’t have access either.”

### **Breast Cancer Diagnosis**

A malignant tumors that begin in breast cells and may increase or metastasize to other parts of the body (American Cancer Society, 2013, p 2., para 1). Participant number 5, born in Nicaragua and later moved to Guatemala with her family due to wars and poverty, had just arrived in the United States when diagnosed with breast cancer. She indicated that she had not had a mammogram in two years because she had no gynecologist. However, when she found a gynecologist a mammogram was recommended. The technologist told her they found something

on her right breast, but to return later for a review of the left breast. The participant returned for another mammogram alone as her family had not yet arrived in the United States. She was very scared and returned frequently to Arlington Free Clinic in Arlington, Virginia. Arlington Free Clinic was able to get her three mammograms and an ultrasound, but the fourth mammogram was done at Inova Hospital in Arlington, Virginia. It was discovered that she had a .7 mm cancer in her left breast called carcinoma in situ equal to stage zero. However, a surgeon was recommended her for an open biopsy.

Participant number 4 was diagnosed with breast cancer in the United States. She was working at the time of diagnosis to keep her insurance. The participant went in for a mammogram because she was having pain in both arms along with fever. The doctor found no cancer, but recommended she return in a year for follow up. She returned in a year for the follow up, however this time the doctor found something and wanted her to get a biopsy. Two days later participant number 4 was diagnosed with stage 2.5 invasive ductile carcinoma. "I was in shock and began crying a lot."

Participant number 6 learned she had breast cancer soon after her move to the United States. She discovered a ball in her left breast and went in for a mammogram. Her mother was diagnosed with breast cancer just prior to her finding the ball in her left breast. Initially in denial, she "didn't want to believe her diagnosis nor did she want to know anything about it."

### **Patient biases from Physicians**

Thais, diagnosed with breast cancer in 2017, indicated patient biases based on race, color and gender when she was initially diagnosed. Thais received three biopsies; she was not given any anesthesia during the first one.

Thais stated, “There is a myth and bias that women of color, Black and Latina, have a higher pain tolerance level and are therefore, given far less pain medication and anesthesia than Caucasian women. A radiology department at one particular hospital in Maryland where I received my biopsies was very uncaring. They did not warn me of the pain I would experience. I was very uncomfortable and did not trust them.”

Ivania stated, “After my biopsy results revealed cancer, the records were sent to her gynecologist. I decided to go to my gynecologist office to learn what to do next. However, the receptionist was indifferent, very rude and the staff not nice or kind. They were insensitive and not compassionate. My doctor wasn’t available that day and the receptionist was not private about my personal health information “though others were around. I felt like a zombie inside.”

### **Challenges of breast cancer diagnosis**

Participant number 7 was diagnosed with stage zero when she went to see a physician due to foot pain. The physician recommended a full exam and mammogram. “I did not have any breast or chest pain nor did I feel anything in my breast tissue. The biopsy revealed I had cancer but very little.” The surgeon operated on her fifteen days later and took out a small ball of tissue. She had six chemotherapy sessions but no radiation was required and was assured no cancer would return. However, in 2016, a mammogram revealed cancer in the same breast where the small ball of tissue was removed. Participant number 7 was told she must have the whole breast removed. Once again the physician told her the cancer would not return. During her second diagnosis her daughter was diagnosed with breast cancer as well. The participant asked,

why my daughter and me? I felt very bad and asked God to help us. I asked God to help me have strength and to accept it. It was the worse and hardest thing. I felt very bad for myself and

daughter to have breast cancer. I've asked God that it doesn't come back to her daughter.

Dee, breast cancer survivor from Honduras, indicates that, "A lot of people die because They don't have the resources as in America for their annual exams. They can only find out Though when they go for an annual exam, however they only go for the exam when they have pain. Then the doctor tells them they have cancer but by then it's too late." Dee's physician in Honduras told her breast cancer is caused by a lack of vitamins. She was diagnosed in the United States. Dee has had four surgeries in the same breast for tumors. The first lump was bleeding and found when she was pregnant. She did not want them to take her baby, so she had the lump removed with only local anesthesia. All the tumors were non-cancerous, Except tumor number three.

### **Family Support**

Maria went to the Physician appointment alone to find out the results. She didn't want to tell her husband and kids until she was sure. Her mother told her, "she was strong, but she was very sad." Maria's mother and all her family gave her lots of support. Maria indicates that telling her kids was the most challenging part of her diagnosis. She was afraid that if something happened to her she would not see her family. Maria shared,

"I felt I would not live anymore – that I would die, the cancer would be my death. Then I said, "No" I am strong and God is with me and to trust myself to the hands of the doctors who are wise. I was trusting God and the doctors."

### **Community Support**

All the women who participated in this research study discovered the breast cancer at some point during their arrival to the United States. Only two of the women indicated that they

had health insurance through their employers or spouse at the time of diagnosis. The remaining ten women were able to utilize a variety of financial resources. These resources were a combination of cancer support programs in the local area, as well as in New York, two local non-profit organizations; and Nueva-Vida of Washington, D.C. and Arlington Free Clinic in Arlington, Virginia. For example, participant number 9 received assistance from Nueva-Vida with a discount card for any services, physicians and treatment procedures. Consequently, the participant was able to receive great care here in the United States.

For some of the women, the church communities provided financial support in addition to other services such as food, BRACA genetic testing, housekeeping and transportation to and from medical treatment appointments. In the case of participant number 1, her son's church paid for everything. In another participant's case, the Physician told her not to worry about cost; that everything would be taken care of. For example, participant number 1, shared her diagnosis with her pastor. The church then had a lap quilt made for her. As a show of support Jacqueline's sister made t-shirt, threw her a party where her relatives including her mother cut all their hair off because she was upset about losing her hair from chemotherapy.

Participants were allowed to voice their experiences of applied meaning and perception in efforts to add to existing literature or new theory development to influence early detection that encourages health behavior modification. Detailed information and data collection from participants were formed into categories or themes as recommended by Creswell (2007, p. 64). Themes were then developed into broad patterns, theories, or generalizations and compared with personal experiences or existing literature providing a different end point (Creswell, 2007, p. 64). Measures of primary interview questions are presented in Appendix B.



### **Evidence of Trustworthiness**

This study proposed to identify trends or patterns associated with breast cancer outcomes among Latinas when confronted with breast tumor or biopsy decision making. Primarily the study population recruitment location area was within the Northern Virginia and immediate surrounding areas such as Maryland and Washington, District of Columbia and was open to all Latinas who met the inclusion criteria as described on the approved recruitment flyers in the area with the recruitment limitation of population of 17 – 25 participants. Yin (2009) suggests this kind of exploratory study is a “justifiable rationale with the goal being to develop pertinent hypotheses and propositions for further inquiry “ (p. 10). This decision was also recommended by the director of Johns Hopkins School of Medicine and supporting area government and non profit agencies as sufficient to gain quality data for coding and analysis. The study encountered an unusual circumstance during recruitment, in spite of this, there were no unusual circumstances encountered during data collection. As previously stated, the study sought to recruit and interview 17-25 Latinas for the study, however twelve Latinas agreed to participate in the research. As stated above, the participant or sample size was the starting place for grounded theory development however, the proposed theory was formed from the categories refining theory sampling of data that answer research questions. This process illuminated new open-ended questions from participants not initially covered in the research questions of this study (Charmaz, 2006, p. 103). Further, according to Charmaz (2006) “memo-writing leads to theoretical sampling” which leads to theory development defined from expansion of categories (p. 103). Further, Creswell (2007) asserts novice researchers begin with a small sample size in order to minimize the impact of frustration and feeling overwhelmed. Participants were in remission or the survivorship lifetime treatment recovery stage. Females that were in treatment,

outside of the remission period or survivorship procedures were ineligible. This is in consideration and continued protection of females undergoing defined treatment of breast cancer identified as vulnerable due to the sensitive nature of chemotherapy and radiation. As previously stated, trends, themes, and concepts were coded to create a story narrative of emerging experiences by participants. Data analysis of categorization utilized Hyper search software, compatible with MAC and PC computers or ATLAS.ti software for assistance, which has been recommended by the Inova Life with Cancer executive staff.

In a Grounded Theory qualitative study, Charmaz (2006) asserted that validity must be established early in the study context; 1) credibility, 2) originality (transferability), 3) resonance (confirmability), and 4) usefulness in data collection and evaluation are required. First, credibility (internal validity) is recognized as truth in findings or implications of sufficient evidence that substantiates claims or empirical data's worth ensuring trustworthiness (p. 182). Additionally, as asserted by Creswell (2007, p. 200) descriptive and detailed collection of participant experiences will provide ongoing transferability (external validity) providing reliability to study. Consequently, participants of this study were not required to complete a follow up interview to verify description of researcher's findings analysis of ensuring their perspective was legitimate minimizing researcher bias or reflexivity. Secondly, tenants of originality (transferability) refer to new conceptual analysis or insights to data or theoretical work that contribute to the population's health outcomes; this includes the ability of findings to challenge current theories and conceptual frameworks, or practices within the research discipline. Originality can contribute to transferability or connecting concepts that are applicable to other contexts (Lincoln & Guba, 1985). For example, the research could potentially be applicable to understand correlations of socio-economics, income, spiritual beliefs, and cultural

structure to other areas of quality care services, or diagnostic services minimizing inequities in the healthcare system. The data collection specific to the Latina female population associated with the breast cancer treatment and support centers included recruitment from other local government, physician offices, and non-profit agencies as well as breast care centers. An audit trail of the student researcher data collection and analysis took place throughout entire process ensuring dependability of data interviews.

Third, resonance or dependability is the ability to make data collected makes sense to participants and appropriately represents their experiences or applicability to other findings or context and can be repeated with reliability (Charmaz, 2006, p. 182; Lincoln & Guba, 1985, p. 120). For example, the study was overseen (audit trail) by the Johns Hopkins School of Medicine IRB, Dr. James Zabora, ScD, Director, Education & Outreach Johns Hopkins Center to Reduce Cancer Disparities, Baltimore, MD, and Walden University Chair, Dr. Kourtney Nieves and Committee, Dr. Magdeline Aagard, and the leadership staff. This practice ensured conformability corroborated by the leadership teams. Fourth, usefulness of the study must answer the question of contribution to the knowledge of literature and social change (Charmaz, 2006). Results can become part of future research added to understanding the population and strategies for servicing effectively. Further, participants completed approved interview questions with student researcher directly related to their access to care and healthcare utilization services. This minimized the researcher bias, and assumptions of findings and interpretation of data.

## **Results**

The purpose of this study was to focus on disparities in breast cancer care experiences within the Hispanic female and Latina communities in the United States. Though the study utilized the grounded theory method for inquiry, it also relied on the Health Beliefs Model that

could build a construct useful in addressing the research questions. The Health Beliefs Model relies on empirical evidence to determine or broadly predict attitudes, intentions, behavior controls, and expectations thereby providing some data on intentions, motivations, and perceptions interrelated to actions. For example, the research question, (i) how does perceived access to breast screenings such as mammography, influence biopsy decisions when a tumor is detected, contribute to delayed or late stage breast cancer diagnosis in Latinas, can provide insight regarding the financial decision making process for vulnerable populations faced with disease. The research question aligns with the perceptions of disease and illness seriousness in the HBM construct.

The information from the interview with participant number 1, established a context of the psychosocial factors leading up to the diagnosis of breast cancer. Her response created a theme coded for emotions and feelings. For example, when participant number 1 was asked about the perception of breast cancer in her country of Nicaragua, she responded, “Death” – It is not as advanced as in the United States. When I was told about the cancer (a ball in my breast) I wasn’t worried.”

Additionally, the detailed information gathered from specific questions asked in interview number one, laid the foundation for understanding the participant’s current state of mind and health (Miles & Huber, 1994, p. 207). How does the participant’s country of origin contribute to their beliefs about those who get breast cancer? What view does the culture have of a woman diagnosed with breast cancer or when she finds a tumor? How concrete is the healthcare infrastructure within the participant’s community? What has been her perception of the physicians in her country of origin compared to physicians in the United States?

The 1<sup>st</sup> research question addresses (i) how does perceived access to breast screenings such as mammography, influence biopsy decisions when a tumor is detected, contribute to delayed or late stage breast cancer diagnosis in Latinas. The women were asked what their family and culture thought of cancer diagnosis, how they learned they had breast cancer, and to describe the role of the physician in their culture and family. These questions were asked to develop a foundation of credibility to the woman's experience from a socio-cultural and spiritual, rather belief if the diagnosis is God's will or if the participant somehow is being punished for a wrong committed against God or a loved one perspective of influence. For example, participant number 1 was asked, why she wasn't worried, when first diagnosed. She responded, "I had faith in God. But, my children and husband were very worried." It also addresses the motivating factors or cues to action perception of the HBM demonstrating the participant's willingness to seek care and to follow through with compliance of prescribed treatments. The participants were able to provide a comparison of physician care, treatment and facilities in their country verses the United States. These interview questions may be found in Appendix B questions 1 through 5 and question 8.

The 2<sup>nd</sup> research question addresses (ii) how can breast cancer health providers, physicians, and professionals improve equitable access to care and breast care facilities that improve health outcomes related to breast cancer diagnosis, and increased survivorship among Latinas. Some stages and types of breast cancer carry a high risk of recurrence. The BRACA test can offer some hope of a woman's chance of facing the disease again. Participant number 10 recommends, "Change the guidelines for the BRACA II genetic test. BRACA II genetic research data currently shows: triple-positive diagnosis has a 60% chance of recurring; a 30% chance of recurrence with treatment; 80-90% chance of non-recurrence rate of return."

Further, the question gives context to how the participant was diagnosed which also addresses feelings and emotions discovered at time of diagnosis. These interview questions may be found in Appendix B questions 6 and 7; in addition section II interview questions 3 through 5 Appendix B continued. The 3<sup>rd</sup> research question (iii) how can breast care health providers encourage early breast cancer detection and biopsy measures with tumor detection. The third research question aligns with the HBM construct related to barriers to behavior such as physician and staff bias. She was given little anesthesia and no warning of pain severity during her first biopsy procedure. For example, participant number 10 stated, “there is a myth and bias that women of color, Black and Latina have a higher pain tolerance level and are therefore, given far less pain medication and anesthesia than Caucasian women.” Participant 10 also refers to inter-cultural bias. She states, “there are bias based on ethnicities even within your own community. It’s believed that minority women have a higher pain tolerance level so fewer anesthesia is given during procedures. Caucasian women are made more comfortable during the same procedures and treatments.”

Interview questions related to the final and 3<sup>rd</sup> research question can be found in questions 2 through 8 in Appendix B. These questions lay the foundation that describe the participants relationship with physicians, knowledge of breast cancer, and financial resources, including health insurance or socio-economic factors influencing biopsy decision, perceptions of long-term survival, fear of recurrence and trust in physician care and opinion, confidence of the women’s long term prognosis. Conversely, these variables change based on where the participant was diagnosed such as their home country or the United States. Patton (2002) asserts this approach would evaluate “why do individuals behave as they do, how do human beings behave,

think, feel, and know, what is normal and abnormal in human development and behavior?" (p. 216).

Primary participant interviews were conducted at the following locations Arlington Free Clinic in Arlington, Virginia, one over the phone in Centreville, Virginia at the home of the Spanish interpreter, one in person at the home of the participant in Herndon, Virginia, one at the home office of the student researcher in Aldie, Virginia; the remaining participant interviews were conducted by telephone at Chantilly Regional Library in Chantilly, Virginia. All interview locations were secured, private and free of distractions whether in person or over the phone. The student researcher and the Spanish interpreter were present for 11 of 12 participant interviews. One participant interview did not require the presence of the Spanish interpreter, as the participant was an English only speaker (See above: Aldie, Virginia).

In addition, both the researcher and the Spanish interpreter wrote memos for each interview. The Spanish interpreter notes were necessary in the instance of English to Spanish interpretation of each interview question. There are many English words that do not translate into Spanish; or vice-versa presenting a potential challenge to the meaning of the interview question addressed. Notes were also documented that observed non-verbal elements of communication, emotional tone when providing certain details of their experiences. Finally, the environment of each location was documented (Charmaz, 2006, p. 103).

Data collected were organized by demographic information, categories of similar responses to focused research questions and compiled for coding and analysis using Atlas.ti qualitative software (Huberman & Miles, 1994; Creswell, 2007, p. 156). This allowed the researcher to gain a general overall understanding of the data information gathered (Creswell, 2009, p.183). This research study was necessary to provide detailed experiences of Latinas

relative to access to care in the health delivery system when confronted with breast tumor, biopsy and finally breast cancer diagnosis.

Next, the researcher reviewed each participant transcript several times to gather similar phenomena within text words, code stings, quotations, statements and experiences. The purpose was to understand how relevant the data applied to the overall research study. The study examined the potential connections between beliefs, cultural context, and socio-economic status contributing to delay breast screenings and the biopsy decision process. Interview findings were collected in a confidential manner and filed in secure location with the Johns Hopkins School of Medicine's filing system to protect participant responses. All data collected for this research, as well as back up data, will be destroyed after five years via shredding methods approved by the cancer center and the selected computer software program.

The goal of the study sought to answer these three research questions; (i) how does perceived access to breast screenings such as mammography, influence biopsy decisions when a tumor is detected, contribute to delayed or late stage breast cancer diagnosis in Latinas; (ii) how can breast cancer health providers, physicians, and professionals improve equitable access to care and breast care facilities that improve health outcomes related to breast cancer diagnosis, and increased survivorship among Latinas; and (iii) how can breast care health providers encourage early breast cancer detection and biopsy measures with tumor detection. These answers are imperative and could help minimize the current financial fallout of the healthcare delivery system and improve access to the United States healthcare delivery system, such as physician care, services, training of staff and utilization requirements as they address Latinas and eventually other female minority groups. Furthermore, the study's intent was an effort to



provide information to breast health care providers that could improve outcomes of survivorship including long-term quality of life when breast cancer is discovered.

### **Summary**

Chapter 4 has provided information regarding relationship to primary themes during data collection and analysis and the discovery of breast cancer among Hispanic females and Latina women. While none of the women were born in the United States, each woman had the ability to obtain various types of support, including health insurance through Obama care, cancer support programs, government assistance, and community and family resources. Only two of the women worked full time jobs that covered health insurance, another was a housewife but had health insurance through her spouse's employment. Other findings of the study indicate their home countries of origin are primarily poor, war ravaged, and lack the basic access to facilities, medical equipment and supplies, and little to no education of basic illness including any type of cancer. Though one of the research questions addressed access to biopsy when a tumor or lump was found, the women evidence demonstrated no barriers influenced obtaining one due to community assistance programs available to them. The study sought to find themes from Hispanic females and Latina's diagnosed with breast cancer, related to perceptions of the disease and illness seriousness, susceptibility, behaviors or cues to action, motivating factors for seeking care, any barriers to follow through of treatment plans, and long term self efficacy as designed by the Health Beliefs Model. The results concluded that each participant perceived the disease as serious and could lead to death. Depending on the knowledge of a family history or friend within their cultural community a participant may or may not have assumed a level of susceptibility to the disease. Conversely, upon learning of her diagnosis each participant demonstrated consistent behaviors associated with compliance to factors such as seeking care,

following physician recommendations for surgery and short and long term treatment planning. Participants with children were more motivated to follow cues to action and self-efficacy stated her desires to live for her children. Chapter 5 will provide research findings based on data interpretations, social change implications and finally, recommendations pertaining to quality care services, or diagnostic services minimizing inequities in the healthcare system to minority populations.

## Chapter 5: Discussion, Conclusions, and Recommendations

### **Introduction**

This study attempted to develop an original theme within the construct of grounded theory of the Health Belief Model regarding Hispanic females and a breast cancer diagnosis. The purpose of the study is to understand barriers to biopsy and requirements for behavioral motivation to adherence when addressing perceptions of risks and susceptibility. The research questions for this study were: (i) How does perceived access to breast screenings such as mammography, influence biopsy decisions when a tumor is detected, contribute to delayed or late stage breast cancer diagnosis in Latinas; (ii) How can breast cancer health providers, physicians, and professionals improve equitable access to care and breast care facilities that improve health outcomes related to breast cancer diagnosis, and increased survivorship among Latinas; and (iii) How can breast care health providers encourage early breast cancer detection and biopsy measures with tumor detection. Breast cancer is the primary cause of death between Hispanic females. Health status may contribute to the predisposition of this and some other illnesses (American Cancer Society, 2014; Corcoran et al, 2012). In addition, while slight decreases (1.6%) in breast cancer diagnosis have been noted between 2009-2012, most cases are determined at the late stage with socio-economic status (SES) and age with 54% at local stage in comparison to 64% of non Hispanic females (American Cancer Society, 2014). Further, higher incidence of diverse cancers and disparities are prevalent among certain underserved populations and racial/ethnic groups. Factors heavily influencing higher incidence of diverse cancers among underserved populations are being underinsured, lack of health insurance, and limited economic resources or low Socioeconomic status (National Cancer Institute, 2014; Gonzales, et al, 2011; Mali, Leake, Mojica, Liu, Diamant & Thind, 2011).

## Interpretation of the Findings

Research consistently demonstrates large disparities in health care and services among minority women in the United States. The Health Beliefs Model is one model that consistently relies on empirical evidence to determine or broadly predict attitudes, intentions, behavior controls, and expectations thereby providing some data on intentions, motivations, and perceptions interrelated to actions. Yet, minority groups in the United States continue to face greater risks of late stage diagnosis and illnesses related to breast cancer leading to death.

Services are rationed favoring the wealthy and a bias structure overriding the majority common good toward minority and underserved populations, whom typically lack equitable resources for care (Yearby, 2011). For example, according to Willson (2009), socio-economic status is one factor strongly identified with persistent health disparities. As noted in chapter 1 of this study introduction, the Center for Disease Control and Prevention (CDC, 2012a) suggests Hispanic females are less likely to participate in screenings compared to their non-Hispanic female counterparts varying per Hispanic female subgroups. Latina's are diagnosed at younger ages, is the leading cause of death, and are diagnosed at more advanced and harder to treat stages (Office of Women's Health, 2014). Hispanic females and Latinas receive little education regarding breast care awareness such as self-reporting, the importance of annual exams and mammograms or symptoms that appear unrelated to breast cancer. Because many are non-citizens of the United States, perceptions of access to care, facilities, and treatment may be considered out of reach.

The mix of countries and cultures in the United States defined as Hispanic or Spanish populations present a challenge for healthcare providers seeking to understand the qualitative experiences this disparate population. As a result of these findings, pervasive challenges exist in

the development of intervention and education to the community. One discrepant finding from the women of this study suggests total trust in the Physician's in the United States; conversely, medical providers and practitioners within the same United States health system of their culture of origin as well as often treated them with disdain.

The method of inquiry for this study utilized a Ground Theory and the Health Belief Model (HBM) approach as a guide to allow emerging themes and categories to arise from within the data collection with minimal barriers to the experiences of the volunteers. The intent of the study was a qualitative analysis of the experiences of Latinas' and their access to care, quality of care, and utilization of services after breast cancer diagnosis, biopsy upon detection of a tumor discovered through self -detection. Erwin et al. (2010) asserts:

Although many studies use and report qualitative research methods and findings to create and inform health education interventions, there is a dearth of methodological information about the interpretation and transformation of these qualitative analyses into intervention content and structure. (p. 694).

The results of this study generated toward the end shared experiences of this population group with anticipated expectations that could reduce late stage breast cancer diagnosis or analyze the biopsy decision making process. As the population of diversity and cultural structures expand in the United States, it is imperative for the U.S. Health Delivery System to address the "contributory variables to divergent outcomes" of such growing diverse groups. Wujcik, Shyr, Clayton, Ellington, Menon and Mooney (2009) contend reasons for variations in delayed diagnostic exams and increased mortality among this population is unclear calling for expanded research of other contributory variables to divergent outcomes (p. 710). This goal not only serves these populations, but also possesses the potential to lessen the level of health disparities and income inequities within the United States.

A possible outcome or consequence of this study may highlight other risk factors for research among Hispanic women of ethnic differences. Another anticipated outcome of this research could utilize data to investigate as a pilot that will give clues as to the potential factors to be studied in a larger group of women among vulnerable minority populations.

### **Limitations of the Study**

Grounded Theory in a qualitative study provides a perspective lens of participant beliefs, and attitudes. As such, this study demonstrated the process of allowing a hypothesis to develop from themes and categories during data collection. Conversely, an interview questionnaire was developed in advance from the initial key research questions. This methodology would appear as a limitation of the study. Research questions and secondary interview questions (the instruments) were pre-approved limiting a larger group of categories not considered from the participant responses. Creswell (2007) asserts a hypothesis is developed as a foundation for research questions forming a theoretical foundation and organized model for data collection. An instrument is then selected to measure attitudes and behaviors for the study with scoring outcomes that validate the original theory or support the hypothesis (p. 29). However, as a novice researcher at this level the pre-approved research questions utilizing the HBM as a guide were extremely necessary. Creswell (2007) asserts novice researchers begin with a small sample size in order to minimize the impact of frustration and feeling overwhelmed.

Although 20-25 volunteers were requested to participate in the study, only 12 women came forward and agreed to share their journey as long as identities were concealed. Transcribed interviews were analyzed through grounded theory's "constant comparative analysis" approach

to data analysis (Charmaz, 2006; Glazer & Strauss, 1967) to understand participants' beliefs and attitudes. Conversely, limited economic socio-economic resources, lower economic status, lower educational backgrounds, and recent changes in the immigration policies within the United States are major contributory factors influencing late stage outcomes for this population. For example, Wujcik et al. (2009) contend reasons for variations in delayed diagnostic exams and increased mortality among this population is unclear calling for expanded research of other contributory variables to divergent outcomes (p. 710).

The study's intent was to shed light on how to meet the public health need of this population as it correlates to late stage breast cancer diagnosis. Though diverse types of breast were diagnosed among this population, no woman in this study was diagnosed above stage 2-breast cancer. Findings may have been compromised due to the low number of willing participants who feared consequence of the new immigration policies. Most of the women arrived to the United States leaving impoverished, war torn countries in Central America with limited or no accessible or quality health care facilities, Physicians, or medical necessities. Most of the participants never had mammograms or breast exam until they arrived in the United States. Therefore, they did not want to return to their country of origin. The three questions posited earlier seeking ways to encourage early detection, increase access to equal breast care assessments and understanding how the comprehensive needs of diagnosis and care, short and long term, are perceived to influence late stage diagnosis or early death have been considered in the findings.

### **Educating the community**

It became imperative that each woman expresses the need for increased education of breast health, care and recognition of breast cancer signs early. Each woman indicated that prior to diagnosis they had no knowledge of breast cancer. This was primarily a result of the extreme limited economic resources and poverty within their home countries of origin. Though they all indicated had breast cancer been found in their country, which was impossible for the majority countries, they would be deceased. There must be education of self-evaluation, community resources, which include financial and emotional psychological support. The support should also include immediate family such as spouses, kids and immediate caregivers not in the medical field. Language Barriers are another concern for this population demographic. As recommended by one participant, each woman's Physician should be informed and educated in their language. The English language has many variations on one word, and the Hispanic communities not all-Spanish language is equal. They, too, have variations. This approach, however, would appear to present challenges such as knowledge of which Spanish dialect is being spoken for full understanding of information required. Consequently, how does an organization explain each process involved in breast care, diagnosis and early detection measures? Patton (2002) asserts this approach would evaluate "why do individuals behave as they do, how do human beings behave, think, feel, and know, what is normal and abnormal in human development and behavior?" (p. 216). Moreover, the strengths of study highlight influences on late stage diagnosis relative to equitable quality of care or access to services.

### **Age of participant**



The mean age for the women volunteering in this study was age 40 years. The women were willing to share their experiences with breast diagnosis as a way to help other minority women become educated before a late stage diagnosis. Participants in this study were older than 34 years of age and appeared to understand the importance of giving their voices to other women as warning that could save their lives; but also as a cathartic release of their own grief of somehow being chosen to bear such an evil and fears of future recurrence. The women suggested more boots are needed on the ground to provide education and encouragement to follow through with treatments in spite of the difficulty of this diagnosis. The primary countries of the participants were Honduras, Nicaragua, Mexico and Bolivia. All of the women believed that they would have died had they remained in their home country.

### **Retrospective account**

Each volunteer shared their experiences willing though the accounts were difficult to express. As each woman recalled the shock and pain of learning of the diagnosis, the emotional and psychological toll was obvious and some were unable to speak as tears began to overtake their words. There was also an obvious feeling of anger shared by the women which soon turned to fear. Fear for their lives, fear of pain, fear for their children regardless of their ages and fear of forced return to their countries where there is little to no medical care. For some, the language barrier between the interpreter and themselves left a few questions unanswered however, the researcher was able to glean meaning with the assistance of the interpreter. One reason for this as explained by the Spanish interpreter is that for every word in English there is no match for it in Spanish.

### **Theoretical Considerations**

The theoretical design for this study was a qualitative grounded theory method to guide the process of identifying causes or themes comparative to delayed breast care exams that could lead to late stage breast cancer in Hispanic women and Latinas. Though interview questions were posited, no prior literature need exist in advance of a grounded theory design. The intent of a grounded theory study is to generate data that recognizes emerging trends, categories and/or themes related to each other based on empirical evidence. Specific open ended questions were developed in advance of the participant interviews as a guide allowing the women to share their experiences related to access to care, quality of care, and utilization of services journey after breast cancer diagnosis, biopsy access or barriers or discovery of breast cancer through self detection. Grounded theorists, for example, generate a theory grounded in the views of participants and place it as the conclusion of their studies. Some qualitative studies do not include an explicit theory and present descriptive research of the central phenomenon” (Creswell, 2007, p. 70). The central social phenomenon of the study explored the lived experiences of Latina American or Immigrant female breast cancer patients or survivors in the United States. The student researcher, DBora Schrett, followed a Generic Inductive Qualitative Model (Maxwell, as cited in Hood, 2007) by noting the themes and views that emerged from the participants regarding their perceptions of access to breast biopsies and their motivations to comply with care.

Transcribed interviews were analyzed through grounded theory’s “constant comparative analysis” approach to data analysis (Charmaz, 2006; Glazer & Strauss, 1967) to understand participants’ beliefs and attitudes. The study results do not suggest the women experienced an inability to take health related actions in their breast health and care. As the Health Beliefs

Model construct asserts 1) perceived susceptibility; 2) perceived severity; 3) perceived benefits; 4) perceived barriers. The HBM relies on empirical evidence to determine or broadly predict attitudes, intentions, behavior controls, and expectations thereby providing some data on intentions, motivations, and perceptions interrelated to actions. The Health Belief Model constructs demonstrate perceptions of disease and illness seriousness, susceptibility, benefits, and barriers examining behaviors of “cues to action, motivating factors, and self efficacy” (Blearning (1998, p. 1). These theories relate to the study approach and research questions by seeking connectors to behaviors associated with access to utilization of care and services, delay in screenings, barriers to biopsy, and non compliance to the process of health actions.

The primary questions were based on the Health Beliefs Model construct.

The goal was to align potential participant results with the Health Belief Model highlights and additional beliefs, attitudes, intention, social norms and behaviors that identify the foundation links between attitudes and behavior under the individual’s control (Manstead, 2011). The results from the study utilizing the HBM construct model; 1). perceived seriousness (severity) – 5 of the women who found a ball or suspected tumor upon self-examination reported the initial denial of a cancer possibility. As such, they delayed seeking medical perceiving the self- finding as not serious based on misconceptions. A few women reported they followed up with breast exam at the encouragement of a friend or family member. Finally, perceived seriousness also influences motivation to comply or adhere to prevention programs as well as self –efficacy efforts of self-exams and seeking medical care; 2). perceived susceptibility – another percentage of the 12 women interviewed stated lack of information, knowledge or family history of breast cancer. The women also reported lack of annual well woman care, medical facilities, and physician care within their home country. They also reported fear- based complexities of

cultural influence. For example, one does not speak of illness or cancers within their small communities' or their culture overall. For example, cancer of any kind is considered a curse or a punishment; (3) perceived benefits – upon acceptance of the cancer findings the women reported benefits such as early findings of biopsy results saved their lives, being in the United States contributed to the early findings and their health status and the benefit of looking out for their daughters at risk for developing breast cancer; and (4) perceived barriers including actions, motivating factors and self-efficacy – the women reported initial barriers were a diagnosis (or lack thereof) within their country of origin. Each woman reported that had they remained in their country of origin they would not be alive today. Upon arriving to the United States barriers were financial and health care insurance for 9 out of 12 of the women participants. Conversely, each woman secured financial assistance and healthcare assistance immediately driven from within the Hispanic community. For example, children, physicians of Hispanic origin, Hispanic based non-profit organizations, and Hispanic based churches. Further, depending on the state of residence service assistance may have been more forthcoming. For example, cancer assistance programs in Maryland, such as Johns Hopkins Hospital, Nueva-Vida of Washington, D.C., Medicare and Medicaid (due to age) and the state of New York for one participant who travels between Maryland and New York for treatments and services. Services and assistance in Virginia were harder to locate and receive however, a few clinics such as Arlington Free Clinic in Arlington Virginia assisted participants and the Hispanic population with wellness care. The Arlington Free Clinic would also connect the women with those serving their community at Virginia Hospital Center in Arlington, Virginia. Citizenship is not a requirement; however, anyone seeking care from the Hispanic communities must show proof of residency for the past 6 months to a year. In contrast, it was stated that access to these services appear to be available,

actual access to equitable services presents challenges due to financial burdens, minimal or lack of insurance, or other perceived social and cultural barriers (Gonzales et al., 2011), the supporting evidence reported by the women of the study contradicted the first two challenges posited by Gonzales, Costaneda, Mills, Talavera, Elder & Gallo (2011). In the past, this evidence may have been substantiated based on where an individual resided and community outreach of physicians and medical facilities in partnership. Nevertheless, as of January 2017, complex and challenging immigration reform has gravely impacted the potential long-term affects of access to care and the financial burden on Hispanic and Latina female wellness and cancers such as breast cancer.

### **Recommendations**

The primary goal of this research was to explore the shared descriptive outcomes in an effort to improve the treatment experiences of a subset of Hispanic women with a confirmed breast cancer diagnosis and the transition to a biopsy for breast cancer. A possible recommendation from the outcome of this research could utilize the data to investigate clues as to the potential factors in the delay of biopsy to be studied in a larger group of women among vulnerable minority populations. Further, this study may highlight other risk factors for research among Hispanic women of ethnic differences. Finally, an anticipated outcome of this research could utilize data to investigate as a pilot that will give clues as to the potential factors to be studied in a larger group of women among vulnerable minority populations.

The recommendations asserted from the data gathered from the interviews of 12 women identifying as Hispanic/Spanish or Latina from various countries currently living in the United States include developing more educational materials specific to diverse language of their culture, knowledge of where to find not only resources but, financial assistance or free services

and access to well-woman care, including breast health. The women interviewed recommended care providers should be trained in the sensitivity of the topic and how to help women feel empowered during such a frightening time in their lives. Recommendations for financial assistance at the time of diagnosis, throughout treatment, and for a specified period of time following completion of treatment are highly required. This should include ongoing nutrition information, medication treatments, and side effects, as well as the long-term effects of these treatments.

### **Implications**

The overall purpose of this study was to provide data results that would influence positive social change implications to Latinas diagnosed with breast cancer in the United States. This was accomplished by exploring the shared descriptive experiences of 12 Latinas with a positive biopsy following mammography. The positive social change implications of the study can influence future program initiatives seeking to improve equitable access to care, breast care services and the quality of life. Further, the results from the study are applicable to other subsets of Hispanic women; as well as other underserved female populations. The intent of this study was not to confirm or dispute current research about breast cancer disparities in the U.S. healthcare system. But to corroborate the evidence that further research aligned with the continuum of care about health disparities are needed. Willson (2009) suggests that in spite of large international databases minimal research exist documenting the individual link between socioeconomic status (SES) and health. Its social change implication demonstrated results applicable to the gaps existing literature on breast cancer and health disparities. For example, on a group level, the responses of the women stated biased opinions by care staff and myths about pain tolerance levels about minority women and their culture influenced equal anesthesia as

Caucasian women. Further, the women experienced lack of sensitivity to the emotional impact of a breast cancer diagnosis. On a community and family support level, the research confirms the necessity for Latinas, family members, and primary caregivers also receive emotional and financial resources. On an organizational level, patient care metrics and performance evaluations for employees, including management and leadership, can be revised to define what quality care looks like in the perception of Latinas. The evaluations should include staff trainings with measurable competencies specific that includes sensitivity to a woman diagnosed with breast cancer, their support systems and understanding cultural similarities and differences within Hispanic communities. These factors indicate staff requirements should reflect education and training specific to the process and practice of care of breast cancer disparities.

A secondary objective of this research study was to explore the final themes and results from the interviews to identify potential factors to be studied in a larger group of women among this vulnerable minority population. For example, the women did not discuss breast cancer survivorship plans or physician recommendations for follow up care beyond initial treatment, such as MRI's or mammograms, follow-up of breast care assessments, what to expect next and daily medication. Upon initial diagnosis each woman reported psychosocial feelings of fear, worry, depression, recurrence concerns and impending death. Understanding these themes among Latinas with a breast cancer diagnosis can contribute to a decrease in late stage diagnosis and survivorship. For example, behaviors associated with non-compliance to aftercare recommendations can contribute to a high incidence of breast cancer. One reason could be language barriers that interfere with compliance recommendations. Though a Latina interpreter was present for each interview, understanding of certain words from the interview protocol did

not translate into the same meaning. This could be attributed to the complex sub-groups and cultural differences within the Hispanic community.

This study attempted to develop original primary themes within the construct of a qualitative grounded theory methodology with the Health Belief Model as a guide in data analysis. The results of this study generated toward the end shared experiences of this population group with anticipated expectations that could reduce late stage breast cancer and analysis of the biopsy decision- making process. For example, Wujcik, Shyr, Clayton, Ellington, Menon and Mooney (2009) contend reasons for variations in delayed diagnostic exams and increased mortality among this population is unclear calling for expanded research of other contributory variables to divergent outcomes (p. 710). As the population of diversity and cultural structures expand in the United States, it is imperative for the U.S. Health Delivery System addresses the needs of such diverse groups. This goal not only serves this population, but also possesses the potential to lessen the level of health disparities and income inequities within the United States. The purpose of the current study was to translate the qualitative findings into an intervention that may enhance access to biopsy and compliance with treatment recommendations among Hispanics and Latinas.

As stated in the previous section of chapter 5, complex and challenging immigration reform has gravely impacted the potential long-term effects of access to care and the financial burden on Hispanic and Latina female wellness and cancers such as breast cancer. Further, with the large diverse range of cultural identity from different Spanish and Hispanic countries around the world now residing in the United States the unresolved challenges and uncertainties caused by immigration reform are sure to complicate further care of Hispanic and Spanish populations, as well as all disparaged populations residing, legally or illegally within the United States. It is



imperative for medical professionals to re-evaluate and re-define awareness and care for such populations; otherwise the financial burden and consequences of health status and doctor interaction with patients will become much greater than any time in the history of the United States.

## Conclusion

As the population of diversity and cultural structures expand in the United States, it is imperative for the U.S. Health Delivery System to address the “contributory variables to divergent outcomes” of such growing diverse groups. Wujcik, Shyr, Clayton, Ellington, Menon and Mooney (2009) contend reasons for variations in delayed diagnostic exams and increased mortality among this population is unclear calling for expanded research of other contributory variables to divergent outcomes (p. 710). Evidence from other purported articles from this study (Willson, 2009; Maly et al., 2011, Yearby, 2011 and Erwin, et al., 2010) suggests significant gaps in qualitative research methods understanding the experiences of disparaged or marginalized groups such as Black and Latina American females to pursue mammography and diagnostic breast exams, and the quality of health care delivery system. Consequently, risk factors persist as a continued result of minimal and flexible resources for the advantage of improving health or warding off unfortunate preventable disease (Willson, 2009).

The Center for Disease Control and Prevention (CDC, 2013a) asserts that “while Black Women have a 40% higher incidence of breast cancer related deaths and mortality rates in American than women of any other ethnic group, Hispanics are less likely to be screened and this varies among Hispanic subgroups” (CDC, 2013b). These subgroups consist of Puerto Rican, Mexican, Cuban, Mexican American, and other Hispanic subgroups. Consequently, limited data exist on Hispanic and Latino culture and breast cancer incidence (Miranda, Tarraf, & Gonzalez, 2011). Current research indicates breast cancer as the leading cause of death among Latinas contributable to health status and predisposed illness (Gonzales, Costaneda, Mills, Talavera & Gallo, 2012). This research study was necessary to prove experiences of Latinas in the Baltimore, Maryland and Fairfax, Virginia areas in an exploratory interview questions approach.

According to Yin (2009) "Even though your data collection may have to rely heavily on information from individual interviewees, your conclusions cannot be based entirely on the interviews as a source of information" (p. 2532). Yin (2009) suggests this kind of exploratory study is a "justifiable rationale with the goal being to develop pertinent hypotheses and propositions for further inquiry" (p. 10).

As previously stated, breast cancer is the primary cause of death among Hispanic females. Health status may contribute to the predisposition of this and some other illnesses (American Cancer Society, 2014; Corcoran et al, 2012). Although decreases (1.6%) in breast cancer diagnosis have been noted between 2009-2012, most cases are determined at the late stage with socio-economic status (SES) and age with 54% at local stage in comparison to 64% of non Hispanic females (American Cancer Society, 2014). Higher incidence of diverse cancers and disparities are prevalent among certain underserved populations and racial/ethnic groups. Factors heavily influencing higher incidence of diverse cancers among underserved populations are being underinsured, lack of health insurance, and limited economic resources or low Socioeconomic status (National Cancer Institute, 2014; Gonzales, et al, 2011; Maly, Leake, Mojica, Liu, Diamant & Thind, 2011).

The U.S. Hispanic population for 2060 is estimated to reach 128.8 million, constituting approximately 31% of the U.S. population by that date (CDC, 2015). Further, to date there are no evidence based research studies on minority groups such as Hispanic and Latinas and other women of color. Randomized clinical trials have included few minority groups and women of color. In addition, 20% of Hispanic and Latina groups are more likely to die of breast cancer as a result of late stage diagnosis (Hutch, F, 2016). The U.S. healthcare system continues to operate in crisis mode under the weight of many complex issues, including financial costs associated

with care, process of patient care, and equitable utilization of resources among all disparaged populations. The positive social change significance of this study laid a foundational framework that can be applied to current intervention guidelines for early detection of breast cancer, and prevention models specific to comply with breast cancer survivorship programs to decrease mortality rates.

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## Appendix A: Letters Submitted



20 December 2016

James R. Zabora, ScD  
The East Baltimore Medical Center  
Johns Hopkins Center to Reduce Cancer Disparities  
1000 E. Eager Street, Room 3016  
Baltimore, MD 21202


Dear Dr. Zabora:

It is a pleasure to confirm the willingness of Arlington Free Clinic to offer a site for you to conduct a portion of your study, "Describing the Experience of Latinas Undergoing Biopsy for a Diagnosis of Breast Cancer" in 2017. We understand that you may want to distribute flyers or place notices in public areas to recruit patients, and our staff will be able to help you identify patients who meet the criteria you have outlined. We understand that some of your interviews will be conducted within our clinic, and that your staff will be responsible for informed consent, data collection, interpretation for non-English speakers and completion of the interviews.


We look forward to working with you and Ms. D'Bora Schrett, the study coordinator, and we understand that we can contact you or Ms Schrett if we have any questions. After the completion of the study and analysis of the data, we will look forward to learning the results of your work so that we might apply your recommendations and improve delivery of care to our Latina patient population.

We appreciate the opportunity to work with you on this important project.

Sincerely,



Nancy White, Executive Director  
Arlington Free Clinic



Date



INOVA BREAST CARE CENTER

Protocol Title: Describing the Experience of Latinas  
Undergoing Biopsy for a Diagnosis of Breast Cancer  
Application No.: JHMIRB study number IRB00105550  
Principal Investigator: Dr. James Zabora  
Date: January 1, 2017

1 January 2017

James R. Zabora, ScD  
The East Baltimore Medical Center  
Johns Hopkins Center to Reduce Cancer Disparities  
1000 E. Eager Street, Room 3016  
Baltimore, MD 21202

Dear Dr. Zabora:

It is a pleasure to confirm our willingness to pass out flyers for the research study, "Describing the Experience of Latinas Undergoing Biopsy for a Diagnosis of Breast Cancer" in 2017. We understand that you may want us to distribute flyers in our office or place notices in public areas to recruit patient volunteer participants. Our staff will be able to identify patients who meet the criteria for this research study to improve delivery of care to the Latina population.

Should we have any questions we may contact you, Dr. James Zabora or the study coordinator, Ms. DBora Schrett. Ms. Schrett may be reached at 703-309-3708.

We appreciate the opportunity to work with you on this important project. Thank you for all your assistance.

Sincerely,

Dr. Hernan I. Vargas, MD

3580 Joseph Siewick Dr., Suite 101, Fairfax, VA 22033  
P 703-207-4320 F 703-391-3598  
[inova.org](http://inova.org)

## Appendix B: Interview Protocols

### Interview Protocol Section I

Date: \_\_\_\_\_

Location: \_\_\_\_\_

Name of Interviewer: DBora Schrett \_\_\_\_\_

Name of Interviewee: \_\_\_\_\_

Interview Number: One, Section I

1. Please tell me how would you describe your family of origin?
2. Please tell me how would you describe your culture's view of a woman with breast cancer?
3. How would you describe the role of your doctor before the breast cancer diagnosis?
4. How do you describe the role of the doctor in your culture or family?
5. How do you view the role of the doctor now as an adult?
6. What role did health insurance play in your knowledge of ability to get a biopsy?
7. What role did health insurance play in your knowledge of your ability to get treatment once breast cancer was found?
8. How would you describe your relationship with your doctor through the treatment process?
9. How did you learn of your breast cancer diagnosis? What was your knowledge breast cancer leading up to this point?
10. What are your thoughts about cutting a cancer tumor and the possibility of it causing the cancer to spread?
11. What had you heard about anesthesia during surgery? What did you believe about anesthesia and surgery?

## Interview Protocol Section II

Date: \_\_\_\_\_

Location: \_\_\_\_\_

Name of Interviewer: \_\_\_\_\_

Name of Interviewee: \_\_\_\_\_

1. How did your spouse/significant other experience the news of your breast cancer diagnosis?
2. What was the most challenging aspect of your diagnosis?
3. What is your understanding about the option to receive biopsy for your condition?
4. What was your decision making process when considering a biopsy? How did you feel?
5. How did you decide to obtain a biopsy?
6. If employed during your breast cancer diagnosis, how did you make decisions to continue, or not continue, to work? How did you decide to tell your employer?
7. How do you feel family and friends perceived you?
8. What were your experiences within the community of support? What types/kinds of resources were available to you?
9. What impact did you perceive your health care insurance status played in your access to quality health care facilities?
10. How did language barriers (if any) interfere or delay your treatment options?
11. What feelings surrounded your diagnosis?
12. What feelings or beliefs influenced treatment options?
13. How did your doctor explain your diagnosis?
14. What types of support services did your doctor offer?
15. In what ways did your doctor's attitude and explanation influence your perception of long term medical care?
16. How did finances influence your decisions for care?



**Appendix C: Consent Form**



Date: April 6, 2017  
Principal Investigator: James R. Zabora, ScD  
Application No.: IRB00105550

## **RESEARCH PARTICIPANT INFORMED CONSENT AND PRIVACY AUTHORIZATION FORM**

**Protocol Title :** Describing the Experience of Latinas Undergoing Biopsy  
for a Diagnosis of Breast Cancer

**Application No. :** IRB00105550

**Principal Investigator:** James Zabora, ScD  
Johns Hopkins Center to Reduce Cancer Disparities  
1000 E. Eager Street, Room 3016  
Baltimore, MD 21202  
Office: 410-955-0303 FAX: 410-955-1342

### **1. What you should know about this study :**

- You are being asked to join a research study. This consent form explains the research study and your part in it. Please read it carefully and take as much time as you need. Ask your study doctor or the study team to explain any words or information that you do not understand.
- You are a volunteer. If you join the study, you can change your mind later. There will be no penalty or loss of benefits if you decide to quit the study.
- During the study, we will tell you if we learn any new information that might affect whether you wish to continue to participate.
- If we think your participation in this study may affect your clinical care, information about your study participation will be included in your medical record, which is used throughout Johns Hopkins. Doctors outside of Johns Hopkins may not have access to this information. You can ask the research team to send this information to any of your doctors.
- When Johns Hopkins is used in this consent form, it includes The Johns Hopkins University, The Johns Hopkins Hospital, Johns Hopkins Bayview Medical Center, Howard County General Hospital, Johns Hopkins Community Physicians, Suburban Hospital, Sibley Memorial Hospital and All Children's Hospital.

### **2. Why is this research being done?**

This research is being done to learn more about how Latinas experience the process of access to care for a breast biopsy. This study may help us to provide better access to care for Latinas.

In order to take part in this study, you must:

- Be a female at least 19 years of age
- Self-identify as Hispanic or Latina
- Have received a breast cancer diagnosis OR are a breast cancer survivor 3 months or more post treatment

#### **How many people will be in this study?**

About 30 Latinas are expected to take part in this study.



Date: April 6, 2017  
Principal Investigator: James R. Zabora, ScD  
Application No.: IRB00105550

## **RESEARCH PARTICIPANT INFORMED CONSENT AND PRIVACY AUTHORIZATION FORM**

**Protocol Title :** Describing the Experience of Latinas Undergoing Biopsy  
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**Application No. :** IRB00105550

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Johns Hopkins Center to Reduce Cancer Disparities  
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- During the study, we will tell you if we learn any new information that might affect whether you wish to continue to participate.
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Date: April 6, 2017  
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1000 E. Eager Street, Room 3016  
Baltimore, MD 21202  
Office: 410-955-0303 FAX: 410-955-1342

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### **1. What you should know about this study:**

- You are being asked to join a research study. This consent form explains the research study and your part in it. Please read it carefully and take as much time as you need. Ask your study doctor or the study team to explain any words or information that you do not understand.
- You are a volunteer. If you join the study, you can change your mind later. There will be no penalty or loss of benefits if you decide to quit the study.
- During the study, we will tell you if we learn any new information that might affect whether you wish to continue to participate.
- If we think your participation in this study may affect your clinical care, information about your study participation will be included in your medical record, which is used throughout Johns Hopkins. Doctors outside of Johns Hopkins may not have access to this information. You can ask the research team to send this information to any of your doctors.
- When Johns Hopkins is used in this consent form, it includes The Johns Hopkins University, The Johns Hopkins Hospital, Johns Hopkins Bayview Medical Center, Howard County General Hospital, Johns Hopkins Community Physicians, Suburban Hospital, Sibley Memorial Hospital and All Children's Hospital.

### **2. Why is this research being done?**

This research is being done to learn more about how Latinas experience the process of access to care for a breast biopsy. This study may help us to provide better access to care for Latinas.

In order to take part in this study, you must:

- Be a female at least 19 years of age
- Self-identify as Hispanic or Latina
- Have received a breast cancer diagnosis OR are a breast cancer survivor 3 months or more post treatment

#### **How many people will be in this study?**

About 30 Latinas are expected to take part in this study.



Date: April 6, 2017  
Principal Investigator: James R. Zabora, ScD  
Application No.: IRB00105550

## **RESEARCH PARTICIPANT INFORMED CONSENT AND PRIVACY AUTHORIZATION FORM**

**Protocol Title:** Describing the Experience of Latinas Undergoing Biopsy  
for a Diagnosis of Breast Cancer

**Application No. :** IRB00105550

**Principal Investigator:** James Zabora, ScD  
Johns Hopkins Center to Reduce Cancer Disparities  
1000 E. Eager Street, Room 3016  
Baltimore, MD 21202  
Office: 410-955-0303 FAX: 410-955-1342

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## Appendix D: Interview Transcripts

Protocol Title: Describing the Experience of Latinas  
Undergoing Biopsy for a Diagnosis of Breast Cancer  
Application No.: JHMIRB study number IRB00105550  
Principal Investigator: Dr. James Zabora, ScD  
Date: March 7, 2017

### Demographic Questionnaire

Please fill in the bubble with the answer that best matches your response.

Date: \_\_\_\_\_

**Region: Where do you live?**

- Virginia
- Northern Virginia
- Maryland
- Washington, D.C.
- \_\_\_\_\_
- Prefer not to answer

**What is your country of origin?**

- \_\_\_\_\_
- Prefer not to answer

**What is your gender?**

- Female
- Male

**Number of children?**

- 0
- 1 to 2
- 3 to 4
- 5 or more
- Prefer not answer

**Age: What is your age?**

- 18 to 24
- 25 to 34
- 35 to 44
- 45 to 54
- 55 to 64
- Age 65 or older
- Prefer not to answer

**Household Income:**

- Less than \$25,000
- \$25,000 to \$34,999
- \$35,000 to \$44,999
- \$45,000 to \$74,999
- \$75,000 to \$99,999
- Greater than \$100,000
- Prefer not to answer

Protocol Title: Describing the Experience of Latinas  
Undergoing Biopsy for a Diagnosis of Breast Cancer  
Application No.: JHMIRB study number IRB00105550  
Principal Investigator: Dr. James Zabora, ScD  
Date: March 7, 2017

**What is your Ethnicity/race? Are you of Hispanic, Latino, or Spanish origin?**

- Latina
- Hispanic
- Spanish
- Black/Hispanic
- White/Hispanic
- Asian/Hispanic
- Other

**What is your occupation at the time of this study?**

- \_\_\_\_\_
- Unemployed
- Prefer not to answer

**What is your level of education?**

- Less than High School
- Some high school (no diploma)
- High school graduate - diploma (GED)
- Some college
- Associate's Degree
- Bachelor's Degree
- Master's Degree
- Professional Degree
- Doctoral Degree

**What is your marital status?**

- Single (never married)
- Married
- Separated
- Widowed
- Divorced

**Are you the primary caregiver in your home?**

- Yes
- No

**Is there a history of breast cancer in your family? (For example, parents, grandparents, siblings, blood relatives)**

- Yes
  - No
- If yes, how many relatives have been diagnosed with breast cancer? \_\_\_\_\_