IDENTIFYING BREAST CANCER DISPARITIES IN THE AFRICAN-AMERICAN COMMUNITY USING A
MIXED METHODS APPROACH

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Utilizing a mixed methods approach in assessing cities and metropolitan areas with the highest rates of breast cancer disparities in African-American communities, this study presents the Affiliate perspective of the Susan G. Komen non-profit organization in combination with available socioeconomic data and academic literature. Analyzed through an anthropological lens, qualitative and quantitative data illuminate the lived experiences and dynamic circumstances in which breast cancer disparities are disproportionately experienced in 21 of the nation's populations of African-Americans. Two main recommendations arose from this research: prioritization of granting to activities such as patient navigation, usage of patient narrative messaging, community-based participatory research methods of program development and implementation, mobile mammography delivery, usage of lay health educators, and self-advocacy education to alleviate barriers to healthcare and supplementation of the current educational activities of the Komen Affiliates through program sharing and leverage of current assets with consideration of current Affiliate capacity. These recommendations may help in alleviating breast cancer disparities present in African-American communities with the highest levels of disparities in the nation.
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ACKNOWLEDGEMENTS

I would like to express my warm gratitude to all of the individuals who worked with me on this project, including my mentors: Lisa Henry and Doug Henry of the University of North Texas and Stephanie Reffey and Becky Royer of Susan G. Komen. These individuals welcomed my ideas, feedback, and fostered a monumental learning process as a result of my research. It is my hope that this research will build upon existing literature to inform and influence future health interventions and knowledge.

This research would not have been possible without the unwavering support from my peers in the UNT Applied Anthropology program, my friends, my family, and notably, my project participants. Each of these individuals reassured the motivations behind my research and uniquely aided and supported me in completing this project.
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CHAPTER 1 INTRODUCTION

1.1 The Public Health Problem

The American Cancer Society estimates that 231,840 new cases of invasive female breast cancer will be diagnosed in 2015, representing 29 percent of all new cancer cases among women. Breast cancer accounts for 15 percent of all cancer related deaths with estimated 40,290 deaths from breast cancer (DeSantis et al. 2016).

Historically, African-American women have had higher incidence rates of breast cancer (Whitman et al. 2012); however, the most recent data suggest that as of 2012, breast cancer incidence rates in African-American women and White women no longer significantly vary (DeSantis et al. 2016). SEER data from the National Cancer Institute show the 2008-2012 age-adjusted incidence rate for breast cancer among White women in the U.S. was 128 per 100,000 women per year compared to the 124 per 100,000 per year for African-American women (DeSantis et al. 2016). Trend data show that overall breast cancer incidence rates in African-American women increased by 0.4 percent per year, but did not change significantly in White women from 2008 to 2012.

African-American women have a 42 percent higher breast cancer mortality rate compared to White women, despite the lower overall disease incidence (DeSantis et al. 2016). From 2003 through 2012, breast cancer mortality declined annually by 1.8 percent for Whites and 1.4 percent for African-Americans (DeSantis et al. 2016). The overall mortality trend reveals that breast cancer death rates have decreased nationally since 1990, corresponding with an increased utilization of screening mammography, differential incidence rates, stage at diagnosis, tumor characteristics (such as grade, hormone receptors, and Her2 expression) and comorbidities as well as access,
adherence, and innovation in treatment modalities (DeSantis et al. 2016). However, the decreases in death rates began earlier and have been larger in proportionate terms for White women than for African-American women (DeLancey et al. 2008). SEER data from 1975 to 2011 indicate that White women had a 23 percent increase in breast cancer incidence and 34 percent decrease in mortality, whereas African-American women experienced a 35 percent increase in incidence and a 2 percent increase in mortality (Howlader et al. 2014) The mortality rate for non-Hispanic White women was 21.9 per 100,000 per year compared to 31.0 for non-Hispanic African-American women (DeSantis et al. 2016).

Through longitudinal analysis, Whitman et al (2011) found that the disparity in breast cancer mortality emerged nationally in the 1990s. Whitman et al (2012) showed that the African-American to White mortality rate ratio, which is evident at the national level, is also seen at the municipal level in the nation’s largest cities. Hunt et al (2013) examined race-specific breast cancer mortality rates and corresponding rate ratios for the 50 largest cities in the U.S. from 1990-2009. In many of the investigated cities, the increase in disparity, measured in rate ratio, increased over time due to the substantially improved outcomes for White populations and the lack of improvements in the African-American population. An estimated five excess African-American deaths per day occur due to disparities (Hunt et al. 2013). In another study, after controlling for receptor status, insurance status, age, and stage at diagnosis, African-American women had a two-fold excess risk of death from breast cancer (Adams et al. 2012).

Regional variations were also found between 1975 and 2004; DeSantis et al (2008) found that breast cancer death rates were decreasing in all 50 states for White women while African-
American death rates increased in 2 states, remained the same in 24 states, and decreased in only 11 states; states with increasing or level rates were in the South or Midwest.

Among African-American women with breast cancer, 33 percent are diagnosed at an age less than 50 years old, whereas 21.9 percent of White women are less than 50 at the age of diagnosis (Clark et al. 2003). Analyzing data trends from 1979 to 2010 in women younger than 50 years old, disease specific mortality rates declined over time for select common cancers and cardiovascular diseases, however breast cancer mortality rates remained higher for African-American women (McCarthy, Yang, Armstrong 2015). In women younger than 35 years old, the incidence of breast cancer in African-American is 1.4 to 2.0 times higher than in Whites (DeLancey et al. 2008).

In an analysis of California Cancer Registry data, Kurian et al (2010) found that White women had a higher proportion of tumors diagnosed at stage I or II compared to African-American women (64.5 percent versus 54.5 percent) and African-American women were less frequently diagnosed with tumors at a size of 2 cm or less (61.7 percent versus 48.6 percent); both tumor size and stage are indicators of poor prognosis. In another study, African-American women were less likely to be diagnosed with stage I breast cancer than White women across all age groups (non-Hispanic White women, 50.8 percent; African-American women, 37.0 percent) (Iqbal et al. 2015). Additionally, authors found that African-American women were also more likely to present with nodal metastases, distant metastases, and triple-negative tumor markers than White women (Iqbal et al. 2015); all significantly decreasing expected prognosis and are indicators of advanced disease.
1.2 Client: Susan G. Komen

Susan G. Komen® (“Komen”) is the world’s largest breast cancer organization, funding more breast cancer research than any other nonprofit while providing real-time help to those facing the disease. Since its inception in 1982, Komen has funded more than $889 million in research and provided more than $1.95 billion in funding to screening, education, treatment and psychosocial support programs serving millions of people in more than 30 countries worldwide. Komen was founded by Nancy G. Brinker, who promised her sister, Susan G. Komen, that she would end the disease that claimed Suzy’s life.

Komen Global Headquarters is located in Dallas, Texas. With more than 100 Affiliates nationwide and internationally, Komen is a grassroots organization addressing breast cancer today. Komen Headquarters, in collaboration with the Affiliate Network (“Affiliates”), utilizes nationwide campaigns to relay specific breast health messaging and advocate to ensure breast cancer is a priority among policymakers to increase access to affordable, high quality breast health and cancer care services. Komen Headquarters funds breast cancer research as well as some national assistance programs such as Komen’s Breast Cancer Helpline and a National Treatment Assistance Program while Komen Affiliates fund community-based educational and assistance programs to meet the breast health/cancer needs of the community to improve breast cancer outcomes.

1.3 Study Purpose

The persistent and complex social, biological, and societal interactions that may contribute to racial disparities in breast cancer outcomes have risen to the forefront of research for numerous national health organizations. Due to the unique position of Komen as a funder and a community
health advocate, it is their aim to bring national focus on the breast cancer disparities facing the African-American community. Therefore, Komen Headquarters launched the Health Equity Initiative to explore the factors contributing to breast cancer disparities in African-American communities, many of which were included in this study. This report along with several other events will inform a national initiative to address breast cancer disparities within African-American communities.

The primary purpose of this study is to fill informational gaps identified by Komen through the collection of the invaluable and cross-cutting perspectives of the Affiliates and their experiential understanding of the factors affecting breast cancer disparities in African-American communities. Other tools to inform the nationwide health equities initiative include roundtables with national and local constituents and periodic qualitative and quantitative data collection through Community Profiles that gathers information from the perspectives of local health care providers, breast cancer survivors, African-American community leaders, and other community members.

The practical purpose of this report is to collect the perspectives of individual Affiliates in order to share the successes and lessons learned by each. The collection of qualitative data will insert the perspectives and narrative knowledge of the Affiliate Network and will focus and narrow the scope of the research to create a comprehensive understanding of the factors at play in African-American health disparities and potential remedies to them. The Affiliate’s perspective is key because of their ability to compare behaviors with qualitative data collected through the Community Profile process and, in turn, compare these concepts to their everyday experiences.
with other races and ethnicities to determine how and why the African-American breast cancer experience is different compared to other races and ethnicities.

1.4 Background

1.4.1 Continuum of Care

The Continuum of Care is the preferred model used by Komen in assessing and understanding how patients move through the medical process of breast screening and cancer treatment. The model is helpful in understanding points of interventions during their continuum of care. The model begins at the initial point of screening for breast cancer, including screening mammography and/or clinical breast exam. It then advances into diagnostic care during which patients undergo a series of testing including but not limited to breast ultrasound, diagnostic mammography, and tissue biopsy in order to confirm a malignant or benign diagnosis. The time taken between screening and diagnosis is frequently used as quality indicator in clinical studies. If a malignant diagnosis is present, the patient would then advance to the treatment phase. The time taken between diagnosis and treatment initiation is also often used as a quality indicator. If no malignancy is detected, the patient would return to screening at the recommended interval. Final diagnosis of malignancy or benign findings is referred to as diagnostic resolution.
Cancer treatment begins after a confirmed cancer diagnosis and a health care provider determines the appropriate plan, often any combination of surgery, chemotherapy, radiation therapy, or hormone therapy. Once treatments have ceased, the woman advances to follow-up care, which may include interval body scans and other types of monitoring to track recovery and quality of life, manage side effects, and if cancer returns, detect disease early. At this point, the patient will return to the screening phase unless additional abnormalities are discovered. Throughout the process, breast cancer education is presented to inform the patient of breast health knowledge, expectations, symptoms, side effects, and other relevant topics; this is often information provided by health care providers. The model serves as a reminder of cyclical stages of breast health and the importance of continued education.
CHAPTER 2 METHODOLOGY

The benefit of a mixed methods approach in the analysis of African-American breast cancer disparities is the delivery of a comprehensive viewpoint with increased contextualization of quantitative data and literature review findings. Quantitative data were initially used in identifying metropolitan areas in need of intervention through surveillance data, specifically disproportionately high mortality rates and large populations of African-Americans.

2.1 Quantitative Data Compilation

2.1 Participant Selection

The quantitative data assessed include U.S. Census Bureau 2010 total population data for identification of the target populations. Data were compiled for the top 50 largest cities and the top 15 metropolitan areas with the largest populations of African-Americans as well as cities with the largest African-American to White mortality rate disparities (Whitman et al. 2012). After identifying the cities and metropolitan areas, the number and percentage of African-American females (ages 18+) were extracted from U.S. Census data for each city and metropolitan level (See Appendix A). Each city and corresponding metropolitan area were ranked on each of the following breast cancer indicators according to the Community Profile Quantitative Data Report (unpublished data): death rates, death rate disparity (ratio of African-American death rate to White death rate), late-stage diagnosis rate, and late-stage diagnosis rate disparity (ratio of African-American late-stage diagnosis rate to White late-stage diagnosis rate). Final selections were calculated by using the average ranking of each indicator. From the ranking, the following cities/metropolitan areas and respective Susan G. Komen Affiliates were selected for further analysis:
Memphis, TN (Komen Memphis Mid-South)
St. Louis, MO (Komen Greater St. Louis)
Dallas/Arlington/Fort Worth, TX (Komen Dallas County, Komen Greater Fort Worth)
Los Angeles/Long Beach, CA (Komen Los Angeles County, Komen Orange County)
Virginia Beach, VA (Komen Virginia Tidewater)
Atlanta, GA (Komen Greater Atlanta)
Chicago, IL (Komen Chicagoland Area)
Houston, TX (Komen Houston)
Washington, DC (Komen National Capital Region)
Philadelphia, PA (Komen Philadelphia)
Detroit, MI (Komen Detroit Race for the Cure)
Baltimore, MD (Komen Maryland)
Cleveland, OH (Komen Northeast Ohio)
Miami, FL (Komen Miami/Ft. Lauderdale)
Charlotte, NC (Komen Charlotte)
San Francisco/Oakland, CA (Komen San Francisco Bay Area)
New York City, NY (Komen Greater New York City)
Jacksonville, FL (Komen North Florida)
Oklahoma City, OK (Komen Central and Western Oklahoma)
Tulsa, OK (Komen Tulsa)
Wichita, KS (Komen Kansas)
Kansas City, MO (Komen Greater Kansas City)
Louisville, KY (Komen Louisville)
Raleigh, NC (Komen Triangle to the Coast)
Columbus, OH (Komen Columbus)
Indianapolis, IN (Komen Central Indiana)
Nashville, TN (Komen Greater Nashville)
Denver, CO (Komen Colorado)

From 2014-2015, Affiliates completed a community assessment ("Community Profile") that included the identification of priority communities and/or populations in their respective service areas that may be at risk of not being able to access and/or utilize quality breast cancer services along the continuum of care. Community Profiles from each of the 28 Affiliates that serve the cities/metropolitan areas listed above were reviewed by Komen staff and 21 of these Affiliates were identified for African-American females in their local service area as being at risk of poorer breast cancer outcomes than their White counterparts. The following metropolitan areas were selected for this study (see Appendix B for Affiliate names and locations):
Affiliates from these respective cities and metropolitan areas were contacted to participate in interviews to collect more detailed information about the community characteristics, issues, and Affiliate activities in the service areas (See Appendix B). A total of 21 Affiliates were identified for the study based on the location of their service area.
2.2 Socioeconomic Data

Quantitative data were compiled from the U.S. Census data to describe the socioeconomic circumstances for each of the city and metropolitan described in this study, collectively presented in Table 1. These data situate the qualitative data collected for this study and represent all racial/ethnic populations within each city. Data describe the setting in which disparate breast outcomes are produced for African-American women and the areas in which Komen Affiliates operate. These data are essential in describing the barriers facing women residing within these communities and to fully understand outcomes and characteristics of the study populations.

<table>
<thead>
<tr>
<th>City</th>
<th>Less than HS Education</th>
<th>Income Below 100% Poverty</th>
<th>Unemployed</th>
<th>Foreign-Born</th>
<th>Linguistically Isolated</th>
<th>No Health Insurance (Women, Age: 45-64)</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Average</td>
<td>15.0%</td>
<td>15.6%</td>
<td>9.2%</td>
<td>13.0%</td>
<td>8.6%</td>
<td>11.2%</td>
</tr>
<tr>
<td>New York City, NY</td>
<td>17.3%</td>
<td>20.3%</td>
<td>10.6%</td>
<td>37.0%</td>
<td>23.2%</td>
<td>13.7%</td>
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<td>Chicago, IL</td>
<td>18.0%</td>
<td>22.6%</td>
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<td>Philadelphia, PA</td>
<td>14.9%</td>
<td>26.5%</td>
<td>15.1%</td>
<td>12.2%</td>
<td>9.7%</td>
<td>10.9%</td>
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<tr>
<td>Detroit, MI</td>
<td>26.6%</td>
<td>39.3%</td>
<td>28.5%</td>
<td>5.1%</td>
<td>4.0%</td>
<td>15.7%</td>
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<tr>
<td>Memphis, TN</td>
<td>21.0%</td>
<td>26.9%</td>
<td>14.4%</td>
<td>6.2%</td>
<td>4.4%</td>
<td>16.0%</td>
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<tr>
<td>Baltimore, MD</td>
<td>18.5%</td>
<td>23.8%</td>
<td>13.9%</td>
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<td>3.5%</td>
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<td>Washington, DC</td>
<td>11.7%</td>
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<td>Dallas, TX</td>
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<td>St. Louis, MO</td>
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<tr>
<td>Atlanta, GA</td>
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<td>Columbus, OH</td>
<td>12.8%</td>
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<tr>
<td>Charlotte, NC</td>
<td>16.5%</td>
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<td>11.3%</td>
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<td>9.1%</td>
<td>14.7%</td>
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<tr>
<td>Nashville, TN</td>
<td>12.5%</td>
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<td>8.9%</td>
<td>11.9%</td>
<td>7.7%</td>
<td>13.0%</td>
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<tr>
<td>Cleveland, OH</td>
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<td>4.7%</td>
<td>4.6%</td>
<td>15.1%</td>
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<tr>
<td>Average</td>
<td>18.0%</td>
<td>24.9%</td>
<td>13.1%</td>
<td>13.2%</td>
<td>8.8%</td>
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Table 1. Selected SES Indicators for Targeted Cities, All Races, U.S. Census Bureau, American Community Survey 5-year Estimates, 2014.
Socioeconomic data collected (Table 1) show the range of barriers facing the communities selected for the study. These cities and metropolitan areas were selected for large total populations and large populations of African-Americans (See Appendix A). Quantitative, socioeconomic data show similarities and slight differences between these communities. The majority of the communities have high rates of the population with less than high school level education; the lowest levels of education, respectively, are most prevalent in Cleveland, OH, Detroit, MI and Dallas, TX. All of the cities/metropolitans have high rates of poverty compared to the national average, ranging from 17 to 39 percent of the population below the federal poverty line; low income levels are most prevalent in Detroit, MI, Cleveland, OH, and St. Louis, MO, respectively. Unemployment rates are highest in Detroit, MI with nearly all other cities above the national average of unemployment. Foreign-born rates are distinctively higher in New York City, NY indicating high rates of cultural diversity.

The majority of cities/metropolitan areas were under the national average of rates of individuals who were foreign-born, or born outside of the United States. Individuals who are linguistically isolated indicated that they do not speak English “very well” in Census Bureau measures (U. S. Census Bureau 2015); these rates are highest in New York City, NY, Dallas, TX, and Chicago, IL. Rates of health insurance describe both private and public insurance coverage for women between the ages of 45 and 64, years which are most relevant to breast cancer screening. The majority of the cities and metropolitans reported rates above the national average of health insurance; however these data indicate the greatest number of uninsured individuals in Dallas, TX and Chicago, IL. Overall, several cities show distinct indicators for barriers to healthcare.
2.2 Review of Literature

Literature reviewed for this study were sourced from academic journals, Google Scholar, Web of Science, Academic Search Complete, Scopus, and PubMed. Additional sources were identified through references listed in initial literature search findings. Second and tertiary searches were completed to identify additional supporting information for levels of increasing specificity, such as those relating to the barriers and types or points of intervention. This was particularly necessary in the barriers section due to the quantitative nature in reporting risk and associations with structural barriers. Literature written or sponsored by prominent authors and organizations (such as the Chicago Breast Cancer Task Force) were also included due to their influence in the field. Searches were performed in an iterative fashion to retrieve adequate data.

Once publications were identified, they were reviewed to obtain relevant information. Primary sources and review publications were used to identify primary areas of interest, as well as identify topics in need of additional information; additional article searches were performed as needed. Articles excluded from this study included studies in which African-American women were not investigated as a distinct population. Additionally, studies solely performed in rural settings were not included as the sample of this study is bias toward urban centers with large, dense populations (See Appendix A).

2.3 Qualitative Data Collection

The protocol for this study was submitted to the University of North Texas Institutional Review Board (IRB). Upon protocol approval, recruitment began with the help of Komen site sponsors, Stephanie Reffey and Becky Royer. Affiliates of interest were identified through preliminary data collection, as previously described in Quantitative Data Collection, and were
based on their service area covering cities and metropolitan areas with higher rates of breast cancer disparities and large populations of African-Americans. Email introductions were initially sent to the selected staff of each Affiliate by Komen Headquarters’ sponsors to introduce the investigator and the study purpose (See Appendix D). The staff solicited for recruitment were mission staff, those primarily involved with grants management and outreach activities; these individuals were the primary contacts when available, and executive and assistant directors were contacted if no mission staff were available. This varied by Affiliate due to variation in staffing and Affiliate size, ranging from 15 staff to 2-3 volunteers. The investigator then sent more specific follow-up emails requesting individual interviews between the investigator and the affiliate staff (See Appendix E).

Prior to IRB approval, the investigator interned with Komen Headquarters for seven months working with the Community Profile Reports, collecting and cleaning data, and with grant outcome data. During this time, the investigator became familiar with the relationship between Komen Headquarters and Affiliates, the organizational structure, and the role of Affiliates. This would prove invaluable in communicating with the Affiliate staff about their primary source of data—the Community Profile—and the process behind the results.

The investigator’s training and background in applied medical anthropology and public health informed and influenced nearly every step of the project planning, data collection, and analyses. Methods of applied anthropology and public health were implemented to assist in identifying the complex relationship between culture, society, and biology. Understanding how these forces work together and against each other to influence disparities in breast cancer
outcomes may help to identify practical and sustainable solutions to improve health outcomes (Hahn and Inhorn 2009; Van Willigen 2002).

As the hallmark method of applied anthropology, in-depth, semi-structured interviews were the primary mode of qualitative data collection for this study. The benefit of employing semi-structured interviews lies in the ability to adapt questions and probe for expanded responses in a conversational setting to gain greater insights as the participant allows.

The interview guide (see Appendix C) was partially developed based on the key constructs of the Health Belief Model, a psychosocial model commonly used to organize theoretical predictors of health actions of secondary prevention methods (Champion and Sugg Skinner 2008; Levine and Sorenson 1984). The Health Belief Model is the widely used conceptual framework in behavioral research as a guiding framework for health behavior interventions (Pasick and Burke 2008). Interview questions were constructed to probe for Health Belief Model theoretical constructs such as perceived threat, perceived seriousness, perceived control, and competing concerns. The limitations of this framework are noted within the literature, however due to existing protocol in place by Komen, the Health Belief Model was implemented to frame interview questions.

Interview questions regarding access to services and health care were based on the Susan G. Komen Continuum of Care model (See Figure 1, p. 7) to assess barriers and facilitators to each step within the model. Additional contextual information regarding Affiliate mission work addressing breast cancer disparities and involvement in coalitions was also collected to capture the activities of the Affiliates.
Twenty-four hours prior to the appointed interview time, an informed consent notice was emailed to each participant (See Appendix F). This was reviewed prior to each interview and verbal consent was obtained (See “Intro” in Appendix C). A total of 28 Affiliate staff were recruited and interviewed from 21 Affiliate locations (Table 2). Fortunately, interview requests were well received and five Affiliate interviews were conducted with multiple participants, rather than one informant as requested. This had a positive impact on the quality of the data as discussions and negotiation occurred throughout the interview between participants.

<table>
<thead>
<tr>
<th>Number of Participants</th>
<th>Number of Interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>16</td>
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<tr>
<td>2</td>
<td>3</td>
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<tr>
<td>3</td>
<td>2</td>
</tr>
</tbody>
</table>

Table 2. Quantitative Summary of Interviews and Participants

All interviews were conducted via telephone, the preference of the participants as video chat or Skype were also options for communication. Two interviews were conducted in-person at the respective Affiliate offices to avoid technological complications, to augment rapport with participants, and to collect contextual observations. Interviews typically lasted 30 to 40 minutes, with a range of 22 minutes to more than one hour.

All interviews were audio recorded and transcribed verbatim. Per IRB protocol, all identifiable data were excluded or replaced in transcripts with generic or substitutive terms, i.e. “[County A]” replaced Dallas County, pseudonyms replaced names of individuals identified, etc. Additionally, for the protection of anonymity, audio recordings were destroyed and names of contacts were dissociated from transcripts.
Qualitative data were systematically analyzed using the inductive method of grounded theory through thematic coding to form conceptual categories (Bernard 2011). Given that the data collection instrument was informed by theoretical models, to some degree the data analysis process was also influenced by said models. The Socioecological Model was used as a guide to interpret barriers to breast health care, recognizing the broad and dynamic context in which health decisions are made, including intrapersonal, interpersonal, organizational, community, and policy levels of influence (National Cancer Institute 2005).

Themes were identified within text data via manual coding. Prominent and high-frequency themes were preliminarily identified during data collection and later confirmed in data analysis. Data were reviewed using Dedoose encrypted software application to assign codes (See Appendix I), examine relationships, and report analytics. All quantitative data were analyzed and reviewed in Microsoft Office Excel.
CHAPTER 3 LITERATURE REVIEW AND THEORETICAL FRAMEWORKS

3.1 Literature Review

Potential contributing factors to disparities in breast cancer mortality are complex and multifaceted and include both biological and social determinants as well as healthcare access and quality, health literacy, and health behaviors (Campbell et al. 2009; Cullen, Cummins, and Fuchs 2012). To understand the true complexity of racial disparities in breast cancer, it is necessary to understand the components that have shown to contribute to disparities. Review of available literature was completed to present significant findings relating to breast cancer disparities. Assessment of the current findings of academic sources are presented in summary form by topic to provide a basis for understanding breast cancer outcomes and disparities.

Topics within the academic literature, including mammography, health services, and structural, clinical, and personal barriers, foreshadow and parallel the forthcoming perspectives of the Affiliates and their understandings of factors affecting breast cancer disparities. Collecting the Affiliate perspectives and combining them with evidence from the literature synergistically illustrate the diversity of the factors influencing breast cancer disparities in the African-American community and the lived experiences of African-Americans within the healthcare system. These data reveal similarities and differences in known barriers and factors documented in the literature when compared to the experiential understanding of the Affiliate staff.

3.1.1 Mammography

Screening mammography remains the primary modality of identifying breast cancer at early stages, when chances of survival are highest. Current U.S. Preventive Task Force recommendations indicate biennial screenings beginning at the age of 50 through age 74 for
women without increased risk of breast cancer, while previous recommendations suggested annual screening mammography after the age of 40 (Siu 2016). Screening mammography recommendations were updated in 2009 and affirmed in 2016 after the U.S. Preventive Services Task Force reviewed the effectiveness of screening mammography, specifically false-positives, benign biopsies, anxiety, over-diagnosis and over-treatment (Siu 2016); false-positive mammography is associated with excess anxiety and iatrogenic fear of diagnostic testing in African-American women (Padgett et al. 2001). Changes in screening guidelines have shown to cause confusion in women’s understanding of what age to initiate mammography screening, particularly in women age 40-49 who may have initiated screening, but are now advised to discontinue until reaching the recommended age of 50 (Squier et al. 2011; Wang et al. 2014). Change in screening guidelines may be particularly relevant to African-American women due to increased incidence prior to age 50 compared to White women (Habtes et al. 2013).

The probability of having a breast cancer diagnosed at an early stage is significantly correlated with population rates of mammography screening after adjustments for age, income, and education (Sassi, Luft, and Guadanoli 2006). Historically, African-American women have had lower rates of mammography screening compared to White women. As mentioned earlier, differences in screening rates between African-American and White women are insignificant today. According to the 2010 National Health Interview Survey, among women 40 years and older, 50.6 percent of non-Hispanic African-American and 51.5 percent of all non-Hispanic Whites reported having a mammogram within the last year (DeSantis, Naishadham, and Jemal 2013).

Several widely cited studies have found that self-reported annual or biennial mammography use was quite high and that racial and ethnic differences in mammography use
have generally disappeared (Blackman, Bennett, and Miller 1999; Breen et al. 2001). Previous research has shown that self-reported data are prone to overstatement, particularly among racially diverse women (Champion et al. 1998; McPhee et al. 2002; Rauscher et al. 2008). Several studies have shown, through chart reviews and medical records, that self-reported annual or biennial mammography use is inaccurate and over-estimated (Centers for Disease Control and Prevention (CDC) 2005; Whitman et al. 2007). Additionally, studies have shown that women of low socioeconomic status over-report more than other women, rendering the use of the self-reported mammography tool as a misleading measure in the uptake mammography (Whitman et al. 2011).

Tumor characteristics, specifically tumor grade, may also contribute to differences in cancer outcomes. African-American women are frequently diagnosed with higher-grade tumors than White women regardless of screening usage; the tumor grade (I-III) indicates the aggressiveness of the disease and is a strong predictor of breast cancer survival (Elston and Ellis 1991; Chen et al. 1994). Smith-Bindman et al (2006) found that adherence to mammography screening does not impact the tumor grade at diagnosis, rather it is associated with delayed diagnosis, impacting tumor size, stage, and metastasis. These results are consistent with other studies showing regular mammography screening intervals by African-Americans may reduce breast cancer mortality rates (Smith-Bindman et al. 2006; Grabler et al. 2012).

Ravesteyn et al (2011) found that differential mammography uptake demonstrated a relatively small (7-8 percent) variance in mortality; this reveals that abnormalities detected by mammography versus symptomatic presentation may not significantly impact rates of survival. However, the strongest predictor of breast cancer survival remains stage of disease at diagnosis (Ward et al. 2004). In addition, patients with breast cancer diagnosed following an abnormal
screening mammogram have better long-term survival than those with tumors of the same stage that were found by other means (Shen et al. 2005; Joensuu et al. 2004).

Anthropologically, screening mammography is used as a means of extending the medical gaze into the asymptomatic population through technological facilitation (Klawiter 2008). Since the 1980s, mammography has become the population screening tool to identify early, or asymptomatic, breast cancers ideally for the best prognosis and least burden of disease. This adoption of technology has spurred “proactive discourses of health care seeking” firmly entrenched within health policy in the U.S, meaning health care policy often operates under the assumption that patients actively seek out health information (Andersen, Tørring, and Vedsted 2015; Klawiter 2008).

3.1.1.1 Quality of Care

Although mammography uptake rates between racial and ethnic groups are similar, differences in quality of imaging and follow-up for abnormal imaging results remain. Improvements in early stage diagnosis and treatment through technological advances made in the past 20 years are likely to be unequally diffused, widening the disparities between African-American and White women (“Breast Cancer Disparities” 2014). Phelan et al (2005; 2004) argue that rapid improvements in treatment are distributed unequally on the basis of disparities in knowledge, money, power, prestige, and social connection, therefore individuals with higher incomes, better knowledge, and better social connections are more likely to benefit from improved technology.
Availability of quality screening mammography has been shown to be disproportionately available and/or utilized by African-American women. Analyses of urban mammography quality found that facilities serving racially diverse women were less likely to be academic or private institutions, less likely to have digital mammography, and less likely to have breast imaging specialists (Ansell et al. 2009; Rauscher et al. 2011). Disparities in access to digital mammography are particularly relevant to screening and diagnosing breast cancers in the African-American population due to their effectiveness in breast cancers in pre- and perimenopausal women younger than 50 with dense breast tissue (Pisano et al. 2008). These characteristics are more commonly observed in African-American diagnosed with breast cancer women than White women (Carey et al. 2006).

Specialization in breast imaging has shown to increase accurate identification of cancers at a rate nearly twice as high as general radiologists when reading screening mammograms (Sickles 2002). African-American, Hispanic, and uninsured women are more likely to receive inferior quality mammograms from facilities at non-academic centers, facilities without breast imaging specialists, and facilities without digital mammography (Rauscher 2011; Whitman 2012). Quality accredited breast cancer screening, diagnosis, and treatment centers are disproportionately available and accessible in the United States, which may impact access to health care and screening and delays in diagnosis and treatment.

Decreased accessibility in terms of proximity and availability are highlighted in a report made by the Department of Human and Health Services (1998):

Geographic maldistribution of health care providers and service is one of the most persistent characteristics of the American health care system. Even as an oversupply of
some physician specialties is apparent in many urban health care service areas across the country, many inner-city and rural communities still struggle to attract an adequate number of health professionals to provide high-quality care to local people. This is the central paradox of the American health care system: shortages amid surplus (p. xiii).

This shows the inequity in availability of quality health care and services for inner-city African-Americans such as those in this study and highlights the issue’s roots in structural inequality.

3.1.1.2 Delay in Diagnosis

Differential rates of timely diagnostic resolution after abnormal screening may also contribute to disparities in breast cancer outcomes. Delays in diagnosis as short as 90 days are associated with decreased breast cancer survival (Richards et al. 1999); although shorter interval criteria have been argued to allow for up to one month of treatment delay without impact on prognosis (Gwyn et al. 2004). For some women this period between abnormal mammogram or presentation of breast symptoms and abnormal follow-up may represent a period of liminality. In this context, liminality refers to the transition from a healthy, disease-free state to a state of confirmed disease and uptake of the sick role (Gifford 1986).

The ambiguity of this liminal state may cause a woman to drop out of the continuum of care due to denial or fatalistic perspectives. However, Granek and Fergus (2012) reject the concept of denial as a mediating variable between symptom discovery and physician assessment and offer three derived themes explaining delayed presentation of breast irregularities. According to the first theme identified, participants felt obligated to take the right or moral course of action by presenting to their doctors; this involved social experiences of obligation, shame, confession, and guilt. Second, as a distinct stage of liminality, women wavered between deliberately ignoring symptoms and being aware of them (Granek and Fergus 2012). Lastly, participants employed
passive resistance as a form of agency. These themes emerged in two distinct ways: First, women, well aware of their disease, forwent disclosure of their symptoms to partners in order to retain control and agency over their bodies by resisting pressures. Second, despite disclosure of symptoms to a partner, women refused the medical gaze until benefits of seeking care outweighed costs (Granek and Fergus 2012). These concepts may contribute to delays in symptomatic presentation or delayed or lack of follow-up after abnormal screening exams.

Significant delays in the steps leading to diagnosis of breast cancer are well-documented for African-American women throughout the literature (Elmore et al. 2005; Adams et al. 2009; Komenaka et al. 2010; Sheinfeld Gorin et al. 2006; Press et al. 2008). One fifth (22.1 percent) of African-American women experienced delays greater than 60 days, with a median of 29 days and an interquartile range of 74 days. Fewer (18.3 percent) White women received delay in diagnosis of more than 60 days, with a median of 21 days and an interquartile range of 41 days. Additionally, Press et al (2008) found the median number of days to diagnostic follow-up after an abnormal mammogram was 20 days for African-American patients and only 14 days for White patients. Combined, these data illustrate the prolonged delay experienced by African-American women in obtaining diagnostic resolution.

Delay in diagnostic follow-up may also be impacted by the patient understanding of screening mammography findings (Pérez-Stable et al. 2013). Jones et al (2007) found that it was not only significantly more common for African-American women overall to have inadequate understanding of mammographic results, but also more common for African-American women to have inadequate understanding in the case of abnormal imaging when compared to White women. Adequate and effective communication of results is pivotal in follow-up of abnormal
imaging and is also a missed opportunity to reinforce regular screening in women with negative imaging; in accordance with guidelines, regular screening is needed to maximize the efficacy of early detection by screening mammography (Michaelson et al. 2003).

Allen et al (2008) found that inadequate or unsatisfactory interpersonal communication, perceived disrespect by providers and staff, logical barriers, and anxiety and fear of diagnosis were the most common issues cited for delays in follow-up. Qualitative data shed light on the many ways information can be misunderstood, misconstrued, or discounted—either because of vocabulary used, the language employed, or the mode of communication. The comprehension of screening results is strongly associated with receipt of timely follow-up (Kerner et al. 2003) and is therefore an opportunity for improvement of timely follow-up.

Overall, there are numerous variables impacting delays in diagnosis. In a population-based study, women who were younger, less educated, in poor health, and perceived low risk of hereditary cancer were less likely to complete follow-up after an abnormal mammogram (Yabroff et al. 2004). Another study found increased diagnostic delays associated with being African-American, low-income, perceiving discrimination, being notified of recall by letter, and decreased comprehension of mammography findings as risk factors associated with delays in diagnosis (Pérez-Stable et al. 2013). Conversely, one study found significant predictors of timely follow-up to include older age, a referral from a hospital-based practice, private insurance, and being referred for evaluation of abnormal mammogram (Battaglia et al. 2007). There are many known barriers to mammography; however, barriers to timely follow-up are more elusive in published research. Lack of appropriate follow-up and/or delay in diagnostic workup undermines the efficacy of mammography in aiding early diagnosis of breast cancer. This is especially relevant to the
African-American population given that a major contributing factor to the mortality disparity is stage at diagnosis.

3.1.2 Treatment

Delay in initiation of treatment of breast cancer may impact health outcomes in terms of survival in African-American women (Bleicher et al. 2015; McLaughlin et al. 2012). Delays raise concern of the cause of delays, although it is difficult to discern the point at which delays more commonly occur (Connors et al. 2014; Bleicher et al. 2015). No definitive guidelines exist as to when to initiate surgical treatment, which is often the first step in treatment of breast cancer, although benchmarks of 30 and 90 days are often used as quality measurements (Fedewa et al. 2011). Recent data suggest that overall survival may be decreased in women with stage I and II cancers when time to surgical treatment is prolonged; impact of survival in women with stage III-IV was not significant (Bleicher et al. 2015). Prior research revealed inconclusive results on the impact of delay in surgical treatment (McLaughlin et al. 2012; Brazda et al. 2010; Sainsbury, Johnston, and Haward 1999; Yoo et al. 2015). In a large population-based study, Silber et al (2013) found that African-Americans were more likely to have prolonged treatment delays.

Guidelines for initiation of chemotherapy are better defined. European Society of Medical Oncology endorses chemotherapy initiation two to four weeks after surgery (Senkus et al. 2015). Data suggest that initiation of chemotherapy greater than 12 weeks after surgery compromise overall survival for early breast cancers (Lohrisch et al. 2006). Data show increased delays in initiation of chemotherapy for African-American women when compared to White women (Landau et al. 2009; Vandergrift et al. 2013).
Delays in initiation of chemotherapy, similarly to delays in initiation of surgical treatment, may not be uniformly impactful among women with breast cancer. One study found that in women less than 40 years old, African-American women were more likely to have significantly decreased survival when chemotherapy initiation was delayed greater than six weeks (Smith, Ziogas, and Anton-Culver 2013). Additional risk factors of increased delay of chemotherapy initiation included public insurance, low socioeconomic status, additional surgeries performed including immediate breast reconstruction and re-excision, and transfer of care after diagnosis (Smith, Ziogas, and Anton-Culver 2013; Vandergrift et al. 2013).

After treatment initiation, studies have demonstrated that African-Americans more frequently receive inappropriate treatment of breast cancer. As defined by the 2000 National Comprehensive Cancer Network practice guidelines, primary treatment of breast cancer includes total mastectomy or breast conserving surgery followed by adjuvant radiation therapy (Carlson et al. 2000). Qualitative findings suggest that lack of patient understanding of radiation therapy and its connection to survival or perceptions of radiation as an optional treatment act as barriers to completion of primary treatment in African-American women (Noel et al. 2015). Reported by Li et al (2003), SEER data from 1992 to 1998 showed that African-American women with stage I or II breast cancer were 40 percent more likely to not receive standard of care in primary treatment. Medicaid patients are less likely to initiate or complete recommended radiation therapy following breast conserving surgery (Ramsey et al. 2010). Additionally, researchers have found that African-American women were more likely to receive nonstandard chemotherapy regimens than Whites, including lower doses proportions (actual versus expected dose), relative dose, and discontinuation of chemotherapy (Griggs et al. 2007). Nonadherence to prescribed medical
guidelines and disparities in treatment can produce disparities in outcomes in African-American women.

3.1.3 Clinical Trials

Clinical trials serve pivotal roles in improving health outcomes and advancing treatment regimens; however, African-American and other vulnerable populations disproportionately participate, negatively affecting the generalizability and the validity of results (Robinson and Trochim 2007). Analyses of clinical trial participation show African-American patients were 1.8 times more likely to refuse than White patients (Penberthy et al. 2012). Reasons cited include no interest in trials, pressures from family members, feeling overwhelmed by the decision-making process, or no reason given. A follow-up study performed by Brown et al (2013) showed that patients had altruistic intentions to join clinical trials, however risk of increased side effects and discomfort with randomizations were cited as reasons for refusal. Numerous studies cited lack of trust in the healthcare system and/or the individual physician as determining factors in participation in clinical trials (Haynes-Maslow et al. 2014; Rivers et al. 2013).

Providers play a critical role in the recruitment of clinical trials. Recommendation of a clinical trial has shown to be a strong predictor of patient participation (Eggly et al. 2008; Grunfeld et al. 2002). Providers often act as the gatekeeper to informing patients about the existence of clinical trials and patient eligibility (Avis-Williams et al. 2009; Wang et al. 2008); however, studies showed decreased frequency of recruitment of African-Americans for clinical trial due to lack of provider suggestion (Fisher and Kalbaugh 2011; Baquet et al. 2006). Lower level of health literacy may also act as barrier to African-American patients in their ability to evaluate and seek out health information (Evans, Lewis, and Hudson 2011).
Low levels of participation by African-Americans in clinical trials produces inequality of access to innovative technologies and treatments. Despite a nearly 20 year effort to increase participation by underrepresented populations in clinical trials, overall accrual rates of clinical trials have not significantly improved (Brown et al. 2013; Kwiatkowski et al. 2013).

3.1.4 Structural Barriers

3.1.4.1 Transportation Barriers

Inability to access care due to a lack of transportation is often cited as a barrier to breast health care and other health services (Hendren et al. 2011; Rask et al. 1994; Silver, Blustein, and Weitzman 2012). Transportation barriers may include lack of access to a personal vehicle, lack of access to public transportation, distance to physician, and affordability of transportation. Inadequate patient access can lead to missed appointments, delayed care, and missed or delayed medication use, all of which potentially contribute to delayed breast cancer diagnosis and poorer health outcomes, such as higher burden of disease and decreased survival rates. Overall, evidence supports that transportation remains a significant barrier, especially for vulnerable populations such as minority, low-income, uninsured, and under-insured populations.

The influence of private vehicle access, either owning a car or being able to borrow a car, was found to be positively correlated with access to health care in multiple studies despite travel time (Flores et al. 1998; Guidry et al. 1997; Ide, Curry, and Drobnies 1993; Silver, Blustein, and Weitzman 2012; Peipins et al. 2012). Flores et al (1998) found, of patients who cited transportation as reason for delayed care, 62 percent of those patients cited not having access to a car as the specific barrier over excessive distance, expense, or inconvenience of public transportation. Similarly, data analyses of a 2001 National Household Travel Survey found that private cars
continue to dominate urban travel among every segment of the population, including low-income, racial minorities, and elderly (Pucher and Renne 2003). The significance of the availability of cars is marked within the literature as the preferred method of transportation to medical care and increased access to health care.

Public transportation has the potential to impact vulnerable and underserved communities who have decreased access to private vehicles and financial constraints, however current implementation has not shown to significantly improve access to mammography screening. One study found the use of public transportation as a means to access medical care among urban, low-income populations was associated with delayed medical care and lack of medical home or regular source of health care (Rask et al. 1994). Another study found no difference in mammography screening rates between women residing in counties with low usage of public transportation versus counties with higher usage (Coughlin and King 2010). Spatial analyses performed in Chicago and Atlanta showed significantly increased distance and travel times for predominantly African-American neighborhoods with less access to public transportation (Peipins et al. 2012; Zenk, Tarlov, and Sun 2006).

Access to and reliance on public transportation remains a barrier disproportionately experienced by low-income African-American women in accessing mammography facilities. African-Americans disproportionately experience travel burden, measured in travel time and distance, compared to Whites (Probst et al. 2007). There are several possible explanations for this: 1) racially diverse and low-income communities are more likely to be medically underserved, increasing distances to health care (Gaskin et al. 2012); 2) primary care physicians may be less likely to accept Medicaid or other public insurance plans, increasing distances to health care for
populations with high rates of public insurance (Perloff et al. 1997; Cunningham and Nichols 2005); and 3) racially diverse populations are more likely to seek out racially and linguistically concordant providers (Chen et al. 2005; Traylor et al. 2010; Saha et al. 1999). These preferences, along with a national shortage of racially diverse providers, may contribute to increased travel time and associated expenses (Dept. of Health and Human Services 2013).

3.1.4.2 Socioeconomic Status

The interplay of socioeconomic status and breast cancer outcomes is a well-documented topic within the literature. However, as evidenced by conflicting research findings, researchers have found it difficult to distinctively account for variabilities in breast cancer outcomes due to tumor biology, socioeconomic status, and race/ethnicity separately. Hypotheses have been made that racial disparities are artifacts of shared socioeconomic status, rather than true disparities between races/ethnicities. Studies have found, with equal access to healthcare, comparable breast cancer outcomes after controlling for socioeconomic status (Maloney et al. 2006; Roach et al. 1997; Curtis et al. 2008; Du, Fang, and Meyer 2008). Furthermore, additional studies performed by Parise and Caggiano (2013) have showed differences in degree of racial disparities across strata of socioeconomic status and stage at diagnosis. Other studies show low socioeconomic status, not race, was associated with poorer breast cancer outcomes (Bradley, Given, and Roberts 2002; Byers et al. 2008; Sprague et al. 2011; Clegg et al. 2009; White et al. 2014). While the direct financial costs of cancer screening and treatment are easily quantifiable as barriers to care, the indirect costs of long-term cancer care and survivorship for low socioeconomic individuals remain more ambiguous and may cause greater relative economic hardship (Darby et al. 2009).
Inconclusive research findings of the impact of socioeconomic status on breast cancer outcomes may be obscured by inaccurate measurements of socioeconomic status. Socioeconomic status indicators collecting individual measures of income, education, and other commonly used socioeconomic status measures are not available at the individual level in many population studies (Robert et al. 2004); socioeconomic status measurements are therefore limited to geographic and contextual data such as census tract and zip code data. Several studies found with the same level of education and income, African-American women are more likely than White women to live in neighborhoods of low socioeconomic status, further obscuring contextual and geographic inferences of socioeconomic status for African-American women (Cohen et al. 2003; Massey and Fong 1990). Additionally, in instances when research methods collect individual level data, data are confined to single medical institutions rather than cancer registry databases and are less generalizable (Lantz et al. 2006).

Research shows breast cancer incidence rates are higher in areas of increased socioeconomic status (Mackillop et al. 2000; Yost et al. 2001; Harper et al. 2009; Clegg et al. 2009); this may be partially due to increased access to screening, which has shown to increase incidence rates in postmenopausal women (Lantz, Remington, and Newcomb 1991; Morrell et al. 2010). Additional studies have found that increased incidence rates are also impacted by the frequency of known risk factors for breast cancer such as late age at first birth, low parity, and the use of hormone replacement therapy, which are more commonly reported in women of higher socioeconomic status (Heck and Pamuk 1997; Palmer et al. 2012). Increased incidence of subtypes of breast cancer, specifically those with Her2 overexpression (a negative prognostic factor), have also shown to be positively associated with socioeconomic status (Akinyemiju et al. 2015). Lack of
paid sick leave has shown to significantly impact use of cancer screening and medical seeking behaviors, which most commonly reported by service industry workers (Peipins et al. 2012). Environmental, social, and cultural factors may also need to be considered in relation to the impact of socioeconomics on breast cancer outcomes.

3.1.4.3 Insurance Status

In 2014, 88.2 percent of all African-Americans in the U.S. were enrolled in either public or private health insurance, with 54.0 percent of African-Americans in the U.S. covered by private insurers (Smith and Medalia 2015). African-Americans accounted for the largest percentage (44 percent) of enrollees for government-funded insurance plans when compared to other race/ethnicities (Smith and Medalia 2015). Comparatively, Whites reported the highest rates of overall health insurance coverage at 92.4 percent (Smith and Medalia 2015). Differences in insurance coverage among the African-American population is largely due to low wages and jobs without employer-paid health benefits (Newman 2005). Several studies have suggested that the presence and type of insurance have clinical implications on breast cancer outcomes in African-American women. Furthermore, insurance status alone is not accountable for regular interval mammography usage, as the National Health Interview Survey revealed only 77 percent of insured women were up-to-date with mammography screening in 2013 (CDC 2013).

Prior to the Affordable Care Act (ACA), Medicaid recipients and the uninsured were less likely to undergo breast cancer screening, more likely to receive late-stage cancer diagnoses, and were less likely to survive breast cancer (Roetzheim et al. 1999; Osteen et al. 1994; Riley et al. 1994; Potosky et al. 1997; Ayanian et al. 1993). Overall, individuals with public insurance have not fared better than the uninsured in terms of breast cancer morbidity and mortality (Moy et al. 2005).
Medicaid and uninsured women have lower access to primary care physicians (Cossman et al. 2014). However, insurance coverage alone does not account for racial differences in stage a diagnosis (Roetzheim et al. 1999; Komenaka et al. 2010; Hoffman et al. 2011). Data post-implementation of the Affordable Care Act have yet to be sufficiently reported, though preliminary data show little change in utilization of preventive cancer screening with elimination of cost-sharing in the insured population (Han et al. 2015). Qualitative data analyzing barriers to adherence to screening mammography post-ACA implementation suggest women may not have accurate information regarding no-cost screening mammography, indicating a need for dissemination of information regarding increased accessibility under the ACA (Wells et al. 2015).

3.1.5 Clinical Barriers

3.1.5.1 Lack of Primary Care

Overall, having an established primary care physician is one of the strongest indicators of mammography use and overall improved breast cancer outcomes including reduced odds of late-stage diagnosis and increased survival (Roetzheim et al. 2012). Studies have found that primary care providers play a pivotal role in screening and diagnostic follow-up (Jones et al. 2005; Mickey et al. 1997; O’Malley, Forrest, and Mandelblatt 2002). Increased number of visits to a primary care physician was associated with higher rates of mammography, although it was more impactful for White women than African-American (Burns et al. 1996). Physicians have significant potential to educate African-American women about the potential benefits of participating in breast health behaviors including cancer care and screening as gatekeepers to preventive medicine (Nekhlyudov and Braddock 2009; Ahmed et al. 2009; Ansell et al. 2009).

3.1.5.2 Providers
Non-board certified physicians are more likely to practice in medically underserved areas (Bach et al. 2004; Gerend and Pai 2008; Nekhlyudov and Braddock 2009; Newman et al. 2001). Physicians who serve predominantly African-American clientele may be less likely to be informed or to adhere to appropriate preventive screening recommendations and are more likely to deliver nonstandard cancer treatments (Gemson, Elinson, and Messeri 1988; Tamblyn et al. 2002; Nekhlyudov and Braddock 2009; Bach et al. 2004; Freedman et al. 2011). One study found that providers in urban and suburban areas may be less likely to recommend regular screening intervals and necessary diagnostic follow-up. The top reasons provided for not adhering to such guidelines include the complexity of coordination of care multiple health systems, provider cost-benefit analysis for patient, and provider knowledge of recommendation guidelines (Khoong et al. 2014).

Having an established primary care physician has shown to positively impact survival rates, decrease risk of late-stage diagnosis, and improve survival rates among Medicare beneficiaries (Fisher et al. 2013). Screening recommendations made by physicians were identified as a strong predictor of cancer screening (Lubetkin et al. 2008; Lian, Jeffe, and Schootman 2008). Overall, physicians play a key role in breast cancer screening and clinical outcomes for vulnerable populations if guidelines are properly followed.

Patient-physician interactions may be educationally or culturally inappropriate to African-American patients (Lubetkin et al. 2008; Nekhlyudov and Braddock 2009); research suggests women at lower socioeconomic statuses may require increased emotional support for improved uptake of cancer-related knowledge (Chen et al. 2008). A qualitative study of African-American breast cancer survivors in Memphis, TN noted challenges in communicating with providers during cancer care regarding lack of provider sensitivity to patient’s pain, feelings that providers had
ulterior motives behind health care recommendations, and concerns that providers did not disclose adequate information about treatment regimens and side effects (White-Means et al. 2015). More than 30 years of sociolinguistic studies have documented power imbalances in patient-provider interactions, often suggesting providers fragment or disassociate the patient’s lived experience from the disease itself (Andersen, Tørring, and Vedsted 2015).

Patient-provider racial concordance or congruity showed to foster a “safe environment” facilitating conversation, accurate data collection, and comprehension of cultural phenomena (Jackson 1991). Approximately 75 percent of all African-Americans receive care by racially discordant medical providers as African-Americans represent 5 percent of the physician workforce (Chen et al. 2005; Meissner et al. 2011). Racially discordant medical interactions have been noted to be less positive, productive, and informative than racially concordant interactions (Cooper-Patrick et al. 1999; Johnson et al. 2004; Siminoff, Graham, and Gordon 2006). African-American patients are less likely to be trusting of their providers (further discussed as “medical mistrust”), causing negative and less productive patient-provider dynamics (Doescher et al. 2000; Halbert et al. 2006). The lack of racially diverse physicians and providers may be indicative of a greater policy issue deterring African-American populations to work in health care (Saha et al. 1999). A functional limitation of primary care physicians in cancer treatment and survivorship may be in the lack of communication between oncologists and primary care providers regarding patient prognosis, treatment status, and other health information relating to supporting health care in low-income and racially diverse communities (Shen et al. 2015).
3.1.6 Personal Barriers

3.1.6.1 Perceived Risk

Perceived risk is a well-documented predictor of breast cancer screenings. African-American women historically have underestimated their risk of breast cancer (Lucas-Wright et al. 2014; Orom et al. 2010). Perceptions of low risk have been associated with conflicting cancer information, lack of personally relevant cancer information, lack of perceived control over health outcomes, race (i.e. “White woman’s disease”), and lack of family history (Allicock et al. 2013; Orom et al. 2010). Perceptions of high risk are associated with higher levels of cancer knowledge, poorer health status, family history of breast cancer, and having discussed breast cancer with a health care provider (Lucas-Wright et al. 2014). Researchers found that African-American communities are not likely cognizant of the disparity in breast cancer mortality for African-American women (Kaiser 2013). To develop interventions that encourage the adoption of screening, it is important to understand the relationship between perceived risk and screening behaviors (Lucas-Wright et al. 2014).

3.1.6.2 Fear and Fatalism

Cultural factors of fatalism and cancer fear are more commonly reported by African-American women than White women and act as barriers to breast cancer screening (Spurlock 2006; Mitchell et al. 2002; Phillips, Cohen, and Moses 1999). Fatalism, generally, is the perspective that health is out of the control of the individual and is a matter of luck or fate (Straughan and Seow 1998). In the case of cancer, fatalism is often defined as an individual’s belief that “when cancer is present, death is inevitable” (Spurlock 2006; Mitchell et al. 2002). Combined, these
concepts reduce perceived control in preventing and managing disease, decrease optimism, and decrease perceived life expectancy (Drew and Schoenberg 2011).

Cancer fatalism has specifically focused on reasons for delayed presentation of symptoms, non-participation in efficacious screenings or treatments, and lack of diagnostic follow-up (Drew and Schoenberg 2011). Others have linked higher rates of fatalism within societies to decreased breast cancer screenings or no measurable effect (Mayo, Ureda, and Parker 2001; Chavez et al. 1997). A case study performed by Conrad (1996) found, in a religious setting, that African-American women linked cancer fatalism to moral and religious wrongdoing.

Fear of cancer may impede screening behaviors in African-American populations and promote screening behaviors in the White population (Peek, Sayad, and Markwardt 2008). Studies also noted that individuals with fatalistic outlooks on breast cancer may be at greater risk of disease because they are less likely to engage in preventive health behaviors and more likely to delay seeking health care (Gullatte et al. 2010; Niederdeppe and Levy 2007).

3.1.6.3 Medical Mistrust

There is a historical basis of unethical treatment of African-Americans by the medical community that has provided the basis for medical mistrust within the African-American community (Boulware et al. 2003; Jacobs et al. 2006). Incidences like the Tuskegee Syphilis Experiments act as hallmark examples for medical mistrust within the African-American community (Brandon, Isaac, and LaVeist 2005; Katz et al. 2009); however, researchers found that racial differences in medical mistrust likely spur from broader historical context and personal interactions with the healthcare system, such as perceived discrimination, negative interactions,
and perceptions of institutional mistreatment, rather than the impact of Tuskegee legacy alone (Brandon, Isaac, and LaVeist 2005).

Greater physician trust is an indicator of a patient’s likelihood of accepting recommended care and to participate in productive patient-provider encounters and overall satisfaction of care (Ayanian et al. 1999; Connelly and Campbell 1987; Doescher et al. 2000; Keating et al. 2002). Inversely, greater degrees of medical mistrust are predictors of underutilization of health services (LaVeist, Isaac, and Williams 2009). Improved communication skills have been shown to increase patient’s trust of a medical provider (Peek, Sayad, and Markwardt 2008). Improving patient trust of providers and of the medical system may positively impact screening uptake and treatment adherence.

3.1.6.4 Spirituality

Religious and spiritual beliefs have been identified as important factors in healthcare decision-making of African-American women (Bourjolly 1998; Dessio et al. 2004; Underwood and Powell 2006). Spirituality is more frequently reported by African-Americans in many regions of the U.S. compared to Whites (Taylor, Chatters, and Levin 2004). Spirituality is noted as a coping strategy among African-American women facing breast cancer (Henderson et al. 2002; Henderson, Fogel, and Edwards 2003). Spirituality has shown to help African-American patients develop a positive outlook, increase social support through church social networks, and reduce fear associated with cancer (Henderson et al. 2003; Christman et al. 2014).

African-American women are more likely to utilize spirituality in decision-making regarding serious medical conditions such as cancer and heart disease; however, compared to minor illnesses,
religion may act as a barrier to care in the case of serious medical issues (Dessio et al. 2004). High perceptions of God as the locus of control are associated with decreased adherence to breast cancer screening methods in African-American populations (Kinney et al. 2002). Studies found that strong spirituality is positively associated with delayed presentation of self-detected breast symptoms (Gullatte et al. 2010). Spirituality and strong connections to religion and faith are factors characteristic of many African-American communities, and if utilized appropriately, spirituality may be a strategy to improve breast cancer outcomes.

3.2 Theoretical Framework

The theoretical framework of this research includes a combination of public health behavioral change models and applied anthropology theories. Combining these two perspectives increased the understanding of the multi-faceted barriers to breast health and breast cancer outcomes as well as the understanding of decision-making in the context of health behaviors.

3.2.1 Socioecological Model

The Socioecological Model (SEM) is a theoretical model commonly used in public health to examine the influencing factors on health behaviors and outcomes. The term ecology refers to organisms and their environment. The model emphasizes “the interdependence of environmental conditions within particular settings and the interconnections between multiple settings and life domains” (Stokols 1996). The SEM recognizes and identifies the broader context in which health decisions are made, including the intrapersonal, interpersonal, organizational, community, and policy levels. The core assumption of the SEM is that health is affected by the dynamic interaction between each of level of influence including physical and social environments, including human
interactions, with reciprocal feedback between each level (National Cancer Institute 2005; Stokols 1996).

Each of the levels identified in the SEM adds expansion in scope to incorporate broader context beginning with the individual (See Figure 2). At the core of the model is the individual actor, with layering influence represented by intrapersonal, interpersonal, organizational, community, and policy levels. Starting at the individual level, intrapersonal factors are comprised of personal characteristics of the individual including perceptions, attitudes, and knowledge. The interpersonal level includes factors associated with social relationships with friends, family, and providers that influence the individual. Organizational, also referred to as institutional, factors include employers, clinics, and churches. Research institutions, public health departments, and the media represent the community level, while public policy drives the macro-level influences through federal agencies and legislators at the local, state, and national levels.

Figure 2. Adapted Socioecological Model, Center for Disease Control (2015)
Application of the SEM to cancer reveals the multi-faceted barriers and opportunities for intervention and policy improvement to drive improved outcomes. Synergistic interventions including components from multiple levels have the greatest impact on health promotion and health outcomes (CDC 2013). Utilizing the SEM in the organization and analyses of barriers identified by Affiliates demonstrates the complex and dynamic social, political, and economic environments in which the target populations live and die. The SEM allows for a holistic and dynamic examination of the varying components that encourage or inhibit breast cancer screening and treatment adherence.

3.2.2 Qualitative Epidemiology

Bridging qualitative study and public health is the concept of qualitative epidemiology. This approach interprets and expands the agent-host-environment triad utilized to understand disease within public health frameworks through an anthropological lens. Traditional epidemiology has relied on a positivist perspective in which social reality is stable and risk is uniformly distributed, and quantitative analysis techniques are adequate to determine relationships within the triad (Frohlich, Corin, and Potvin 2001; Popay 2003). Primarily, qualitative epidemiology moves past the definition of illness\textsuperscript{1} as a purely biological outcome to include a psychosocial unit. The approach further deconstructs the meaning of environment and host to include the larger picture of broader contexts explaining changes in statistical outcomes of morbidity and mortality (Agar 2003). As present above, much of the public health literature relies on statistically significant relationships in determining what public health refers to as the social determinants of health. These

\textsuperscript{1} Illness is the opposite of health, as defined by the World Health Organization as the complete state of physical, mental, and social well-being, and not merely the absence of disease or infirmity (Ustun and Jakob 2005).
determinants often report predetermined variables, limiting reporting to single variables and ignoring the complex interactions between and among them. These differences in the acquisition and utility of knowledge sources represent an epistemological debate and on-going paradigm shift present in behavioral and community health studies within public health.

Including a broader scope of relevant knowledge and understanding of the interactions of health, environment, and illness allows for deeper understandings and interpretations of the factors influencing health, opening responses past limited quantitative variables. Paul Farmer (2001) calls for “radical contextualization” through anthropological methods to achieve a holistic understanding in which a specific dimension is present (Navarro 1986). Qualitative study of health and illness allows models to account for the dynamic role of cultures as webs of significance and how culture and health change in a given context or through time and space (Corin 1995; Lee 2010).

3.2.3 Applied Anthropology

In conjunction with public health efforts to improve population health and promote healthy lifestyles, applied medical anthropology seeks to provide practical and applicable solutions to health topics. Using a varied toolkit, including theory, methodologies, and concepts, deeper understandings of health issues can be achieved. At the crux of medical anthropology is the intention to identify and understand the social processes that underpin inequalities in health and help identifying solutions and opportunities for improvement (Chapman and Berggren 2005).

Given the basis of applied medical anthropology, it is ideal for the exploration of factors affecting breast cancer disparities observed in the African-American community. Specifically,
elements of anthropological methods, theory, and practice contribute to a better understanding of the social processes that underpin racial/ethnic health disparities and help identify opportunities for interrupting them (Chapman and Berrgren, 2005).

Overall, anthropologists have called health behavior research to move away from individualistic perspectives of rational decision-making underlying numerous models for behavioral change and move towards the recognition of health behaviors in the broader social, cultural, political, economic, structural, and historical context (Burke et al. 2009). A challenge of the SEM is just this: it relies on preexisting and hallmark health behavior theories and constructs for intervention at each level of influence, including those of the Health Belief Model. Applied anthropology inserts the social context, including the logic, knowledge and beliefs grounded in the context of people’s lived experience and the broader environments of political, historical, and cultural phenomena (Williams 1995).

3.2.3 Health Behaviors and Rationalistic Decision-Making

Decision-making is well-studied in medical anthropology, often counterering the rationalistic models of decision-making presumed by many behavioral change models utilized by public health practitioners. According to a review of 13 publications produced by the National Cancer Institute (NCI), Davis (2008) found that an ideal patient in these narratives is diligent about engaging in early detection practices in the presymptomatic stage of the narrative. According to the texts, she regularly does breast self-examination, has an annual mammogram, and sees her physician for a manual examination. She also stays informed and aware of health issues. When the woman finds an irregularity, something that might be breast cancer, she immediately seeks out her doctor so that he or she can verify the symptoms (pp. 71)
This reveals the individualistic and rationalistic assumptions in biomedical expectations of individual health behaviors and promotes the proactive health care seeking discourses (Andersen, Tørring, and Vedsted 2015). Moreover, health is increasingly viewed in a neo-liberal and moral sense, and it is justly deserved by those who perform appropriate behaviors (Abrums 2000). Assumptions of rational decision making in the biomedical framework fail to connect with the lived experiences of body—bodies that have personal experiences and that take part in social relationships and cultural meanings (Schep{}er-Hughes and Lock 1987). Deconstructing rational decision-making and linking health behavior actions and inactions to the larger context and environments is a strength of the anthropological perspective. In the case of breast cancer, it adds to the understanding of why women participate in or forgo screening, treatment, and health services contributing to racial/ethnic disparities.

3.2.4 Practice Theory and Habitus

The inclusion and consideration of the broader context argued for by anthropological theory allows for a more holistic understanding of the influences of health behavior and builds upon preexisting health behavior theories. Social practice and practice theory, developed by Pierre Bourdieu (1990), helps to understand behavior in social and cultural context, within the wider structures and patterns of social life on individual behavior (Jenkins 2002; Williams 1995). Practice theory emphasizes health behaviors as products of social and cultural environments, which in turn contributes to and alters environments.

Furthermore, Burke et al (2009) poses the concept of habitus alone is not sufficient to explain individual behaviors. Habitus refers to the “embodied history, internalized as second nature” and reflects the influence of past events on individuals’ perceptions of current conditions,
how they anticipate the future, and accounts for how social conditions are reproduced (Bourdieu 1990, p. 56). Past experiences influence the present and are heavily influenced by socioeconomic status; these experiences unconsciously inform perceptions, thought, and action. Habitus is a product of social forces rather than individual psychology and exists in and through the practices of individuals and their interactions with their environment; concepts of individual agency and social structures are continually interconnected and co-constitutive in this framework (Burke et al. 2009). Habitus is an integral component of behaviors and in turn, behaviors are a product of larger social, cultural, and historical forces (Crossley 2004).

A critical element of the concept of habitus is the absence of conscious awareness in the influence of the past; therefore, influences are observable rather than reportable in conscious attitudes and beliefs (Burke et al. 2009). This relates to the Affiliate’s perspective captured in this study in their ability to compare perceptions and behaviors between and within racial and ethnic groups in their service area. Habitus provides individuals with “class-dependent, predisposed, yet seemingly ‘naturalized’ ways of thinking, feeling, acting, and classifying the social world and their location within in” (Williams, 1995, p. 586).

Given the basis of habitus, Bourdieu suggests practice theory as the relationship between external constraints, such as economic and sociopolitical conditions, and predispositions or unconscious internalizations of social constraints (Bourdieu 1990); these perceptions become engrained in the individuals as right and proper within a given cultural or social context (Burke et al. 2009). Practice theory supports the unconscious role of habitus within with conditions of economic, social, and other cultural processes and the emerging practices of daily life with the interrelationship of social structures and these conditions (Burke et al. 2009).
3.2.5 Redefining Health Behavior Environments

Outside of the internalized impacts of the broader context on everyday individual decisions, the perspective of critical medical anthropology is appropriate for the investigation and interpretation of breast cancer disparities in African-American communities. The premise of this approach is the acceptance of health as an inherently social and cultural concept rather than mechanistic condition, encouraging scholars to identify the intersection of biology and culture in producing health disparities (Leatherman and Goodman 2011).

Themes of the critical medical anthropology approach includes four ideologies for analyses. First, understanding root inequalities, such as those shaped through political economic processes described by Wolf (1983), as results of geographic and historical processes is a necessary step in advancing health disparities theoretical framing (Leatherman and Goodman 2011). The critical approach focuses on the power relationships and structures produced by socioeconomic inequalities and perceived social inequalities (Wilkinson 1996; Sen 1992). Second, critical analyses of the structured inequalities as products of social and political implications of race, class, and gender and how they impact living conditions, exposure to pathogens, access to health care and other resources creating disparities (Schultz and Mullings 2006); this ideology supports identifying the underlying, driving inequalities rather than the presence of the disparities in health alone (Leatherman and Goodman 2011). Furthermore, a critical medical anthropology approach employs reflexivity in the production of scientific knowledge in regards to research questions, methods and analyses, findings, funding source, and the impacts on the lived experience (Leatherman and Goodman 2011). The fourth ideology of this approach is the interplay of social
structures and human agency, an individual’s capacity to act, in constructing environments and affecting their lived experiences.

Based on the aforementioned ideologies, critical medical anthropology focuses on the social origins of disease and the influence of imbalanced power relationship on health and illness (Corin 1995). In investigating a failed community health intervention in Philadelphia, Balshem (1993) found systemic “othering” of the at-risk populations by providers, basing stereotypes on ethnicity and concepts of fatalism, and lack of responsiveness. Balshem attributed this as a means to divert attention from the structural perpetuation of environmental exposure associated with industrial jobs, rather than the medicalization of health risks. Nguyen and Peschard note that by naturalizing structural inequalities such as this, “those lower on the social ladder find themselves blamed for conditions over which they have little control” (2003). An assumption of this approach is that all activities and behaviors operate within the larger political and economic environment. In this model, anthropologists focus on the social production of disease and the social context of biomedicine and biomedical practice (Singer 1990).

3.2.6 Race and Health Disparities

A critical examination of the role of race and racism shows that race becomes biology through social and political discourse and practices, as opposed to race based on identifiable biological differences. Discourses today represent race as a cultural construct rather than bad biology. Perceptions of biological bases of race undermine understandings of the relationships between known factors explored in the literature and health outcomes. Race is the not cause of disease, rather it describes the associated social environments in which health outcomes are unequally created and expressed. Anthropological understanding of race derives from deeply
rooted, historical and social inequalities (Chapman and Berggren 2005). Anthropologists contend that these inequalities become a part of biology through embodiment of social inequalities and narrowly define public and individual worldviews relating to health and illness (Gravelee 2009). Rejecting racial-genetic determinism, this study investigates the role of broad-scope environmental factors on racial disparities in breast cancer outcomes. Relying on racial classifications is a limitation of this study, however holistically recognizing and analyzing the environmental factors is in hopes to use race as a cultural construct rather than biologically defined grouping.

3.3 Evidence-Based Interventions

Evidence-based interventions (EBI) relevant to the scope of this study are behavioral interventions aimed at increasing breast cancer knowledge, uptake of screening mammography, and decreased time for diagnostic resolution. Evidence-based interventions are behavioral interventions shown to be effective through sound scientific testing (Highfield et al. 2015a). Multiple evidence-based interventions are recognized by the Community Preventive Services Task Force (CPSTF), which inform Research-tested Intervention Programs (RTIP) identified by the National Cancer Institute (The Community Guide 2016). These programs and intervention components (See Appendices G and H) are developed and tested by researchers, have proven to positively impact one or more behaviors or psychosocial outcomes among individuals, communities, or populations. These interventions are known and accepted as appropriate and effective interventions. Analysis by the Center for Disease Control and Prevention found client-oriented strategies, including small media, client reminders, and reduction of structural barriers, as the most commonly used EBIs among National Breast and Cervical Cancer Early Detection
Program grantees (DeGroff et al. 2016). Challenges in implementing EBIs include resource limitations, lack of culturally appropriate interventions, and limited skills for adapting EBIs for local population use (Steele et al. 2015).

Debate continues if programming should be based on clinically-tested interventions or from a “ground-up” perspective, deriving from successful community-based practice (Highfield et al. 2015b). Fidelity during implementation of an EBI is essential to ensure the success of the program; however, adaptation is also a necessary component to appropriately implement programming for a targeted, culturally distinct population (Highfield et al. 2015b). To effectively adapt interventions to the target population, needs assessments and formative research are needed to inform changes in the new setting, followed by pilot testing adaptations in the population. One study found that appropriately adapting an EBI to a given setting may increase the effectiveness of the program (Highfield et al. 2015a). However, few cancer-specific studies have evaluated effectiveness of adapted EBI in new contexts (Highfield et al. 2015b).

Intervention Mapping may be a promising resource for public health planners in adapting EBIs to new contexts (Highfield et al. 2015a). Intervention mapping is “a systemic approach for developing theory- and evidence-based health promotion interventions” consisting of outlined steps comparing candidate EBIs to community program needs (Highfield et al. 2015a). Program planners make adaptations to EBIs when mismatches occur between needs and existing program protocols. Evidence-based interventions are promising within the literature and for vulnerable populations, however problems remain within their implementation and respective impacts in target communities.
3.4 Conclusion

In the context of the theoretical perspective employed for this study, the varied literature reviewed above highlight the diversity and complexity of the factors affecting breast cancer outcomes and how they contribute to the health disparities experienced by African-American women. These findings framed and informed the qualitative data collection and analyses of this study and are referenced as such. Literature reviewed support the qualitative data of this study and will be cross-referenced to show validity of Affiliate perspectives.
CHAPTER 4 AFFILIATE QUALITATIVE DATA

The purpose of qualitative data in this study is to capture the perspectives of select Susan G. Komen Affiliate staff on the factors impacting racial disparities in breast cancer outcomes and the climate in which they are produced. Affiliates provided data-driven and experiential knowledge, much of which was gathered through the Community Profile process to identify barriers, assets, perceptions, beliefs, and behaviors of the African-American women in their service area. Capturing the Affiliate perspectives brings experiential knowledge and key understandings of the community to better understand the settings in which disparities in breast cancer outcomes are produced, including the barriers and current efforts to alleviate them.

4.1 Service Area Population

Affiliates reported varying diversity within of the service area populations; some reported homogenous groups, while more commonly, Affiliates reported great variation in demographics. Service areas varied significantly from only a few counties to the majority of a given state; service areas included locations of interest outside of the selected cities and metropolitan areas. Descriptive indicators supplied by Affiliates included insurance status, race and ethnicity, poverty level, location, rural versus urban, and physician availability. An Affiliate described:

We have an extremely diverse population in that we have just about every diversity you can talk about. We're actually not extremely culturally diverse; I think in our last community profile, I think we're 88% White, so there's that, but we have some urban areas, we have rural areas, we have some frontier counties, so extremely underserved. We have some counties that 100% medically underserved, so we kind of have all the way across the gamut.

Most [communities of the service area] are relatively not diverse. Most [of the communities] are rural and high, high majority of White women. A lot of those clients are also aging and have a lot of rural barriers. Our actual Affiliate is located in [County A], which is near [the City] and the capital of the state is. That is where we do have a very diverse population. I don't have the numbers in front of me of exactly what that level of diversity
is, but we do have like an urban population, and then also a suburban population. The diversity does include Asian, Hispanic, and African-American women.

As is evident from the quotes above, for many Affiliates, knowledge was drawn from the whole of the service area with focus on African-American women dispersed throughout. Demographic variability is partially compounded by the size of the Affiliate service area. Several Affiliates noted that the sheer volume of residents within cities was a strain on resources located within the service area:

And it’s just over, but over ten percent of the population of [this state] lives inside [this city’s] limits. We are [among the] 16 largest cities in the country, but we’re only [within the] the 44th largest metros. So that show that also shows how the problem compounds. Our city can’t support the poverty that all large metros have. Everybody is in the city. 165,000 or however many we have... and the majority of us are poor and there’s not enough infrastructure around to help.

Understanding the social, political, and cultural environments of each service area is a benefit of the Affiliate perspective in situating data within the larger Affiliate service area and contrasting between racial/ethnic groups.

4.1.1 Service Area Population: African-American Population

In all of the sampled cities, African-Americans represent a significant portion of the population as a sample bias of the study, although some Affiliates noted racial/ethnic diversity across their service areas. A number of descriptors specifically for African-American women, included location, religion, socioeconomic status, and knowledge and were used to illuminate the circumstances of their health behaviors.
4.1.1.1 Location

Affiliates noted that African-American communities, specifically those in need, clustered in distinct areas within the service area.

We do see the highest [percentage] of minorities in [A County]. There’s a high population of African-American women and the highest population of Hispanic women is over in that county. And then [B County] also reflects some of those same demographics, so higher African-American population compared to the other service area.

I would say the majority of [African-American] women in our service area tend to live in the more urban areas. The higher population. You know we’ve looked at some of the zip codes and what not, and they tend to be more in the city versus out in the bigger suburb areas where a lot of the screening centers are popping up.

As shown in the second quote, when describing the areas in which African-American populations live, Affiliates often noted that this was discordant with where breast cancer screening services were offered. Another Affiliate states:

[This county] is a really large county and pretty much everything is in the [northern part of the city] or in the medical district, and then when you get into the [southern part of the city] where the African-American people live, there’s one screening facility and one facility that does screening and diagnostic.

This disparity in physical access and transportation burden experienced by African-Americans was noted within in the literature. Targeting transportation barriers, among others, may be especially impactful for African-American populations who travel longer distances and have poorer access to public transportation and private vehicles.

4.1.1.2 Religion

Affiliates described the importance of religion and the church as a defining characteristic of the African-American population within their respective service areas.
The African-American community is of high faith. Collectively, they are inspirational with their commitment to their religion. The majority of the African-American community is Christian. They have tiny churches and they have humongous churches. But they all have a deep faith.

Compared to other races and ethnicities, Affiliates more commonly cited African-American women as connected to the church and the congregation; this is consistently noted within the aforementioned literature. Many of the Affiliates viewed religion as an asset to the African-American community for its sense of community and resilience within a large, municipal culture of disadvantage. Utilizing the spirituality and religiosity of the African-American community as a point of intervention may improve social and community support and involvement.

4.1.1.3 Socioeconomic Status

Nearly every Affiliate interviewed in this study expressed that African-American women were more likely to be in a lower socioeconomic status within their service area. Education level, jobs held, and financial constraints were all gauges of socioeconomic status according to the Affiliates.

Education levels of African-American women were noted to be lower, specifically in the segments of the populations Affiliates reported to be the target populations or the most in need. Affiliates expressed that lower education levels were limiting factors in the types of jobs held within the community, which in turn limited financial resources. An Affiliate described the lower socioeconomic status within the African-American community as a defining feature of communities with lower breast cancer outcomes:

I think it's more socioeconomic status... It's very difficult to group African-American women into one category. It would come down to socioeconomic status... It's level of education,
it's profession, it's earning potential... You can't, it's hard to paint it with one brush, you can't.

Simply put by one Affiliate: “It’s just that it’s a poverty issue, and our poor people happen to be African-American.” The specific positions held by African-Americans were described to be hourly pay and/or outside of traditional 9 to 5 work hours with little to no benefits, such as paid time off or sick leave.

A lot of [African-American women] are hourly, so they're just not going to get paid if they're not at work.

A lot of what came out is that many women work third shift, so even having a Saturday clinic during the day is not going to help them because they still will be working... They want to put food on the table before they actually pay for the mammogram, lots of stuff.

Data previously described in the quantitative socioeconomic data (Table 1) show the prevalence of low-income households in the study cities; the data provided by the Affiliates and their understanding of the service areas contextualize the quantitative data, revealing the lived experience described by the quantitative data and reasons for the low socioeconomic statuses reported by Affiliates for African-American women in these cities and metropolitan areas. The effects of socioeconomic status are pervasive in many aspects of life and should be considered in directing the types of barriers addressed in breast health interventions.

4.1.1.4 Sources of Trusted Knowledge

Sources of knowledge of breast cancer within the African-American communities was a marked characteristic reported by Affiliates. Sources of breast health knowledge were distinctive in the African-American community and included two categories: who and where. A shared theme amongst the two categories is trust.
Who African-American women sourced their knowledge of breast cancer from distinctively varied compared to other races and ethnicities, according to Affiliates. This included doctors, first ladies of the church, friends, and family. All of these individuals were perceived to be trusted resources in the African-American community and may represent individuals who lay education training may be most effective in dissemination of knowledge. Several Affiliates noted the importance of relatability as a distinguishing feature of who serves as sources of knowledge to the African-American community, as mentioned within the literature reviewed above.

Just the trust issue again, they’re willing to share their story when they can relate to other women. That’s what we hear over and over again is that ‘I just need to be able to relate’ and be comfortable and not judged. Perception, in my opinion, perception is reality, so if you’re worried about that going in then you’re never going to be to open up.

Churches were by far the most common response for where African-American women obtain breast health knowledge. Affiliates noted churches as organizational assets to breast health education because of the social buy-in associated with presenting educational materials and programming within churches. Affiliates also reported that churches provide the trusted environment for women to feel comfortable talking about their experiences and receptive to other people’s knowledge and experience of breast cancer. Affiliates reported that African-American source knowledge from physicians, however this statement was frequently qualified by “certain physicians” or “trusted physicians”, often referring to physicians in the community who have gained rapport with the African-American community; as noted within the literature, positive patient-provider interactions mitigate perceptions of medical mistrust. Reportedly, these physicians are well-known within communities; Affiliates noted practical restraints on time and availability of providers Due to this, Affiliates reported that African-American women often turn
to other “credible” sources of knowledge such as friends and family. The benefit of these sources of knowledge as explained by two Affiliate staff:

A: I think people want to be able to relate to the messenger. I think the messenger either looks like me, or understands the community that I live within, or has come from the community. You kind of have this underlying connection to that person.

B: You feel like they’ve walked in your shoes.

A unique characteristic noted by Affiliates about the African-American community was that once a woman was to understand the breast health information, she felt it necessary to go back to her community to inform other women. However, the breast health information provided by lay individuals, who are not necessarily trained, is prone to contamination of misinformation, misunderstandings, and myths.

I think there’s more of a tendency to listen to family members, church members, and sometimes they can get good information and sometimes they do not get good information.

Several Affiliates noted that the “word-of-mouth” knowledge of breast cancer was based on previous interactions with loved ones diagnosed with breast cancer.

Anecdotally, a lot of what we hear are people talking about how it was explained to them when their grandmother died or had breast cancer, and that being the basis for their understanding of breast cancer.

Affiliate staff appeared to be increasingly aware of the value of a relatable source delivering Affiliate educational messaging and have adopted this concept as a tactic for reaching African-American communities.

I think it should certainly be a mixed delivery of African-American and Caucasian people. I wouldn’t want them to think that we’re only sending out African-Americans, but I think that it’s important for them to know that we have African-American people on our staff.
and we relate to them. But I find that I’m very well accepted in the African-American community.

Another Affiliate weighed in on the contradictions of heeding this method:

African-American women want to talk to African-American women. A lot of times, we've been told this by our board advisors a lot that they don’t want a White woman to come in and preach to them about what they need to do. On the other hand, what we try to make this a community-led program so it is kind of peer-to-peer. Then often we get in requests because they want to have a doctor come in and talk, or they want to have someone from an organization come in and talk. It sort of cuts both ways, a need for somebody to come in and be an expert, but then there's also a sense of not wanting someone outside the group to come in. That’s kind of a complicated thing.

Less frequently mentioned were Federally Qualified Health Centers (FQHC), sorority groups, beauty salons, and children’s schools. Two Affiliates named FQHCs for doing an adequate job of distributing information to the community. Sorority groups were named, as a trusted place where sensitive topics such as breast health can be discussed and resources are available. The latter two places, beauty salons, and children’s schools were places frequented by African-American women and were talked about as potential intervention sites.

Overall, educating trusted individuals within the community may be a successful form of dissemination of breast health information given the characteristics of the community described above: reliance and importance of word-of-mouth knowledge, sources of knowledge within in the community, and the need for relatability with the source.

4.2 Barriers

The Affiliates were asked to name barriers to each stage of the Continuum of Care split into two phases 1) entering the continuum through screening and 2) remaining in the continuum through diagnosis, treatment, and survivorship (See Appendix C). Barriers between these two phases did not significantly differ, with one noted exception, therefore responses were analyzed
collectively. Affiliates frequently discussed that barriers were augmented in diagnostic and cancer care services due to their chronicity. Affiliates’ perspectives on barriers to the continuum of care were frequently reported in lists; although some barriers were more influential than others, the Affiliates expressed that it was the culmination of all the barriers on the list that made breast health a low priority within the African-American population. These barriers were analyzed using the socioecological model framework.

4.2.1 Intrapersonal factors

Intrapersonal barriers, according to the socioecological model, include barriers relating to the individual level of influence such as behaviors, knowledge, attitudes, and beliefs (NCI 2005). Affiliates noted health, knowledge, perceptions, and competing priorities as intrapersonal barriers to breast health in the African-American community.

4.2.1.1 Health

Affiliates perceived disparate morbidity of chronic diseases in the African-American population as competing priorities to breast health. Affiliates mentioned three diseases as top health concerns for the African-American population: diabetes, cardiovascular disease, and obesity. Other diseases mentioned by Affiliates include cervical cancer, mental health, and substance abuse.

Affiliates reported the collective treatment of chronic diseases within the African-American community has resulted in testing and treatment fatigue due to their burden of disease. Affiliates expressed that breast health messaging can become obscured by other health promotion and maintenance messaging such as that performed by the American Heart Association and smaller
scale diabetes initiatives. Affiliates also recognized that disparate health outcomes are not siloed in biological differences, they can be a symptom of a larger socioeconomic issue:

We were told [by Community Profile participants that] diabetes is their number one concern. I'm guessing hypertension and blood pressure and all of that, I think just comes with the territory of the kind of lifestyle they live, unfortunately, because they struggle financially and they're working so much.

Affiliates believed preventive health as a whole was not necessarily a priority of African-American women due to other competing concerns. Chronic diseases were closer to the forefront of women’s minds due to the symptomology and need for maintenance. Comparatively, breast cancer is something that may remain asymptomatic and non-painful for years. An Affiliate explained:

Like I said before, you can have a lump in your breast and OK, I doesn't hurt so you can ignore it. But if you've got something going on with your blood pressure and you've got something going on with your blood sugar, it's a major concern because it's all about our diet, lack of exercise, smoking. Basically, African-America, has a history... [of] a very high fat diet, and you have a lot of hypertension in African-Americans and that goes along with diabetes.

4.2.1.2 Knowledge

Knowledge as a barrier was visible at two levels. The first is knowledge of breast cancer symptoms leading to late-stage presentation. The second is knowledge of breast health resources for screening and navigation thereafter. The latter relates to the fragmented delivery of health care through the organizational structure, further discussed at the organizational level, which also relates to generalized knowledge of resources available.

Affiliates reported that African-American women were more likely to have a misunderstanding of the signs and symptoms of breast cancer as well as the improved prognosis if breast cancer if diagnosed at an early stage.
Well they appear with a later diagnosis because they’re late in recognizing or in facing the knowledge that they need help. And when they appear, the diagnosis is elevated.

I think that first of all you need to know what to look for. I think a lot of people out there still are focused on finding lumps. So a lot of them are surprised, a lot of people in the community in general are surprised to hear about of some of the other kinds of symptoms to look for... And just really emphasizing the fact that if you are getting screened regularly you are more likely to find your cancer early and it's easier to treat. I think it's also the education piece that breast cancer isn't a death sentence.

Both quotes show potential educational messaging points that could be leveraged to increase the perceived importance of breast cancer screening and diagnosing breast cancer prior to the presence of a palpable mass. Lack of knowledge of healthcare services and system also operates as a barrier to African-American women. Two Affiliates discussed mammography screening programs which have shown a decrease in barriers of transportation and scheduling issues:

We, as the Affiliate, fund a lot of mobile units, but then women don't know where the mobile units are, they don't know how to schedule a mobile unit. They know it exists, but they don't know how to access it, at a general level. If someone knows enough to call Komen, or call a hospital, they can get to that next step, but not everybody knows those things.

Availability, we heard a lot that they don't know what the hours are. The County Hospital, for a while, and they might still be doing this, but was having clinic hours at their breast center, they were open until, like, seven or eight, which made it a lot easier for working women to be able to go after hours.

In both scenarios, due to the lack of knowledge of the available resources, barriers for African-Americans persisted at higher levels than in women who were knowledgeable of accommodating health service programs.

4.2.1.3 Fear

Twelve Affiliates discussed fear as a barrier to screening and diagnostic testing and treatment. In the cases of screening and diagnosis, African-American women are fearful of
knowing if they have cancer, which relates to known perceptions and impacts of fatalism reviewed within the aforementioned literature. Screening mammography may show a potential abnormality and diagnostic testing may confirm the presence of a malignancy, therefore screening and diagnostic testing may be avoided.

During breast cancer treatment, Affiliates reported that African-American women are fearful of the costs associated with treatment and additional testing. Fear persists in considering treatment options as they are perceived to be painful. Additionally, African-American women fear that they will not have the social support needed to undergo and complete treatment regimens. One Affiliate described it as a “domino effect” in which women pass through one phase of the continuum and the fear translates to the next phase.

4.2.1.4 Mistrust

Ten of the Affiliates reported barriers related to individual mistrust of the health care system. Primary reasons for mistrust of the health care system were derived from the historical context of the Tuskegee Syphilis Experiment and institutionalized racism. Mistrust of the healthcare system leads African-American women to believe that their health care will be compromised or subpar due to their race/ethnicity. Medical mistrust was reported to be a distinct characteristic of the African-American population and may be a pertinent point of intervention aimed at increasing participation in health care and health promotion programming.

4.2.1.5 Perceived Susceptibility

Some Affiliates reported perceived susceptibility as a barrier to screening uptake, while others stated that African-American women understood their risk but were not able to act
appropriately to mitigate risk; yet another group of Affiliates described that it was dependent on the demographics of the person, if they accurately understood their risk of breast cancer or not. Consensus was not obtainable in these responses, despite the noted importance of perceived risk as an indicator of screening behaviors.

Of the Affiliates who believed risk perceptions were too low, perceived susceptibility was confounded by the understanding of breast cancer as a “White woman’s disease” or an “old lady’s disease”, in which older, White women are the only ones who are diagnosed with breast cancer; this idea is indeed evident in the national racial incidence data as described above. The second group reported that African-American had a falsely inflated sense of perceived susceptibility because of the extent of breast health messaging and previous exposure to family history of breast cancer, which may shed light on the unintended consequences of health messaging previously mentioned in the literature. The third group rationalized varied perceived susceptibility based on demographics, primarily education level, positively correlating with accurate understanding of incidence.

4.2.1.6 Perceived Seriousness

Perceived seriousness among African-American women, as reported by Affiliates, was markedly high compared to other races and ethnicities. As stated by one Affiliate, previous experience with other women’s late-stage breast cancer shaped other women’s perceived seriousness:

Many people have been touched by [breast cancer] and the cases that they have been touched by have been, unfortunately often, much later stage diagnosis so the experience of being touched by it has also been ... more traumatic in that people are diagnosed in a
much later stage so the treatment modalities are ... Often require a great deal more even than an earlier stage diagnosis would.

Affiliates commonly reported high perceived seriousness as fatalism:

I would say that they do perceive themselves to be more likely diagnosed. I don't know that they necessarily perceive where they are in the continuum. I don't think that they have the perception about late stage diagnosis versus earlier stage diagnosis.

These experiences are consistent with morbidity and mortality data showing increased number of late-stage diagnoses among African-American women and increase mortality rates when compared to White women. As the Affiliate described, African-American women may not consider their clinical prognosis after a diagnosis of breast cancer. Perceived seriousness is much higher in the African-American community due to the increased exposure to late-stage breast cancer diagnoses.

4.2.1.7 Perceived Control

Perceived control relates to the control an individual has over their risk prior to diagnosis by introducing or continuing risk-reducing habits such as balanced diet, maintaining a healthy weight, breastfeeding when available, and other behaviors known to reduce risk. Affiliates reported low perceived control primarily due to limitations of socioeconomic status.

No. That's primarily because of they don't ... Often times African-American women in this community particularly see themselves as not having control over their situation, and be apathetic. I don't think they necessarily feel that they can influence their risks of having breast cancer.

Other Affiliates noted that once African-American women understood their risk of breast cancer and risk reduction strategies, they felt empowered to make lifestyle changes. Affiliates noted that at that point, African-American women were more inclined to share their knowledge
with other women to enlighten them. This was less commonly reported compared to women with low perceived control.

4.2.1.8 Competing Priorities

Within interpersonal relationships for African-American women, Affiliates noted that women take care of themselves last due to relationships and prioritization of family's needs over their own. Ten Affiliates mentioned this concept as a barrier to screening, diagnosis, and treatment. Affiliates described African-American women's health as being on the “backburner” to other more demanding and critical needs to the family. Affiliates described this decision-making by the individual:

They're the lowest possible priority, so that also impacts whether or not they are proactive in preventive healthcare.

It's just having a lack of time, or not prioritizing their health is a barrier to screening. Putting their family first, really. Focusing on their family, and their health is last on the list.

Those are, for lack of a better phrase, lax concern for their own health. They're are not in the forefront of their own lives, often, their family [is].

These specific quotes relate to the concept of women’s needs on the “backburner” as a barrier to screening, however this also translates to treatment and survivorship phases in the continuum of care, increasingly so because of the increased frequency of medical appointments that are associated with screening, diagnosing, and breast cancer treatment.

4.2.2 Interpersonal

Barriers relating to processes and primary social groups including family, friends, and peers who provide social identity, support, and role definition are referred to as interpersonal barriers
(NCI 2005). Affiliates noted caretaking responsibilities and physician interactions as the primary interpersonal barriers to breast health among African-American women.

4.2.2.1 Caretaker

Affiliates frequently cited caretaker responsibilities as barriers to obtaining care. Ten Affiliates noted either childcare or eldercare as the primary responsibility of the female in the house. Additionally, Affiliates noted that African-American women prioritize their caretaker responsibilities over breast health. Of the Affiliates who noted childcare as an obstacle, they also noted that there would be no other form of childcare available due to single-parenting, financial constraints, or prioritization of partner’s work schedule.

4.2.2.2 Physician Interactions

As previously mentioned, Affiliates described African-American women as being keen on physicians who they trust. Inversely, Affiliates described physicians who were not trusted by the African-American community as barriers. These individual physicians often lack cultural competency, lack understanding of African-American women’s perspective, or have done something to lose trust of the African-American community, which was then communicated throughout the community.

There’s a strong feeling among African-American women in the impoverished community that they are not listened to by the medical community. That they are asked a question, then their answer is not really considered. That they go and they’re going to get told something, and they’re going to get shifted from doctor to doctor and nobody’s really going to listen to them and just give them instructions. There’s a lack of... it’s confidence in them being able to be a partner in their healthcare.

The concept of relatability as a strong predictor of effective educational message delivery in the African-American community persists at the level of the provider; trust and understanding
of their daily life circumstances are critical in good patient-provider relationships for African-American women.

4.2.3 Organizational

Organizational level barriers are represented by the rules, regulations, policies, and informal structure which may inhibit or promote health behaviors (NCI 2005). The health care system was the only organizational level barrier identified by Affiliates.

4.2.3.1 Healthcare System

The health care system design is a major barrier to breast health in African-American women as reported by Affiliates. The design of the health care system is complex and lacks fluidity. Affiliates reported that the fragmentation of the various steps in diagnosis and treatment allowed for numerous opportunities for women to exit the continuum of care. One Affiliate described:

What has happened and what seems to be contributing to the alarming mortality rate is the odd way that care is delivered in [this] State, particularly in [this city]. A woman might have her mammogram at facility A, if she's diagnosed, she has her diagnostic testing at facility A and she might have her surgery at facility A, but now she needs to get chemotherapy. Facility A doesn't do chemotherapy, so she needs to go to facility B.

Who makes sure that she gets to facility B? She might get to facility B for the chemotherapy and then somebody says, you also need radiation therapy. Facility B and facility A don't do radiation therapy, she needs to go to facility C. Somewhere along the line there were some studies done in hospitals here in [the city], a woman falls off the map somewhere along that line... Any number of things can go wrong. There seems to be a school of thought that the very high mortality rate could be not necessarily because of disease or that it was diagnosed at a later stage, but because she didn't complete treatment.

Although the Affiliate describes this scenario as “odd,” analysis showed that this was not an uncommon narrative. Affiliates stated that only a few of the larger healthcare systems provided
continuous care in one location. Other barriers identified include lengthy waitlists, absence of reminder calls, lack of nurse navigation, and limited clinic hours.

4.2.4 Community

The National Cancer Institute defines community level barriers as the “social networks and norms which exist as formal or informal among individuals, groups, and organizations” (NCI 2005). Affiliates identified survivorship services, transportation, work, and financial barriers to breast health services for African-American women.

4.2.4.1 Survivorship

Although many of the barriers to screening, diagnostics, and treatment are translatable to survivorship, one theme emerged as the primary barrier to survivorship according to the Affiliates: lack of or absence survivor support groups in the community. Without close, convenient, and culturally relevant support groups, African-Americans source knowledge of survivorship from friends, family, and other trusted resources. This was perceived to be a barrier to survivorship because Affiliates noted quality of life can be decreased without appropriate psychosocial support.

4.2.4.2 Transportation

Ten Affiliates named transportation as a major barrier to screening, diagnosis, and treatment. Affiliates noted that either public transportation was not available in the communities of the service area where African-American women live, or medical facilities were significant distances from African-American communities; both increase the difficulty of reaching medical facilities for screening, diagnostics, and treatment and were consistent with travel barriers identified within the above literature.
I think that has to do with where the hospitals and health care systems aren’t located in predominantly African-American communities, so it's hard for them to get there.

When we’re talking certain neighborhoods, certain demographics of people, they might go to the community health center… most of the FQHCs do not do mammography. They might do clinical breast exams but they’re going to send you somewhere else. So that’s another appointment, another date on the calendar and you have to figure out how you’re going to get to that location. That’s multiple appointments on multiple dates, time away from work, time to try and figure out how you’re going to get there or ask for a ride, and so forth.

4.2.4.3 Work

Due to the nature of positions held by low-income African-American women, work related barriers were commonly cited by Affiliates. As previously discussed, African-American women in target communities often work hourly jobs without paid time off and with relatively inflexible scheduling.

And if you work hourly and you don’t get off days and you don’t get paid vacation, so you can’t take off during the day to go have a mammogram, even if you were to have some kind of coverage or know that you could get the Komen grant. They’re not open and you’re not able to get a mammogram and 8 o’clock at night or on the Saturday or Sunday afternoon.

In many cases, the financial need for hourly pay outweighs the benefit of attending a breast cancer screening for both insured and uninsured women; additionally, the literature revealed paid time off may significantly impact health behaviors. Several Affiliates noted the success of workplace mobile mammography delivery, however this was limited due to mobile mammography availability.

4.2.4.4 Financial

Financial constraints were a recurrent theme within barriers to breast health services reported by Affiliates. Due to low socioeconomic status of target populations of African-American women, financial constraints are ever-present in decision-making. Affiliates often cited that when
faced with a decision of health care or “putting food on the table,” the latter was consistently the favored choice. Financial constraints limited African-American women’s participation in health care in general and in breast health as well.

4.2.5 Policy

4.2.5.1 Un- and Under-insured

Rates of un- or under-insurance in African-American communities were noted to be a significant barrier mentioned by nine Affiliates. Uninsured individuals bear the burden of fully paying out of pocket costs for preventive care, effectively limiting access to screening given other competing financial priorities.

Under the Affordable Care Act (ACA), breast cancer screening is covered at 100 percent for those insured; however, cost of services needed thereafter (diagnostics and treatment) fall under the discretion of the insurance company and plan. Affiliates noted insurance coverage as a barrier after the point of screening due to out of pocket costs associated with diagnostic testing and treatment. Affiliates noted that this “gap” created a new population in need of financial support. For survivors with insurance, diagnostic mammograms are commonly prescribed for monitoring and are not covered by insurance, resulting in increased cost of survivorship services.

Inadequate health insurance instigates higher financial burden in diagnostic and cancer care services. An implication of the ACA noted by the Affiliates was the nature of the health insurance plans offered by the health exchange. These high-deductible plans require monthly premiums and large deductibles to be met prior to implementing co-insurance coverage. The
overall out-of-pocket cost outweighs available financial resources and acts as a barrier to diagnostic and cancer treatment specifically.

4.2.5.2 Affordable Care Act

As previously discussed, Affiliates noted the impacts of the Affordable Care Act (ACA) on African-American women’s access to healthcare plans; participants also noted the impact of the ACA on the medical community in their ability to evaluate and treat patients under new health insurance plans and expanded Medicaid. Affiliates reported implementation of the ACA has created barriers to breast health services due to decreased numbers of physicians accepting Medicaid and marketplace exchange insurance plans and increased outsourcing to suburban clinics. Due to the complexity of the health insurance exchanges, state and national enrollment platforms acted as barriers to breast health as Medicaid expansion was inconsistently adopted between states and platforms were generally difficult to navigate according to the Affiliates.

4.2.5.3 Medical Home

Lack of medical homes among the African-American population was also noted as a barrier to screening. Medical homes are patient-centered points of medical and non-medical care which holistically oriented to meet the patient’s needs. Additional characteristics of medical homes include accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective (Dept. of Health and Human Services N.d.). Medical homes were considered a policy issue due to their tie to insurance status, policy promotion of established care, and overall availability of medical homes. To some degree, medical homes were related to lack of insurance, as one Affiliate explained:
Well first of all, if you don’t have any health insurance, then you’re really in a bind. You
don’t have anybody to write any order for a mammogram because you’re not seeing a
doctor unless you’re desperately ill. You’re not getting that preventive care that you
need. And even with some of the insurance or the insurance-like plans that are offered
here, you don’t have full coverage, so you end up paying a lot out of pocket.

Affiliates generally agreed that lack of a medical home led to later stage at diagnosis, decreased
screening frequency, and increased use of the emergency department; these understandings are
consistent with poorer breast cancer outcomes previously noted in the absence of established
physician care.

4.3 Affiliates as Mechanisms of Action

Komen’s Affiliate network serves as the grassroots basis through which community-based
actions are performed. Affiliate offices are the “on the ground” network of both staff and
volunteers fulfilling the community-based mission of Komen, while Headquarters conducts
national and international efforts, commonly referred to as “mission work”. Affiliates acting as the
mechanism of action was prominent in descriptions of the role they serve within the Komen
organizational structure. The various actions of the Affiliate include local granting, community
outreach, involvement in community partnerships and coalitions.

4.3.1 Education

A fundamental activity of the Affiliate network is education through community outreach
and provision of educational materials to build awareness and knowledge of breast health.
Methods of outreach mentioned by Affiliates include educational luncheons, TV interviews,
symposiums, health fair presentations, and other forms of community outreach. Many Affiliates
noted the guiding principle of educational outreach is to fulfill Komen’s mission in ending breast
cancer and improving breast health.
Adaptation in delivery methods of educational materials and messaging was mentioned by Affiliates to meet the needs of target populations. One Affiliate described the concept change as:

We've been doing these, what I call 'one and done' education sessions for many, many years, and we are not moving the needle, [specifically in the area of highest need].

Affiliates who mentioned this need for change in education noted that education alone was not enough to alleviate disparities; if a woman had knowledge of breast cancer symptoms, but did not have increased access to healthcare, then health outcomes are not likely to be affected. These concepts are consistent with a larger paradigm shift in public health, recognizing the ecological context of health behaviors (Glanz, Rimer, and Viswanath 2008).

Although message tailoring for cultural appropriateness was mentioned in regards to numerous topics, Affiliates frequently mentioned cultural tailoring and competency in educational messaging. One Affiliate staff member noted the need for messaging specific to African-Americans:

I think that there is a need for more education around issues that are specific to African-American women living in urban areas so that they can understand their risks and the message is tailored to them. I think we try to do that but we have more to learn.

Another staff member emphasized the potential impact of tailored educational programs in saying:

I think [health education and health promotion programs] definitely have to be tailored and designed for the specific population you're trying to reach. Often times we have mass messages that are not necessarily designed or tailored for the population that needs that information...programs that are designed for African-American women who fall in this low socioeconomic status, who may have low health literacy and may not understand some of the general messages that are being conveyed.

Affiliates commonly stressed the importance of cultural tailoring at the micro-level, levels of neighborhoods and distinct populations within them, which is a necessary adaptation to ensure
the success of group educational sessions in African-American communities as noted in the literature. Combined, these ideas show the efforts of Affiliates to improve relevancy and competency of educational messaging to augment the impact of current methods and materials.

4.3.2 Collaboration

Collaboration is a fundamental component of the Affiliate network’s activities as they work to organize and collaborate with local, state, and national organizations. Collaboration reported by the Affiliates was participation in coalitions aimed at reducing breast cancer disparities. In varying capacities, a majority of interviewed Affiliates currently participate or plan to participate in coalitions. Four of the Affiliates who did not participate in any type of coalition attributed lack of involvement to Affiliate capacity and competing priorities. Collaborations were among the most common planned activities:

I will say that one of the main focuses that we have over the next couple of years is to increase those coalitions, and try to take better advantage of what others are doing well, as opposed to trying to do everything ourselves.

Coalitions varied by levels (local, city, metropolitan, and state) and by size. Coalitions include metropolitan tasks forces, state cancer coalitions, and community steering committees and advisory boards all of which partner Komen Affiliates with other community organizations, healthcare systems, county health departments, non-profit organizations, and local universities or research institutions; these coalitions were primarily aimed at decreasing breast cancer disparities experienced by African-American women by aligning committee agendas with community needs, increasing access to prescription medication, funding for cancer care, quality screening policies, and access to health care. Additional topics of the coalitions included structural barriers and technical assistance, patient navigation, screening promotion, and to build awareness of breast
cancer disparities in African-American communities. Overall, the coalitions acted as groups for discussions and to strategize for improved breast health outcomes. One Affiliate noted the activities of a task force:

We are starting a breast health task force here, specifically in [this City], to serve [this County], because that’s where we see the biggest disparities in outcomes for African-American individuals. It’s also the place where we know we have evidence-based programs on the ground that aren't reaching the target populations, for one reason or another. We’re bringing together providers, some survivors, some community members, to try and figure out what is working for everyone, to share best practices, what has gone wrong, where can we reduce duplication and increase collaboration, to make a more substantial impact in moving that needle.

The majority of Affiliates who reported disparities-focused coalitions were in their infancy: gathering data, assessing priorities, deciphering roles and functions, and generally forming the cohesion of the coalitions. Although Komen has long-recognized the issue of racial disparities in breast cancer, coalition formation may be impacted by increased awareness of disparities at a broader level. Collaboration between organizations has shown to improve health outcomes and drive health policies changes, as shown by the successes of the Chicago Metropolitan Breast Cancer Task Force in Chicago, IL (Metropolitan Breast Cancer Task Force 2015).

4.3.2.1 Convening

Among the organized partnerships Affiliates participate in, Affiliates frequently fulfill the role of convener to assemble coalitions and collaborations. Affiliates explained:

One of the primary things that came out of [Community Profile data] was that Komen is a neutral convener that can bring people together to network and at least start conversations as to what issues are happening and ways to address them.

As the Affiliate we can push funding, mobile units, but we can’t pay to have a screening facility opened. We can work as the Affiliate, to hopefully be a convener, and try to help convince more facilities to come into the community directly.
In this example, Affiliate staff directly state that Komen has a neutral position with exceptional connections within the community to bring together organizations for the common cause; this idea permeated throughout other mentions of coalitions and community organizing performed by the Affiliate staff. Affiliates convene between community groups to leverage assets for the greater good to improve health outcomes.

The flexibility, and in some cases fluidity, of the Affiliate as a participant, convener, and funder allows for Affiliates to fulfill the various roles to support coalition initiatives as needed:

We kind of helped found that group. It’s kind of been a makeshift of the state, the local health department in that county is coming regularly and then a couple of other groups... I think out of that group is where we’ll see navigation coming along. That may be the point where Komen becomes more of the funder rather than a participant, necessarily.

Interchangeability in roles allows for Affiliates to actively work in promotion and steering and to financially support specific services as needed to alleviate the barriers identified and prioritized by the coalition.

4.3.3 African-American Focused Programs

More than half of the Affiliates noted programs that specifically serve African-American women. These programs included Worship in Pink/Pink Sunday and include culturally tailored information in a faith setting.

Affiliates reported the success of faith-based programs is partly dependent on the uptake of the program by key gatekeepers in the church such as the health ministry, first lady, and pastor. In some cases, African-American community volunteers and interns have served as liaisons to the African-American church communities as an “in” for the Affiliate and programming; the
effectiveness of utilizing gatekeepers as a means of increasing community participation is evidenced in the intervention literature, specifically in CBPR methodologies.

As noted by one Affiliate, the programs are not universal among the Affiliate network and vary in implementation:

Almost every Affiliate seems to use Worship in Pink, but we all have different versions, we all have different ways of doing it. Some of us even call it different things. It seems to be really well-liked, so I would think that systemizing that program somehow and making it an actual program that Affiliates could deliver, but is shared. We could share the materials and not necessarily have to all create them from scratch. It would be something that would be nice. Some of us have already started sharing our resources with each other and kind of going off of them and doing stuff like that so we're not all recreating the wheel, and I just wish we had a standard protocol for that program.

Variability in implementation can be beneficial in allowing cultural tailoring to a specific African-American community; however, as suggested by the Affiliate staff, standard protocol or resources for the basis of the program may improve outcomes and uptake within the community. One Affiliate who reported particularly successful adoption stated:

In the last three years we built that program from about 6 participating churches that were mostly White, to specifically tailored, culturally competent information for Black churches in our area...We grew that from about five or six, like I said, mostly White churches to this year, to over 54 churches. Although, those are not all in Black churches, because we actually do two things: we reach rural White churches and urban Black churches. They kind of are tailored each separately.

Furthermore, the Affiliate attributed the success of the program to a culturally relevant form of education: church hands.

In the Black churches, we do church hands, which we've found to be a really effective way in leading information that will kind of trace the community because it'll be used to get home, left in church pews, and we put educational information and linkage to building that program to try and link people to services if they have barriers, with phone numbers to call if they need help and things like that.
This type of educational delivery targets the high value African-American communities have shown to place on religion and spirituality, as noted in the literature. Other Affiliates reported as many as 376 total churches involved over a six year timeframe. Widespread usage of faith-based interventions implemented by Affiliates was reported with positive, non-quantified measures.

4.3.4 Advocacy

Another core activity of Komen, performed at both the Affiliate and national level, is advocacy. Advocacy engages public policy makers to prioritize breast cancer at the federal, state, and local levels and increases “access to affordable, high quality breast health, and cancer care services” (“2015 Advocacy Priorities” 2015). Six of the sampled Affiliates noted advocacy in the mission activities. Advocacy was mentioned by the Affiliates one, two, and three times at the local, state, and national levels respectively. Additionally, topics of advocacy included oral parity, access to cancer care, and Medicaid coverage of treatment regimens. Focusing organization-wide advocacy on breast cancer disparities has the potential to impact access to cancer care resources for vulnerable populations, such as African-American women. Increasing health equity through policy change is a channel to supplement lower-level interventions performed by the Affiliate, by Headquarters, and through granting.

4.3.5 Grants

The Community Profile process uses quantitative and qualitative data to align Affiliate granting priorities with areas or populations at highest risk of not meeting Healthy People 2020 targets for breast cancer mortality and late-stage diagnosis. Grantee activities vary by area to appropriately support the women in need within the respective service area. Reported grant
activities include: education sessions, screening, diagnosis, treatment, clinical reminders, patient navigation, and psychosocial support services.

The function of Komen Affiliates as individual funders connects Affiliates to the community through shared goals with grantees. Numerous Affiliates noted that grantees, such as hospitals, community organizations, churches, and researchers were not only grantees, but also partners in the cause:

I don't know if I would call them coalitions or collaboratives, but we fund a number of grantees. We consider them our partners; we give them the funding to be able to do these programs that they carry out ... we fund a number of grantees that target the African-American communities.

The majority of Affiliates named granting as the primary mechanism through which they carry out mission work. Many of the Affiliates reported that grantees in their area focused primarily on providing medical services, i.e. screening, diagnostics, and treatment. Affiliates attributed this need to products of health care policy creating new populations requiring financial assistance for diagnostic or cancer care. One Affiliate discussed this funding priority, post-implementation of the Affordable Care Act:

This is what's been an interesting development since the passage of the Affordable Care Act. You see a lot of low-income individuals enrolling into these plans, where they have low premiums but very, very high deductibles. Screening, of course, is covered under the essential health benefits, so theoretically they could go in and get their mammogram and not have to pay a dime, but if they actually need further diagnostic testing, their deductibles are so high that they can't actually afford to move forward in the process.

A lot of the grantee programs that we fund, where primarily they targeted the uninsured, are now shifting to this, what I call new gap population of the under insured, where they have insurance, but it's not sufficient or substantial enough to actually meet their health needs in that moment.
In areas with high levels of poverty and in states where Medicaid was not expanded under the Affordable Care Act, Affiliates have continued to fund screening mammograms, ultrasounds, and diagnostics:

This Affiliate because we are in such a poverty stricken area, for the last five years has focused on funding mammograms, ultrasounds, diagnostics, and a little bit of treatment. We are the only providers outside of the U.S. government and insurance companies who provide funding for mammograms. [This state] in effect does not have the Affordable Care Act. There are no other grant providers or fund providers if you do not qualify for the breast and cervical cancer program, [this state’s] version of Medicaid or have private insurance.

Without other forms of assistance for women in need of services, Affiliate’s priorities remain in funding medical services. In areas where the uptake of marketplace insurance policies have increased the number of insured, Affiliates reported that they were working with grantees to move away from fragmentation in healthcare to increase of care within the service area.

We don’t expect every grantee to provide the entire continuum of care because that’s just impossible... but we do expect them to assist with navigation if they do not provide the entire continuum. They can’t just say, ‘You have a suspicious finding, you need to find somebody else who can do a diagnostic test.” We expect them to link the patient with the next step.

Overall, granting performed by the Affiliate appears to be changing to appropriately meet the needs of the community under a variety of circumstances.

4.3.5.1 Screening Promotion

Screening promotion within the African-American community specifically refers to the coordination of screening mammography and clinical breast exam services. Five of the participants specifically described the Affiliate coordinating services through grants and with community organizations to bring services to the community via mobile mammography and referrals to
radiology centers or physicians; an additional participant noted that this was a previous activity, however it was no longer in place due to unavailable equipment.

4.3.5.2 African-American Focused Grants

Thirteen Affiliates named specific grants serving African-American women as a part of their mission work. The Witness Project (Erwin et al. 1996) and other evidence-based programs were mentioned as grantee activities within the community. Other grantees noted that while grants are not restricted to African-American women, that is primarily who they serve because of the specific locations that they target. Grants are frequently implemented in low-income, underserved populations that include both Hispanic and African-American women. One Affiliate noted that although priorities clearly instruct grantees to prioritize African-American women, this may not always be the case:

I can just say from our community grants... African-American women have been the target population. And so that’s been a focus of our community grants. We try to push funding towards that. But then when we get back who our grants serves, it’s usually about 57 percent Hispanic women. So from our grantees, we hear back that the Hispanic women just flood to the mobile units through strong word of mouth through the communities... So a lot of our grantees overwhelmingly see Hispanic women even though the focus and what’s been identified as the need is African-American women.

In another service area, an Affiliate reported a similar scenario in educational programming:

We've had all these evidence-based programs in practice for many years to try to reach [African-American] communities, but like I said, they will educate African-American women, but they're screening White women. The people that they're educating aren't motivated to actually go get the screenings, for one reason or another.

Although this is not a generalizable finding for all Affiliate granting, it does raise concern for the impact of funding on the intended population. Funding priorities and grant outcomes may require
evaluation to ensure grant activities are appropriately implemented; the importance of outcome
evaluation is high in assessing the effectiveness of the programming, including populations served.

4.3.6 Capacity

A marked difference amongst Affiliate interviews was capacity of the Affiliate in relation to
budget, staffing, partnerships, and other variables increasing the reach of Affiliate mission work.
This information was both implicit and explicitly stated by Affiliates and may influence the
potential impact of the Affiliates in their respective areas.

A common indicator of Affiliate capacity was the reported proximity to large or well-known
health care systems, including academic and/or hospital-based research institutions; this may be
due in part to an urban sample bias, as these types of institutions more commonly reside in large
metropolitan areas. Oftentimes Affiliates were in partnerships or granted with these institutions
and felt that they were an asset in providing needed resources to the communities, innovative
research, and increased funding and availability of services.

It's so unique that we have so many resources. It's a big city and we have so many health
care systems and so many hospitals, so many clinics. It's just baffling that we still have such
high breast cancer disparity rates here.

I think there's something upwards of like 200 places where you could go and get screened...
We have, I think, 18 different FQHC locations, we have two free clinics, a couple patient-
centered medical home organizations. We call it [a] conundrum, where there are all these
services, all of these evidence-based programs readily available to people, including
programs that cut down the costs and will enroll you in insurance and the people who need
them the most aren't accessing them.

Both of these quotes illustrate the benefit of having access to sufficient and proficient
health care systems within close proximity to the Affiliate, although the impact is less than desired.
Affiliates reported increased capacity through partnerships and referrals to health care systems as
needed, overall strengthening the resources of the Affiliate and their impact on breast cancer outcomes.

A staple of the Komen organization is the involvement and reliance on community volunteers, often breast cancer survivors and co-survivors. Affiliates mentioned two ways in which volunteers increased their capacity: supporting increased workload and increasing community outreach. One Affiliate mentioned volunteers as a way to augment the impact of a small Affiliate staff:

We have one of the best volunteer organizations, I think. Everything is done by volunteers, the majority of the work. We have a very small staff but they do a very good job... In our community profile, we try to make sure that we look at what our priorities are every year and we make sure that we target those top minorities in meeting our goals and objectives. Some Affiliates have developed programming to educate volunteers so that they may speak on behalf of the Affiliate:

We have the Komen Education Ambassador program, so we have individuals that are volunteers that are trained to go out and speak on behalf of [the Affiliate], about Komen, about [the Affiliate], and of course about breast health, education and awareness. And we will have them in all 13 counties in the next couple of years, but we've had this ambassador program for a few years.

Another Affiliate mentioned a similar Komen lay educator program as a means to increase the cultural relativity and audience receptivity of educational outreach:

But now when the opportunities come to us, sometimes we'll say, 'Gosh, I can go out and do this talk, but wouldn't it be more impactful if [Tonya Banks] gave this talk instead?' Then I would call her and say, ‘Hey, can you come do this talk on behalf of yourself and the Sisters of Promise?’; and sure, she'll do it. That kind of thing.

Including culturally familiar individuals in the delivery of health education is noted within in the literature as an effective means of delivery. In this specific case, the affiliate hoped to increase rapport and impact on the audience by having a community member, who happened to be racially
concordant, go to speak at an engagement rather than the Affiliate staff; this was perceived as a means to increase cultural competency.

These two types of assets show potential for an increase in capacity for each Affiliate. Augmenting existing activities and programs by partnering with community resources and community members may help to expand the impact of current Komen Affiliate programming.

4.3.6.1 Affiliate Limitations

Limitations significantly varied between Affiliates; limitations included staffing size, funding decreases, and program issues. These factors were perceived to limit the impact of Affiliates on breast cancer outcomes at varying degrees. Conservative staffing at the Affiliate level is common due to the nature of non-profit organizations. Komen’s funding as a whole has decreased by nearly $150 million between fiscal years 2011 and 2013 (Susan G. Komen 2014), causing fewer grant funds to be dispersed. With these ideas in mind, an Affiliate explained:

We have implemented and have available to the community a resource for Worship in Pink, so for the communities who want to take on breast health in a more specific, targeted way. Unfortunately, because of our staffing size and other requirements, we have not been able to go out and actually implement that particular program as a specific initiative to focus on the African American community. It’s something that’s available, but we haven’t been able to really implement it.

In some cases, drops in funding at the Affiliate level have caused Affiliates to become more resourceful in the ways in which they carry out mission work.

So our grant funding has significantly decreased since 2011, so we wanted, as an Affiliate, to figure out how else we could work within the breast health community without just being a bank to people, without just writing a check.

Affiliates commonly mentioned decreased funding in the context of granting. Several Affiliates noted issues with screening and diagnostic programs including failure of mobile mammography
units, lack of awareness of Affiliate-funded cancer care programs, and screening uptake by individuals other than the target population.

4.3.6.2 Expansion

The theme of expansion is evidence of planned progress by the Affiliates to better address the needs of the service area and the African-American community and grow current successes. Planned expansion was evident in nine of interviews with the sampled Affiliates. Expansion refers to the Affiliate’s plans to improve existing programs and priorities, data measurements for increased accuracy, and to discover best practices through the assessment process.

The concept of assessment resonated throughout planned Affiliate expansion. A total of 16 Affiliate interviews cited mechanisms of assessment to improve impact of programs, including in-house and grantee programs. Mechanisms of assessment included pre- and post-tests at educational events, altered surveys to improve measurements, assessment and negotiation of Community Profile data, formative community assessment, analysis of grant data, and improved outcome measurements. In the context of improving grantee outcome assessment, an Affiliate explained:

Even after the education session, if they sign up and get their mammogram that one year, no one here is even tracking data to see if those women are coming back. [Grantees] are just trying to reach their target numbers; it doesn't matter who it is. We're really trying to reframe that conversation.

In the context of community educational programs delivered by the Affiliate, an Affiliate noted:

An example of that is with our Worship and Pink program, we've been successful in really building relationships with these churches...That's been successful, but then we had a follow-up after we have the [Worship in Pink] program in November we go back and meet with the people and ask them how it went and what we should do next year to improve it. It's kind of a community-based participatory program.

Another Affiliate confirmed the benefit and intentions of a similar evaluation protocol:
I would say every year we want to continue to grow Pink Sunday and expand upon Pink Sunday. This is why we do the evaluation.

Through these expansion, the impact of each Affiliate is augmented and has the potential to improve effectiveness and reach of current and future Affiliate activities.

4.4 Affiliate Suggested Interventions

Potential and actual interventions mentioned by Affiliates were reliant on several core ideas to increase the effectiveness of the programs. First, successful breast health interventions are not one step, at minimum, they navigate patients to the next step, i.e. screening to diagnostic or treatment to survivorship; this idea is consistent with the increasing focus on coordination of care in models such as patient navigation and medical homes. Second, successful interventions do not create additional burden for participants; they alleviate barriers while being built-in to other aspects of social and daily life. This is imperative in targeting vulnerable populations who have little expendable time such as paid time off. Thirdly, interventions must be culturally tailored to the specific population at-hand, a resounding notion among noted, successful interventions. Lastly, when appropriate, community members should be engaged in the decision-making and the steering of the programs so that there is community investment in programs, as utilized in CBPR methodologies. These are the core values of successful interventions as described by Affiliates.

4.4.1 Education

As identified by Affiliates, educational intervention can be used to increase understanding of risk of breast cancer and importance of screening in the African-American community. Specifically, educational messaging needs to be tailored to the “microgroup” of women to whom it will be delivered. Tailoring should be performed based on socioeconomic status, perceived
barriers, and cultural knowledge. When messaging is delivered in-person, it should be from a lay health educator, doctor, or a credible source who is relatable and understanding of the context of everyday life and barriers specific to low-income, low health literate African-American women. Messaging suggested by Affiliates includes breast self-awareness, clinical risk, screening guidelines, early detection, risk reduction strategies, and available resources. Affiliates noted the benefits of beginning education at younger ages, including high school aged girls.

Moreover, educational messaging should be ever-present in the media and throughout the year, rather than focused in October, breast cancer awareness month. Specific media outlets, including social media, should be chosen based on audience demographics to decrease fatalism and increase perceived benefit of screening mammography. Education should also be targeted to places frequented specifically by African-American women, such as beauty salons, churches, and schools. Education remains a fundamental component of intervention, however in nearly every context, it should be paired with an additional level of intervention according to the Affiliates.

4.4.2 Mobile Mammography

Mobile mammography was cited by six Affiliates as an appropriate intervention for African-American women to increase screening uptake; mobile mammography is a grantee activity, not performed by the Affiliates themselves. Mobile mammography alleviates transportation issues such as inadequate public transportation and long distances to screening facilities. Affiliates reported that mobile mammography performed at places of employment are ideally partnered with employers to allow women to leave work for screening, effectively eliminating work related barriers. Partnering employers, mobile mammography, and insurance companies could lead to
comprehensive employee wellness plans. Mobile mammography was also suggested to be performed at predominantly African-American churches, a location identified as a trusted place.

The versatility of mobile mammography decreases barriers and increases convenience. According to Affiliates, successful mobile mammography implementation included educational sessions prior to screening appointments and followed with navigation as needed. Mobile mammography sites should be well communicated to the intended audience with clear scheduling instructions.

4.4.3 Medical Home

Several Affiliates mentioned the concept of a medical home as a way to improve screening uptake and adherence to recommended screening guidelines. Medical homes, as described by Affiliates, are places in which patients make contact with the medical community and are treated comprehensively. An Affiliate explained, if a woman visited her dentist, the dentist would inquire about the woman’s last Pap smear and screening mammogram, i.e. preventive health care, effectively treating the whole person rather than one part. This would increase the accountability of the patient and act as a reminder and maybe delivered by nearly any point of contact with the health care system. Affiliates described limited patient-provider interactions as the primary barrier to medical homes and comprehensive care.

4.4.4 System Fragmentation

Affiliates noted intervening on structural barriers as an integral part of a successful breast health program. Affiliates suggested improvements such as extended clinic hours, sliding scale fees, childcare, and non-traditional financial support, including utility bills, mortgage and more,
are ways to decrease barriers to screening, diagnosis, and treatment. Affiliates noted that it is not just the content of the programming that needs to be effective, but also the barriers that are decreased through the program delivery.

4.4.5 Community Assets

Community assets were among the unique characteristics identified within the African-American community. Assets identified by Affiliates include strong religiosity, medical professionals in community, proximity to health care, and dependence on narrative knowledge. Strong religiosity brings women to church frequently, and as one Affiliate described church members become a “captive audience”. Dependence on narrative knowledge means that women’s stories could have a powerful impact on the community, such as stories of survivorship and early detection. Not all African-American communities are long distances from urban health care; those that are close in proximity to major healthcare systems should be connected to the community to effectively deliver screening and cancer care. Lastly, several Affiliates reported that the African-American community had numerous individuals working in healthcare; these individuals are potential sources of accurate health information for the community or other types of advocates. This was not a finding within the literature above, rather a shortage of racially diverse healthcare workers was noted nationally. Community assets identified by Affiliates may inform future interventions in the African-American community.

4.4.6 Navigation

Navigation was among the most commonly mentioned intervention to help women remain in the continuum of care. Eighteen of the sampled Affiliates discussed navigation as a potential intervention to increase fluidity between stages of the continuum of care. The defined role
Navigators significantly varied by Affiliate with definitions ranging from solely social work positions to genuine friends of the patients assisting women in every aspect of cancer care and life, which are consistent with the varying models of patient navigation.

According to Affiliates, navigators should begin assisting women at the point of screening. Navigators should follow-up with no showed screening appointments in attempt to reschedule. After screening is performed, navigators help women understand their mammography reports and what the physician has said; this may improve the noted misunderstandings of mammographic findings in African-American populations.

If diagnostic testing is indicated, navigators guide the patient to the appropriate resources for funding, transportation, childcare, and other services as needed. Upon diagnosis, a navigator may help with the logistics of diagnosis and treatment on long-term implications on transportation, finances, home life, and more. If diagnostic testing returns negative, the navigator follows-up with annual reminder calls for screening.

During treatment for breast cancer, the navigator is “coordinating the big picture,” according to one Affiliate. Navigators make sure the patient attends each appointment and each treatment and follow up when patients do not attend. Navigators assist patients in finding any additional resources needed during treatment to decrease barriers and competing priorities.

During any part of the process if emotional support is required the navigator provide such, physically sitting with the patient or holding their hand were common examples; emotional support is not well-documented in the literature and may be unique feature of the Affiliates’ understanding of navigator duties. Affiliates described the navigator herself as someone who has
a calling for the position and a partner in the patient’s care through survivorship. Nurse navigators are easily accessible points of contact who have sufficient time to befriend the patient and gain their trust through support of all natures.

CHAPTER 5 RECOMMENDATIONS AND DISCUSSION

5.1 Recommendations: Promising Practices

To marry the interventions within the literature and Affiliate perspectives and suggestions on interventions, “promising practices” are identified with inclusion criteria of positively impacting breast health outcomes of interest with culturally and socially appropriateness. Themes between promising practices became evident throughout the literature review and Affiliate interviews. The predominant finding from the review of existing literature and qualitative data is that interventions must be culturally appropriate in content, setting, expectations, and delivery; components which may not necessarily be integral components of existing programming and practices. As suggested by Pasick, Hiatt and Paskett (2004), essentially all major types of community-based screening interventions have been effective in some studies; however, no intervention works for all individuals or in all settings. Utilizing Affiliate insights may help to direct intervention messaging and direction as a mediating perspective between clinical research and community practice.

5.1.1 Patient Navigation

Patient navigation was originally developed in response to findings from the American Cancer Society National Hearing on Cancer in the Poor in 1989 (Freeman, Muth, and Kerner 1995). Since then, the Freeman Model of Patient Navigation has been recognized as an evidence-based intervention, increasing screening uptake, decreasing time for diagnostic resolution, increasing adherence to mammography guidelines, and increasing timely treatment initiation (Robinson-
White et al. 2010; Frelix et al. 1999; Freeman, Muth, and Kerner 1995; Marshall et al. 2015; Battaglia et al. 2007). However, due to inconsistencies in implementation this intervention will be discussed as a promising practice to explore the varying models currently used for patient navigation. Although the prescribed role of patient navigators fluctuates in application (Frelix et al. 1999; Freeman, Muth, and Kerner 1995; Marshall et al. 2015; Battaglia et al. 2007), the term patient navigator has become an umbrella term generally describing a patient advocate working with patients suffering from one specific disease with the goal of improving outcomes through reducing delays in the continuum of care and identifying and reducing barriers to accessing cancer care (Wells et al. 2008); these navigators are typically assigned within health institutions at the point of abnormal mammogram.

The Commission on Cancer mandated as of 2015 that all accredited care centers will implement patient navigation (American College of Surgery Cancer 2012). Pertinent limitations of patient navigation assessment remain in the form of lack of standardized outcomes for the varying models of patient navigation. Disambiguating the duties and scope of patient navigation is key in the success of the intervention. Reviews show that patient navigation as a whole focuses on intermediate outcomes of screening and diagnosis rather than survival and mortality (Reiter et al. 2014; Braun, Allison, and Tsark 2008); shifting the focus from measurable short-term outcomes to long-term outcomes of survival rates could improve the understanding of the effect of patient navigation on breast cancer disparities in African-American populations.

5.1.1.1 Freeman Model of Patient Navigation

Dr. Harold Freeman developed the first patient navigation program in Harlem, New York by focusing on barriers to timely care between the point of a suspicious finding and the resolution
of the finding by further diagnosis and treatment (Freeman, Muth, and Kerner 1995). Current implementation of the Freeman Model of Patient Navigation includes outreach for prevention and early detection and navigation through diagnosis and treatment, continuing through survivorship to end of life (Freeman and Rodriguez 2011). A 22-year assessment of Freeman’s Model of Patient Navigation implemented in New York City and combined free and low-cost mammography found patient navigation to dramatically improve diagnoses of early-stage breast cancer (6 percent versus 41 percent) and five year survival rates (39 percent versus 70 percent) (Freeman and Rodriguez 2011).

5.1.1.2 Patient Navigation Research Program

The National Cancer Institute developed the Patient Navigation Research Program (PNRP) to assist vulnerable populations in obtaining timely diagnosis and initiation of cancer treatment, increased patient satisfaction and care, and cost effectiveness for breast, cervical, colorectal, and prostate cancers (Freund et al. 2008). Secondary outcomes measure completion of therapy, quality of care through evaluation of therapeutic regimens, and patient communication with navigator. Patient navigation within the PNRP model is defined as “the logistic and emotional support needed to achieve completion of diagnostic and treatment care” beginning at the point of abnormal cancer screening or new cancer diagnosis (Freund et al. 2008). The goal of patient navigation is “to facilitate timely access to quality care that meets the cultural needs and standards of care for all patients” (Freund et al. 2008). Notably, patient navigators according to the PNRP model provide emotional support and teach health literacy and medical advocacy.

PNRP navigators have shown to effectively reduce structural barriers to health care, particularly effective in low-income and racially diverse populations (Rodday et al. 2015). A smaller
study found navigated patients with social service barriers experienced longer delays than patients without barriers (Primeau et al. 2014). Recognizing the impact of social service barriers (such as lack of insurance, financial, housing, employment, dependent care, adult care), specific barriers may need to be addressed to fully realize the effect of navigation on timely diagnostic resolution (Primeau et al. 2014). In another study, patient navigators identified two-thirds of patients with breast abnormalities reported barriers compared to half of women with cervical abnormalities (Katz et al. 2014). Patient-focused barriers (fear, attitudes, perceptions of testing and treatment) and systems-level barriers (communication with providers, literacy, and language) were the most commonly reported type of patient barrier (Katz et al. 2014). Patients with established medical care may be less likely to benefit from patient navigation, as they identify barriers to health care less frequently (Paskett et al. 2012). Understanding trends in the success of patient navigation is essential in understanding appropriate implementation settings and adaptations.

PNRP navigation may be more impactful in settings with limited resources and a history of patients with poor follow-up rates (Freund et al. 2014; Dudley et al. 2012). Navigated patients received significantly quicker diagnostic resolution, particularly requiring tissue biopsy, compared to non-navigated patients at a publically funded hospital in Washington, DC (Hoffman et al. 2012). Additionally, PNRP navigated patients were more likely to receive hormonal therapy than non-navigated patients, while breast radiation therapies were not impacted by navigation (Ko et al. 2014). Patient navigation may increase participation of African-Americans in cancer clinical trials (Ghebre et al. 2014; Steinberg et al. 2006). Navigation may be more impactful in settings with limited resources and in populations with poor follow-up rates (Freund et al. 2014; Dudley et al. 2012).
Among the PNRP case studies two unique interventions showed promise in impacting breast cancer outcomes. Dudley et al (2012) combined the PNRP model with Promotoras, or lay health workers, to effectively increase the case load compared to patient navigation alone. The navigator focused on interventions aimed at alleviating barriers to health care, while the Promotora facilitated dialog between the medical provider and the patient and assist with cultural and socioeconomic barriers (Reinschmidt et al. 2006). Findings revealed a decrease in time from definitive diagnosis to initiation of treatment for racially diverse women (Dudley et al. 2012).

A second unique study combined PNRP navigation and patient activation, also known as communication coaching, to impact diagnostic and treatment delays in breast cancer care (Hendren et al. 2010). Patient activation is an individual intervention aimed at empowering patients to ask more appropriate and relevant questions during medical visits and may be a means of improving cancer care for disadvantaged patients (Harrington, Noble, and Newman 2004). This model delivered patient navigation and patient activation simultaneously among study participants at either low- or high-intensities based on the number of barriers the participant identified, however data are not yet available (Hendren et al. 2010).

5.1.1.3 Community Health Workers

Community health workers (CHW) are healthcare workers often working within the communities. In patient navigation roles, these individuals conduct community outreach to educate target populations about screening, arrange for screening mammography, and facilitate initiation of treatment (Hunt et al. 2015). Navigator-patient relationships bolster social support and foster strong patient-provider relationships (Jean-Pierre et al. 2011). Wells et al (2011) found CHW were effective in increasing mammography uptake in urban settings when the CHW was
racially concordant with the targeted population. Acceptance of community-based CHW navigators is independent of socioeconomic status and significantly increases with age and increase perceived risk (Halbert et al. 2014).

Bone et al (2013) in a randomized controlled trial implemented community-based participatory research methodologies to guide a CHW navigation intervention. This study found women in the intervention group were more likely to be up-to-date with self-reported mammography screening; the effect of the intervention was strong among women who were not up-to-date with mammography and also found a higher loss to follow-up rate for low literacy women (Marshall et al. 2015).

5.1.1.4 Nurse Navigation

Nurse navigators work to ensure timely diagnosis after screening abnormality. Key activities of nurse navigators include national training or certification, arranging interpreters as needed, reminders for appointments, and documenting missed appointments. In an underinsured, low-income population, 81 percent of study navigated participants received diagnosis in 60 days or less (Palmieri et al. 2009). Basu et al (2013) found with nurse navigation, diagnostic resolution was significantly shorter in older women compared to younger women. Additionally, nurse navigation has shown to have a positive effect on African-American cancer clinical trial participation (Holmes et al. 2012).

5.1.1.5 Community-Based Participatory Research in Patient Navigation

Successful patient navigators are individuals who are “culturally familiar”, i.e. cultural insiders who are familiar with every day, population-specific barriers to health care and culturally sensitive (Vargas et al. 2008). Numerous studies combined methodologies of community-based
participatory research (CBPR) to involve community stakeholders and medical personnel in study design and project steering (Freund et al. 2014; Steinberg et al. 2006; Halbert et al. 2014; Braun, Allison, and Tsark 2008; Bone et al. 2013; Fleisher et al. 2012; Drake et al. 2015). These studies were commonly informed by community steering committees and implemented community-based, lay navigators nearly unanimously.

5.1.1.6 Patient Satisfaction across Models

Patient satisfaction is a key outcome in the quality of care delivered by the navigator. A telephone-based PNRP model found no improvement of patient satisfaction within the African-American participants (Post et al. 2015), however a Freeman Model of navigation was associated with increased patient satisfaction (Ferrante, Chen, and Kim 2008). Fleisher et al (2012) found a PNRP navigation program to significantly impact patient satisfaction of care. As evidence shows, patient satisfaction varies by type of patient navigation implemented and may further impact loss to follow-up (Thind, Liu, and Maly 2011).

5.1.2 Usage of Patient Narratives

Patient narratives are becoming increasingly utilized in clinical medicine to improve patient-provider communication (Charon and Wyer 2008; Kalitzkus and Matthiessen 2009). Narratives recount patient experiences with health care and provide meaning, context, and perspective for a patient’s given predicament (Greenhalgh and Hurwitz 1999). The utilization of narratives in the African-American community in educational materials was identified as a promising practice within the relevant literature for several reasons: 1) the African-American community has a rich history of oral storytelling and narratives have cultural meaning; 2) storytelling or narrations are comfortable and familiar modes of giving and receiving information.
3) narratives have the potential to change cancer-related beliefs and motivate health behaviors (McQueen et al. 2011; Green 2006; Freimuth and Quinn 2004; Petraglia 2007; Wells et al. 2015).

The effectiveness of narratives in health education and communications have shown to influence behaviors through attitudes, norms, self-efficacy, and intentions (Freimuth and Quinn 2004; Petraglia 2007; Nicholson et al. 2008; Green 2006). Narratives provide examples for behavioral change, decrease fatalism, deliver support, enhance understanding, and assist in complex decisions (Green 2006; McQueen et al. 2011). Houston and colleagues (2011) found that narratives are impactful in reducing racial disparities in disease management. Methods of dissemination such as mass media communications via African-American-preferred radio and print media are promising methods of dissemination of health messaging, while web-based educational messaging and programs may be less preferential for the African-American population (Hall et al. 2015; Santos et al. 2014). Given this information, health messaging should be cautiously and appropriately disseminated due to the findings of Nicholson et al (2008). This study found that bringing public attention to the presence of disparities within African-American communities had unintended consequences of decreasing utilization in populations with high levels of medical mistrust (Nicholson et al. 2008).

The hallmark example of usage of narrative in breast cancer is the Witness Project, an evidence-based intervention recognized by the National Cancer Institute (Erwin et al. 1996; “The Witness Project” 2015); however, additional usage of narratives in educational materials and health promotion advertising may be beneficial in prompting behavioral change. In a study assessing the effectiveness of video-recorded narratives, African-American women reported
positive feedback in assessment of topics including coping, support and relationships, healthcare experiences, follow-up care, quality of life, and treatment side effects (Pérez et al. 2013). Additionally, Pérez et al (2013) found that educational messaging was effective in African-American populations when the participant felt that the storyteller thought like them or had values similar to their own. Literature shows that African-American women prefer to hear from women who have had the same cancer, have lived through treatment, and resumed daily or “normal” life (Giese-Davis et al. 2006). Educational messaging via video-recorded or other small media narratives on varying topics of breast health have potential to increase screening uptake in low-income women (Gathirua-Mwangi et al. 2015).

5.1.3 Community-Based Participatory Research

Community-based participatory research (CBPR) is a methodology that fosters research and community capacity building, as well as promotes ownership and sustainability by mobilizing underserved communities as political and social actors in addressing cancer disparities (Scarinci et al. 2009; Wallerstein and Duran 2010; Baker, White, and Lichtveld 2001; Cardarelli et al. 2011; Rodriguez et al. 2009). CBPR is defined as a partnership approach to research that equitably involves participants, such as community members, organizational representatives, and researchers, in all aspects of the research process (Israel et al. 1998). The principles of CBPR can be used to 1) promote collaboration and participation at each stage of the research process, 2) ensure that research programs are community driven, and 3) disseminate useful results in a culturally appropriate forum (Arroyo-Johnson et al. 2015).

The collaborative and engaging nature of CBPR distinguishes it as a methodology which acts to empower and build trust between individuals and participating community-based groups.
and increases cultural competency and aligns communities and researchers to achieve appropriate outcomes (Sofolahan-Oladeinde, Mullins, and Baquet 2015; Gehlert and Coleman 2010); CBPR principles have shown to impact positively breast cancer disparities (Cardarelli et al. 2011; Rodriguez et al. 2009) and have the potential to impact clinical trial participation as well (Greiner et al. 2014; Steinberg et al. 2006). CBPR methodologies ensure cultural competency and relevancy, identify appropriate barriers to care, and overall, provide the emic, community-based perspective in program design and execution (Freund et al. 2014; Steinberg et al. 2006; Halbert et al. 2014; Braun, Allison, and Tsark 2008; Bone et al. 2013; Fleisher et al. 2012).

5.1.4 Mobile Mammography

Mobile mammography is an increasingly utilized service to reach vulnerable populations, specifically those with transportation, work, and insurance barriers. Overall, there is a paucity of literature documenting populations served by mobile mammography units (Brooks et al. 2013). One study found mobile mammography attracts women who have not had mammography screening in 5+ years and who were uninsured (Brooks et al. 2013). Available literature documents not only initial screening uptake by African-American women, but also repeat mobile mammography use (Mizuguchi et al. 2015); this is a significant finding given the African-American patient’s decreased likelihood to adhere to mammography screening. Mobile mammography data show, as expected, African-American women are diagnosed with breast cancer present at a later stage of disease (Brooks et al. 2013). The potential impact of mobile mammography lies in recruiting non-adherent patients and assisting them to remain in the continuum of care through repeat screening, a possible implication for patient navigation to be delivered with mobile mammography.
A strength of mobile mammography is the ability to partner with convenient and trusted venues such as churches and workplaces (Derose, Duan, and Fox 2002). Partnerships with trusted community-based venues may be perceived as an endorsement in the behavior and promote screening outside of the clinical context. Targeting delivery of mobile mammography could improve outreach strategies and enhance cultural competency of services (Derose, Duan, and Fox 2002).

Barriers in assessing the impact of mobile mammography derive from lack of reporting, cost, and availability. Data from mobile mammography services are poorly reported within the literature, leaving deficits in knowledge regarding populations served, frequency of mammography, interval of mammography, and clinical outcomes of populations served. The associated costs of mobile mammography are higher than traditional mammography screening due to the nature of delivery and may be a significant barrier in the sustainability of programs (Naeim et al. 2009), which inherently limits availability (Brown and Fintor 1995). Collection and dissemination of mobile mammography data are imperative in evaluating the success of implementation. Although mobile mammography offers a promising intervention for screening uptake in vulnerable populations, absence of sufficient data to evaluate consistent outcomes may be a limiting factor in funding in its current state (Mizuguchi et al. 2015); more information is needed about populations served, clinical impacts, and uptake in underserved communities. Other considerations associated with mobile mammography are the implications to access for diagnostic follow-up and cancer diagnoses, as needed (Naeim et al. 2009). Overall, data from existing mobile mammography units need to be further analyzed to definitively support mobile mammography usage in medically-underserved, African-American populations.
5.1.5 Lay Health Educators in Culturally Relevant Settings

Lay health educators have shown to increase health knowledge and encourage screening uptake when given appropriate training (Dodani et al. 2011; Quinn and McNabb 2001). Delivering messaging at culturally relevant or appropriate places have shown promise in impacting breast cancer knowledge and breast cancer screening uptake (DeHaven et al. 2004; Linnan and Ferguson 2007); lay health educators differ from patient navigators in their role as informants, rather than coordinators or health care liaisons. Peer education of African-American community members has shown to increase receptivity of messaging from lay health educators within African-American communities (Anderson-Lewis et al. 2012).

Combining lay health educators in culturally relevant settings may help to increase knowledge of breast health in African-American communities by increasing the social knowledge base. Implementing training curricula based on behavioral change theory may improve the impact of lay health educators in assisting women at the various stage of diagnostic resolution (Kobetz et al., 2005). CBPR principles may be a valid method of developing appropriate roles and training for lay health educators as a viable option for community-based lay health educator programs for outreach, education, and promotion of cancer screening and early detection (Gwede et al. 2013).

Faith-based settings for health interventions have shown to be an appropriate place of intervention for African-American communities (DeHaven et al. 2004; Campbell et al. 2007; Dodani et al. 2011). Inserting lay health educators in this setting can increase knowledge of disease and improve screening behavior and readiness for change in a comfortable environment. One study showed improved chronic disease management with the training of a member of church leadership as a health educator (Dodani et al. 2011).
Beauty salons also may be an ideal point of intervention for African-Americans for several functional and cultural reasons. Namely, beauty salons are unique and important institutions within the African-American community (Rudner 2003; Luque et al., 2014; Sadler et al. 2011). Salons are often placed within the communities that they serve and have ease of access. In the U.S., there are upwards of 300,000 salons serving an average of 150 clients weekly (Rudner 2003). Women frequent these locations as often as every four weeks, and for upwards of 45 minutes per visit. Lastly, it is not abnormal for health related topics to be discussed in this setting (Solomon et al. 2004; Linnan et al. 2001). The cosmetologists themselves also represent unique relationships with clients based on loyalty, trust, support and comfort that allow conversation to naturally occur with equal investment (Linnan and Ferguson 2007). Beauty salons are a promising setting for the training and insertion of health promotion small media and lay health educators.

5.1.6 Self-Advocacy

Patient self-advocacy, defined as “the ability to seek, evaluate, and use information to promote one’s health”, works to educate and empower patients in the clinical setting (Wiltshire et al. 2006). This varies from concepts of health literacy by encouraging the patient to become their own “activist” within their own health care and management. An increasing number of patients are seeking health information prior to medical consultation (Brodie et al. 2000; Cotten and Gupta 2004; Niederdeppe et al. 2007), however it is unclear if and when patients use this information to advocate in their medical encounter (Brashers, Haas, and Neidig 1999; Niederdeppe et al. 2007). One study noted active seeking is more influential in cancer care decision-making (Niederdeppe et al. 2007). Differences may be due to lack of medical knowledge (Borgers et al. 1993), authoritative view of provider recommendations (Beisecker and Beisecker
difficulty understanding information provided provider (Friedman et al. 2009; Cooper et al. 2006), or perceptions of providers discouraging shared decision-making (Brashers, Haas, and Neidig 1999; Vranceanu, Cooper, and Ring 2009). Reducing these barriers to create a more informed and self-advocating patient may help increase patient empowerment, perceived control, and aid in adapting to life with cancer (Hagan and Donovan 2013).

One study found that African-American women who asked questions during medical appointments were three times more likely to achieve diagnostic resolution (Kerner et al. 2003). Allen et al (2008) found that women who felt a personal responsibility to engage in their health care were more likely to achieve diagnostic resolution. These findings are consistent with African-American beliefs of individualism in health care seeking (Ragas et al. 2014; Kerner et al. 2003).

Self-advocacy can mitigate the presence of medical mistrust and discrimination in African-American populations (Deshpande et al. 2009; Ashing-Giwa 1999); specifically, self-advocacy may help mitigate perceptions of fatalism which may deter African-American women from screening and/or diagnostic resolution (Powe and Finnie 2003). Several studies have found that African-American women are less likely to participate in self-advocacy (Wiltshire et al. 2006; Elder et al. 2010), while other studies have shown no racial/ethnic differences in participation (Rooks et al. 2012; Rutten, Squiers, and Hesse 2006). Promoting self-advocacy within African-American populations may be a culturally relevant approach to improving mammography adherence and satisfaction with medical care. As suggested by Molina et al (2015), greater understanding of ways to encourage and support self-advocacy in the African-American population is warranted.

5.2 Discussion
Data collected and compiled in this study illuminate the numerous, intertwined qualitative and quantitative variables contributing to breast cancer disparities in African-American communities; no single variable is accountable for producing the observed cancer disparities, rather it is the intricate relationships between variables and the lived experience that contribute to disparate breast cancer outcomes. Improved understanding of the process through which disparities are produced is necessary to better inform and adapt public health interventions. Outlining and presenting the known factors of impact in the literature review, including quality of and access to health care and structural, clinical, and personal barriers, all illustrate the multi-faceted approach needed for successful interventions to improve breast cancer outcomes for African-American women.

Data provided by Affiliates verify many of the barriers identified and reported within the relevant public health literature. The observations made by Affiliates through community outreach, collaborations, and the Community Profile process have provided a network of individuals with invaluable, local knowledge relating to the barriers, successes, and possibilities to improve breast health outcomes in African-American women. The Affiliate perspective is an access point to a more comprehensive understanding of the context of the quantitative data and the lived experience of African-American women within their service areas. The mid-level perspective of the Affiliate Network complements the macro-level perspective of Komen Headquarters to create a comprehensive understanding of the factors affecting breast health, though variation between Affiliates in their capacity and knowledge of African-American populations suggests that there is opportunity for improving current activities of the Affiliates.
Less explored variables, noted by the Affiliates, within the African-American community are the assets of the community. Quantitative data classically dominant epidemiological research relating to breast health and risk factors, however the alternative perspective of the Affiliate, in this case, presents observational comparisons of races and ethnicities to define key differences in assets; this may be especially relevant given the consistencies in barriers within similar socioeconomic statuses (Clegg et al. 2009; White et al. 201). Identified assets may be equally as foundational and informative to health intervention and promotion models, rather than utilizing deficit based models (Morgan and Ziglio 2007). The social networking noted by Affiliates may be used to disperse educational messaging, starting in culturally relevant settings such as churches, beauty salons, and schools.

Current organizational protocols in place, such as the Community Profile, work to familiarize the Affiliates with the communities in most need for breast health services and education. The programs and services of the Affiliates highlight their areas of expertise in impacting the communities in which they operate. Marrying the identified needs of communities with the existing programming of Komen Affiliates may augment the reach and impact of Affiliates as mechanisms of actions for improving breast cancer outcomes in African-American communities.

A strength of this solicitation of the Affiliate perspectives is its ability to reaffirm the need for socioecological considerations and holistic frameworks for health interventions and research. Affiliates emphasized through their reported “lists” of barriers that African-American women have numerous factors working against them: at the individual level with health, in their interpersonal relationships and social responsibilities, in their physical communities, and as products of policies.
and of insurance companies. These lists of barriers are not likely exhaustive, but fit within the larger context effecting even the Affiliate staff as community members themselves. This grounding in their understanding demonstrates their acknowledgement of the broader social and political contexts in which health behaviors are performed and health outcomes are produced.

Documenting the effective activities and interventions utilized by Affiliate and community grantees contributes to the debate of creating ground-up or clinically-proven evidence-based interventions (Highfield et al. 2015). Affiliates reported several programs and grantee activities consistent with the promising practices identified within the literature; comparing community needs to the barriers addressed in each intervention is a key step in selecting successful interventions for a given community. These programs include patient navigation, lay health advisors, and usage of patient narratives. Although community-based participatory research and self-advocacy were not explicitly mentioned by Affiliates, fundamental components of community investment and empowerment were mentioned within existing Affiliate programs and ideologies. Affiliates reported varying roles and services of patient navigation with a common function: assisting women through the continuum of care by decreasing barriers. Differences in patient navigation models described by Affiliates may reflect lack of consistency within the literature specifying roles and tasks of patient navigators (Freeman, Muth, and Kerner 1995; Rodday et al. 2015; Hunt et al. 2015). Unifying the model implemented by Komen Affiliate grantees to target the most relevant outcomes (time to diagnostic resolutions, time to treatment initiation, or types of barriers) for African-American women may improve breast health and breast cancer outcomes.

Affiliate capacity may be augmented by increasing program sharing between Affiliate locations. Several Affiliates directly called for a formalized method of sharing Affiliate
programming or creation of a program “toolkit”, while others discussed programs they would like to implement in the future. In 2015, Komen Headquarters developed an educational toolkit for Affiliates to use with African-American populations; however, study data suggest that the toolkit has not been widely adopted and Affiliates may lack awareness of its availability. Affiliates also called for a formalization of a program sharing platform to facilitate successful implementation and idea-exchange between Affiliates may to improve the quality and quantity of Affiliate programs. Creating and successfully disseminating these types of definitive resources for Affiliates may increase their potential impact within their service area.

Increasing the accountability of each Affiliate in reporting activities addressing breast cancer disparities may help to even differences in capacity between Affiliates. This report serves as the first assessment of disparities focused activities among Affiliates. Increasing the frequency of reporting may help and encourage Affiliates in implementing new and existing programming targeted at African-American women and, again, may help to disseminate successful programming between Affiliates.

Collectively, the Affiliate Network represents significant potential for positive impact on breast health outcomes through their varying and multi-faceted activities currently in place, planned activities, and expansion. Though some points of improvements were evident in the data, such as ensuring intended populations are served and logistical and financial limitations of Affiliate capacity, the Affiliates operate within all of the cities and metropolitan areas experiencing the greatest African-American to White disparities in breast cancer mortality in the nation and therefore are assets to the Komen organization as a whole in impacting breast cancer disparities from the local level. Affiliates are connected conveners who are knowledgeable about their service
areas and the communities within them through organizational processes such as Community Profiles. Utilizing these individuals as mechanisms of change through granting, collaboration, education, and advocacy may help to improve breast health and breast cancer outcomes.

Overall, the Affiliates’ ability to leverage assets and convene with organizations to influence decision-making agendas is a powerful weight and likely a unique position Komen Affiliates. Several Affiliates noted the unique position and success of Komen as a convener, however additional Affiliates should prioritize such activities to maximize impact on breast cancer disparities within their service area. Affiliates as the mechanism of action is a meaningful phrase, implying the potential of the Affiliate Network in impacting breast health outcomes through granting, outreach, and collaboration. The Affiliate Network is a unique asset of the Susan G. Komen Foundation and should be utilized as such.

Limitations of this study center on the generalizability. Each Affiliate’s perspective was aggregated with the other Affiliates interviewed to compile one voice. Although strong similarities were present between interviews, each Affiliate had a unique perspective on the issues at hand. Interviews were limited to the experience of the staff member interviewed and their experiences in the service area and with diverse populations; this was not equally distributed between Affiliates interviewed, often coinciding with capacity. Other limitations were present in the form of quantitative data collection. Preliminary data collected indicating racial disparities in breast cancer mortality and incidence used in this study were limited to secondary data analyses, and to data representing the service area of each Affiliate, rather than the appropriate city or metropolitan, limiting the accuracy of data in study populations.
# APPENDIX A

## Metropolitan/City Population Data

<table>
<thead>
<tr>
<th>City</th>
<th>State</th>
<th>Affiliate(s) service area the City/County is located in</th>
<th>Total Population</th>
<th># of Black alone women, age 18+</th>
<th>% of Black alone women, age 18+</th>
<th># of Black alone women, age 40+</th>
<th>% of Black alone women, age 40+</th>
</tr>
</thead>
<tbody>
<tr>
<td>New York City</td>
<td>NY</td>
<td>Komen Greater New York City Affiliate</td>
<td>8,175,133</td>
<td>897,782</td>
<td>11.0%</td>
<td>538,310</td>
<td>6.6%</td>
</tr>
<tr>
<td>New York-Newark-Jersey City</td>
<td>NY-NJ-PA Metro Area</td>
<td></td>
<td>18,897,109</td>
<td>1,416,518</td>
<td>7.5%</td>
<td>848,283</td>
<td>4.5%</td>
</tr>
<tr>
<td>Chicago</td>
<td>IL</td>
<td>Komen Chicagoland Area Affiliate</td>
<td>2,695,598</td>
<td>368,161</td>
<td>13.7%</td>
<td>224,193</td>
<td>8.3%</td>
</tr>
<tr>
<td>Chicago-Joliet-Naperville</td>
<td>IL-IN-WI Metro Area</td>
<td></td>
<td>9,461,105</td>
<td>661,621</td>
<td>7.0%</td>
<td>393,392</td>
<td>4.2%</td>
</tr>
<tr>
<td>Philadelphia</td>
<td>PA</td>
<td>Komen Philadelphia Affiliate</td>
<td>1,526,006</td>
<td>273,643</td>
<td>17.9%</td>
<td>162,461</td>
<td>10.6%</td>
</tr>
<tr>
<td>Philadelphia-Camden-Wilmington</td>
<td>PA-NJ-DE-MD Metro Area</td>
<td></td>
<td>5,965,343</td>
<td>498,368</td>
<td>8.4%</td>
<td>293,966</td>
<td>4.9%</td>
</tr>
<tr>
<td>Detroit</td>
<td>MI</td>
<td>Komen Detroit Race for the Cure®</td>
<td>713,777</td>
<td>238,327</td>
<td>33.4%</td>
<td>147,100</td>
<td>20.6%</td>
</tr>
<tr>
<td>Detroit-Warren-Livonia</td>
<td>MI Metro Area</td>
<td></td>
<td>4,296,250</td>
<td>395,040</td>
<td>9.2%</td>
<td>235,588</td>
<td>5.5%</td>
</tr>
<tr>
<td>Houston</td>
<td>TX</td>
<td>Komen Houston Affiliate</td>
<td>2,099,451</td>
<td>200,959</td>
<td>9.6%</td>
<td>111,540</td>
<td>5.3%</td>
</tr>
<tr>
<td>Houston-Sugar Land-Bayton</td>
<td>TX Metro Area</td>
<td></td>
<td>5,946,800</td>
<td>397,249</td>
<td>6.7%</td>
<td>216,120</td>
<td>3.6%</td>
</tr>
<tr>
<td>Memphis</td>
<td>TN</td>
<td>Komen Memphis-MidSouth Affiliate</td>
<td>646,889</td>
<td>160,649</td>
<td>24.8%</td>
<td>89,505</td>
<td>13.8%</td>
</tr>
<tr>
<td>Memphis, TN-MS-AR Metro Area</td>
<td></td>
<td></td>
<td>1,316,100</td>
<td>232,604</td>
<td>17.7%</td>
<td>128,824</td>
<td>9.8%</td>
</tr>
<tr>
<td>Baltimore</td>
<td>MD</td>
<td>Komen Maryland Affiliate</td>
<td>620,961</td>
<td>165,427</td>
<td>26.6%</td>
<td>99,717</td>
<td>16.1%</td>
</tr>
<tr>
<td>Baltimore-Towson, MD Metro Area</td>
<td></td>
<td></td>
<td>2,710,489</td>
<td>318,234</td>
<td>11.7%</td>
<td>187,045</td>
<td>6.9%</td>
</tr>
<tr>
<td>Los Angeles</td>
<td>CA</td>
<td>Komen Los Angeles County Affiliate</td>
<td>3,792,621</td>
<td>152,377</td>
<td>4.0%</td>
<td>93,339</td>
<td>2.5%</td>
</tr>
<tr>
<td>Los Angeles-Long Beach-Santa Ana</td>
<td>CA Metro Area</td>
<td></td>
<td>12,828,837</td>
<td>372,508</td>
<td>2.9%</td>
<td>228,077</td>
<td>1.8%</td>
</tr>
<tr>
<td>Washington</td>
<td>DC</td>
<td>Komen National Capital Region Service Area</td>
<td>601,723</td>
<td>133,357</td>
<td>22.2%</td>
<td>82,748</td>
<td>13.8%</td>
</tr>
<tr>
<td>Washington-Arlington-Alexandria</td>
<td>DC-VA-MD-WV Metro Area</td>
<td></td>
<td>5,582,170</td>
<td>591,145</td>
<td>10.6%</td>
<td>352,087</td>
<td>6.3%</td>
</tr>
<tr>
<td>Dallas</td>
<td>TX</td>
<td>Komen Dallas County Affiliate</td>
<td>1,197,816</td>
<td>121,861</td>
<td>10.2%</td>
<td>68,474</td>
<td>5.7%</td>
</tr>
<tr>
<td>Dallas-Fort Worth-Arlington</td>
<td>TX Metro Area</td>
<td></td>
<td>6,371,773</td>
<td>372,077</td>
<td>5.8%</td>
<td>198,870</td>
<td>3.1%</td>
</tr>
</tbody>
</table>

U.S. Census Bureau, 2014 5-year American Community Survey
## APPENDIX B

### Select Affiliate Information

<table>
<thead>
<tr>
<th>Komen Affiliate</th>
<th>City</th>
<th>State</th>
</tr>
</thead>
<tbody>
<tr>
<td>Memphis MidSouth</td>
<td>Germantown</td>
<td>TN</td>
</tr>
<tr>
<td>St. Louis</td>
<td>St. Louis</td>
<td>MO</td>
</tr>
<tr>
<td>Dallas</td>
<td>Dallas</td>
<td>TX</td>
</tr>
<tr>
<td>Greater Fort Worth</td>
<td>Fort Worth</td>
<td>TX</td>
</tr>
<tr>
<td>Greater Atlanta</td>
<td>Atlanta</td>
<td>GA</td>
</tr>
<tr>
<td>Chicagoland</td>
<td>Chicago</td>
<td>IL</td>
</tr>
<tr>
<td>National Capital Region</td>
<td>Washington</td>
<td>DC</td>
</tr>
<tr>
<td>Philadelphia</td>
<td>Philadelphia</td>
<td>PA</td>
</tr>
<tr>
<td>Maryland</td>
<td>Townson</td>
<td>MD</td>
</tr>
<tr>
<td>Detroit Race for the Cure</td>
<td>Detroit</td>
<td>MI</td>
</tr>
<tr>
<td>Northeast Ohio</td>
<td>Cleveland</td>
<td>OH</td>
</tr>
<tr>
<td>Miami-Ft. Lauderdale</td>
<td>Plantation</td>
<td>FL</td>
</tr>
<tr>
<td>Charlotte</td>
<td>Charlotte</td>
<td>NC</td>
</tr>
<tr>
<td>Greater New York City</td>
<td>New York</td>
<td>NY</td>
</tr>
<tr>
<td>North Florida</td>
<td>Jacksonville</td>
<td>FL</td>
</tr>
<tr>
<td>Kansas</td>
<td>Wichita</td>
<td>KS</td>
</tr>
<tr>
<td>Greater Kansas City</td>
<td>Kansas City</td>
<td>MO</td>
</tr>
<tr>
<td>North Carolina Triangle to the Coast</td>
<td>Morrisville</td>
<td>NC</td>
</tr>
<tr>
<td>Columbus</td>
<td>Columbus</td>
<td>OH</td>
</tr>
<tr>
<td>Central Indiana</td>
<td>Indianapolis</td>
<td>IN</td>
</tr>
<tr>
<td>Greater Nashville</td>
<td>Nashville</td>
<td>TN</td>
</tr>
</tbody>
</table>
Semi Structured Interview Guide for Affiliates

**Introduction:** Hello, my name is Natalie Morrissey. I am a graduate student at the University of North Texas working with Susan G. Komen to better understand the affiliate perspective on breast cancer disparities in African-American communities. The information provided will be used fill in knowledge gaps and aid the organization in holistically evaluating disparities in areas with the highest disparities in breast cancer mortality.

I appreciate your time today. I have emailed you the consent form in advance for your review. Please note that 1) this interview is completely voluntary and may be stopped at any time without penalty; 2) you may skip any questions you do not feel comfortable answering; 3) although this interview will be audio recorded, all identifiable data will excluded prior to data analysis and recordings will remain confidential; 4) your participation and responses will in no way impact your relationship as an Affiliate.

**Consent:** Do you have any additional questions about the interview? If there are no further questions, do you agree to participate in this study knowing that you can withdraw at any point without consequence?

1. Tell me about your role in the African-American community in [metropolitan area].

For the following questions, I’d like you respond with the Affiliate’s perspective regarding African-American women in the community, so I may better understand the Affiliate’s perspective on factors affecting breast cancer disparities facing African-American women in the service area.

2. From the Affiliate’s point of view, how big of a health concern is breast cancer for African-American women in the local community?
   a. Why do you think breast cancer is or is not a health concern for African-American women in the local community? Do you believe this is a unique viewpoint, or is this consistent with other races and ethnicities?
   b. What health concerns take precedence over breast cancer for African-American women?
   c. What other types of concerns take precedence over breast cancer for African-American women?
   d. Are either of these types of concerns (health or other) different from other races or ethnicities in the local community? How so?
   e. Who in the local community do African-American women trust to provide them accurate health information? Does this vary from other races and ethnicities in the community?

3. From the Affiliate’s perspective, do African-American women in the local community think that they are more likely to be diagnosed with breast cancer than other races and/or ethnicities?
a. Do African-American women understand their breast cancer risk?
b. Do African-American women feel that they can influence their risk of breast cancer?
c. Where are African-American women more likely to receive their breast cancer information from in the local community?
d. What are some things that can be implemented in the local community to assist African-American women in understanding their risk?
e. What kind of messages would help African-American women better understand their breast cancer risk?

4. The next set of questions is about African-American women accessing and staying in the breast cancer continuum of care (screening through survivorship) in the local community.  
   Accessing screening (i.e. clinical breast exams and screening mammography)  
   a. What are some of the barriers African-American women in the local community encounter when trying to access breast cancer screenings?  
   b. Are the barriers experienced by African-American women different than women of other races and ethnicities?  
   c. What are some things (programs, services, etc) that could be implemented in the local community to help African-American women enter the continuum of care?

   Accessing Diagnostic-Treatment-Survivorship Services  
   a. What are some of the barriers African-American women in the local community encounter when trying to obtain timely diagnostic, treatment, or survivorship services?  
   b. Are the barriers experienced by African-American women different than women of other races and ethnicities?  
   c. What are some things (programs, services, etc) that could be implemented in the local community to help African-American women remain in the continuum of care?

5. Does the Affiliate conduct or lead any initiatives addressing breast cancer disparities within the African-American community?  
   a. If yes, please explain what the initiatives are doing to address breast cancer disparities.

6. Is the Affiliate involved in any coalitions/collaborations/partnerships that address African-American breast cancer disparities in the local community?  
   a. If yes, please explain what activities the coalitions/collaborations/partnerships are doing to address breast cancer disparities.

Closing: Thank you again for your time today. Better understanding the Affiliate perspective on breast cancer disparities will create a more grounded foundation on which to address disparities in the future. If you would like, I can send a copy of the final report upon completion in the fall. Thank you.
E-mail Invitation from Komen Headquarter Staff for Recruitment

Dear (insert name):

You are invited to participate in a voluntary study entitled, “Identifying Breast Cancer Disparities in the African American Community Using a Mixed Methods Approach”, which is being conducted as a collaboration between Susan G. Komen and the University of North Texas under the direction of Natalie Morrissey and Dr. Lisa Henry. The purpose of this study is gather information to better understand the factors influencing breast cancer screening and treatment in African American women in the United States. Interviews will be conducted with community leaders, researchers, and advocates serving in select cities in the U.S.

Interviews will take approximately 45 minutes and will be conducted either phone or Skype, depending on preference. The interview will discuss community barriers and assets to breast health care, diagnosis, and treatment. More broadly, the interview will ask questions regarding your beliefs and perceptions of women’s health in your community. You will not need to provide any identifiable information.

There are minimal risks to participation in this study. Your refusal to participate in this study will involve no penalty or loss of benefits to which you are otherwise entitled and will not affect your relationship with Susan G. Komen or the University of North Texas. In addition, you may discontinue participation at any time without any penalty or loss of benefits. The only direct benefit to you if you participate in this research is knowing that the information provided will be used to inform a nationwide initiative to implement population-specific interventions.

Interviews will be scheduled during late March to mid-April. If you would like to participate in an interview and/or know of someone who would like to participate in this study, please contact Natalie Morrissey by April 3rd:

Natalie Morrissey Phone: (817) *** ****
Email: nataliemorrissey@my.unt.edu

Thank you for your time and consideration.

Sincerely,

Natalie Morrissey, B.A.
MS/MPH Candidate
University of North Texas

Stephanie Reffey, PhD
Evaluations and Outcomes Managing Director
Susan G. Komen
APPENDIX E

Invitation Email from Investigator for Recruitment

Dear Komen (insert Affiliate name):

The Affiliate recently received an email from Komen Headquarters regarding a study about breast cancer disparities in the African-American community. Disparities in breast cancer mortality are disproportionately experienced by African-American women, and it is the aim of this study to capture the perspective of Susan G. Komen Affiliates to better understand the environment surrounding such disparities. Your participation can help to bridge current gaps in knowledge.

Interviews will take approximately 45 minutes and may be scheduled at a time that is convenient for the Affiliate. Interviews will be conducted by either phone or Skype, depending on preference of the individual participating in the interview. The interview will discuss community barriers and assets to breast health care, diagnosis, and treatment. More broadly, the interview will ask questions regarding the Affiliate’s perspective of African-American women’s health in the local community. The person participating in the interview will not need to provide any identifiable information; any information of this type will be excluded prior to analysis to protect your anonymity. During the interview, the individual may discontinue participation at any time without any penalty.

Please provide me with several times within the upcoming two weeks that you are available to be interviewed and indicate your preference of Skype or phone call interview. If you would rather have someone else at the Affiliate participate in the interview, please provide me their name and email address and I can reach out to them directly. I can be reached via email at (nataliemorrissey@my.unt.edu) or phone (817-422-4542).

Thank you for your participation and I look forward to hearing from the Affiliate within the next couple of days.

Sincerely,
Natalie Morrissey
MS/MPH Candidate
University of North Texas
Informed Consent Notice

Before agreeing to participate in this research study, it is important that you read and understand the following explanation of the purpose, benefits and risks of the study and how it will be conducted.

Title of Study: Identifying Breast Cancer Disparities in the African American Community Using a Mixed Methods Approach

Student Investigator: Natalie Morrissey, University of North Texas (UNT) Dept. of Anthropology

Supervising Investigator: Lisa Henry, PhD

Purpose of Study
The primary aim of this study is to identify factors contributing to disparities in breast cancer indicators, such as late stage at time of diagnosis and death rate, and to identify public health practices which improve outcomes in African American communities.

Procedures
In order to participate, you are being asked to consent to individual interviews, lasting approximately forty five minutes to one hour, which will be audio recorded so that they may be later transcribed.

Potential Risks
There are no foreseen risks of this investigation.

Participant Benefits
There will be no direct benefits to the research participants at the time of the study. The benefits of this study are expected in the final product, a white paper. The benefits of the study may help improve breast cancer outcomes.

Safeguards
Complete confidentiality will be maintained in all publications and presentations. No personally identifiable data will appear on any documentation (transcripts) or resulting reports. No signed informed consent forms will be retained, therefore no reports will directly record individuals' names. Recording of verbal consent and interviews will be stored under the following format: “[First Initial] [Last Initial] [date]”. Audio will be transcribed, omitting all identifiable data including but not limited to names, dates, cities, and any unique roles which may indicate the role of a consultant. After transcription, audio recordings will be destroyed to ensure the protection of the participant’s identity. The Student Investigator (Natalie Morrissey) and the Supervising Investigator (Dr. Henry) will be the only people with
access to the data. This data will be stored on a password protected computer. Natalie Morrissey and Dr. Henry will be the only people with the password and key to the office. Data will be kept for 3 years and then shredded. Skype interviewees are asked to place Skype video calls when privacy is ensured; participants are discouraged from placing calls in public areas. During Skype calls, no video will be recorded.

Participant Consent

Questions about the Study
If you have any questions about the study, you may contact Lisa Henry at Lisa Henry@unt.edu or Natalie Morrissey at NatalieMorrissey@my.unt.edu.

Review for the Protection of Participants
This research study has been reviewed and approved by the UNT Institutional Review Board (IRB). The UNT IRB can be contacted at (940) 565-4643 with any questions regarding the rights of research subjects.

Research Participants’ Rights
Your participation in the survey confirms that you have read all of the above and that you agree to all of the following:
-Natalie Morrissey has explained the study to you and you have had an opportunity to contact her with any questions about the study. You have been informed of the possible benefits and the potential risks of the study.
-You understand that you do not have to take part in this study, and your refusal to participate or your decision to withdraw will involve no penalty or loss of rights or benefits. The study personnel may choose to stop your participation at any time.
-You understand why the study is being conducted and how it will be performed.
-You understand your rights as a research participant and you voluntarily consent to participate in this study.
-You understand you may keep a copy of this for your records.
Email text:

[Name],

Thank you for agreeing to participate in this study. I have attached the informed consent for your review. Please review this prior to our scheduled call, as I will ask for your verbal consent to participate in this study. I will call you at [time] on [telephone number]. Please let me know if you have any questions prior to our call.

Thank you again,

Natalie Morrissey
University of North Texas
MPH/MS Candidate
## APPENDIX G

### Evidence Based Interventions by Community

<table>
<thead>
<tr>
<th>Program Name</th>
<th>Organization Endorsement</th>
<th>Orientation</th>
<th>Aim of Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provider Assessment and feedback</td>
<td>CPSTF</td>
<td>Provider-and Client-Oriented</td>
<td>To evaluate providers on their performance in delivering or offering screening to clients and informing providers of the performance in providing screening services.</td>
</tr>
<tr>
<td>Reminders and recall systems</td>
<td>CPSTF</td>
<td>Provider-and Client-Oriented</td>
<td>To remind patients of when their annual/biennial mammogram is due or if follow-up is necessary.</td>
</tr>
<tr>
<td>Reduce structural barriers</td>
<td>CPSTF</td>
<td>Client-Oriented</td>
<td>To reduce barriers including distance to screening location, clinic hours, absence of childcare, language, cultural factors, eliminating or simplifying administrative procedures.</td>
</tr>
<tr>
<td>Small Media</td>
<td>CPSTF</td>
<td>Client-Oriented</td>
<td>To provide tailored, educational small media such as videos and printed material such as newsletters, brochures.</td>
</tr>
<tr>
<td>Group Education</td>
<td>CPSTF</td>
<td>Client-Oriented</td>
<td>To convey information on screening guidelines, benefits of screening, ways to overcome barriers to screening; to motivate, encourage, inform individuals to seek screening; Delivered by health care professionals or trained lay workers.</td>
</tr>
<tr>
<td>One-on-One Education</td>
<td>CPSTF</td>
<td>Client-Oriented</td>
<td>To convey information to the individual on screening guidelines, benefits of screening, ways to overcome barriers to screening based on characteristics unique to the individual; to motivate, encourage, inform individuals to seek screening; Delivered by health care professionals.</td>
</tr>
<tr>
<td>Reducing Out-of-Pocket Costs</td>
<td>CPSTF</td>
<td>Client-Oriented</td>
<td>To minimize or remove economic barriers that increase difficulty for patients to access screening services.</td>
</tr>
</tbody>
</table>

### Research-Tested Intervention Programs (RTIPs)

<table>
<thead>
<tr>
<th>Program Name</th>
<th>Organization Endorsement</th>
<th>Intervention Type</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Friend to Friend</td>
<td>NCI</td>
<td>Group Education</td>
<td>To promote awareness about the benefits of mammography and address individual knowledge, beliefs, and attitudes through influence of social dynamics</td>
</tr>
<tr>
<td>North Carolina Breast Cancer Screening Program</td>
<td>NCI</td>
<td>Group Education; One-on-One Education; Small Media</td>
<td>To provide health information through trained lay health workers, small media to promote awareness and use of breast cancer screening</td>
</tr>
<tr>
<td>Prevention Care Management</td>
<td>NCI</td>
<td>Client Reminder</td>
<td>To increase cancer screening through a centralized telephone care management system</td>
</tr>
<tr>
<td>Proactive System to Improve Breast Cancer Screening</td>
<td>NCI</td>
<td>Client Reminder</td>
<td>To increase screening rates among patient bases through a series of reminders to patients to schedule screening</td>
</tr>
<tr>
<td>Project SAFe</td>
<td>NCI</td>
<td>One-on-One Education; Client Reminder</td>
<td>To help women overcome barriers to timely breast cancer screening through a system of patient navigation counseling and case management</td>
</tr>
<tr>
<td>Reducing Barriers to the Use of Breast Cancer Screening</td>
<td>NCI</td>
<td>Reduce Structural Barriers; One-on-One Education</td>
<td>To increase breast cancer screening practices of community-based physicians through continuing medical education</td>
</tr>
<tr>
<td>Targeting Cancer in Blacks (TCiB)</td>
<td>NCI</td>
<td>Group Education; Small Media; Group Education</td>
<td>To promote awareness of preventable cancer risk factors and increase knowledge of cancer prevention behaviors through culturally sensitive, community-wide intervention</td>
</tr>
<tr>
<td>The Forsyth County Cancer Screening Program (FoCaS)</td>
<td>NCI</td>
<td>One-on-One Education; Small Media</td>
<td>To address barriers to screening in a comprehensive program to improve breast cancer screening through community outreach and clinical strategies</td>
</tr>
<tr>
<td>Project</td>
<td>Implementor</td>
<td>Medium</td>
<td>Description</td>
</tr>
<tr>
<td>--------------------------------------------------------</td>
<td>-------------</td>
<td>-----------------</td>
<td>-----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>The Robeson County Outreach Screening and Education (ROSE) Project</td>
<td>NCI</td>
<td>One-on-One Education; Small Media</td>
<td>To assist women in overcoming barriers to screening using lay health workers to deliver individual, home-based health education</td>
</tr>
<tr>
<td>Using Direct Mail to Increase Screening Mammography</td>
<td>NCI</td>
<td>Small Media</td>
<td>To increase screening uptake through targeted direct mail</td>
</tr>
<tr>
<td>Woman to Woman</td>
<td>NCI</td>
<td>Group Education</td>
<td>To disseminate educational information at the workplace through lay health workers and tailored intervention according to needs and interests of population</td>
</tr>
<tr>
<td>The Witness Project</td>
<td>NCI</td>
<td>Group Education</td>
<td>To increase awareness, knowledge and motivation of breast cancer through story-telling with a religious basis through educational sessions</td>
</tr>
</tbody>
</table>

APPENDIX I

Coding Structure

Title: Description
Affiliate MOA: Affiliate as Mechanism of Action
   Capacity: Capacity of the affiliate
      Limitation
      Expansion
Grants: Grantees and grantmaking done by the affiliate
   Grantee Activities: Grantee activities
      AA grants: Grants specifically funding African-American populations or mostly African-American population
Affiliate Activities
   Advocacy: Public policy related activities
   Education: General education and awareness messaging performed by affiliate
   Screening Promotion: Specific instances where screening is coordinated, referred
Data: Decision-making and needs prioritization for affiliate and service area
   Data source: Where affiliates are obtaining data referenced
   Assessment: Implementation of assessment as a learning tool
Collaboration: Affiliate collaboration with other organization in coalitions, programming, steering, etc
Who: Who is the affiliate serving? Descriptors.
   Service area pop: Descriptors of the whole service area
   African-American Population: Characteristics of the African-American population in service area
      SES: SES factors affecting African-American population
      Jobs: Types of jobs held, implications of jobs
      Jobs: Jobs of AA pop, implications of Jobs
   Education Level: Education level of African-American population
   Location: Location/built environment of African-American population
   Religion: Religiosity of African-American population
   Culture: Culture of African-American population
Knowledge of BC: Knowledge and understanding of BC
   Sources of Knowledge: Sources of knowledge, specifically health behaviors and breast health
      Who- Knowledge: Who provides them with health information?
      Religion- Knowledge: Religion as a way of knowing
      Where- Knowledge: Where does the African-American population receive knowledge?
   Health behaviors: General health behaviors of African-American population
Other Race/Ethnicity: Descriptors of the other races and ethnicities within service area

Barriers: Leveled barriers to breast health, health care, and health in general

Intrapersonal: Individual barriers
  Social Support: Social burdens through relationships
  Backburner: Idea that health takes back burner compared to competing social priorities
  Physician: Patient-provider communication and other interpersonal communications/interactions with healthcare workers

Interpersonal: Social barriers to breast health
  Perception
    Perceived Susceptibility: Perceived Risk
    Perceived Seriousness: Severity of disease, including fatalism
    Perceived Control: Control over health
  Health: Competing health concerns
  Attitude
  Fear
  Knowledge: Knowledge of breast cancer and services

Organizational: Organizational level barriers
  HC System
  Community: Community level barriers

Policy: Policy level barriers
  Greater for African-American: Idea that barriers in general are greater for African-American population

Intervention: Points used to intervene, current interventions, future interventions
  Navigation: Descriptions of navigation models
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