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A Phenomenological Approach to Understanding How Women Make Breast Cancer Treatment Decisions within the Context of Communities

Lailea Noel

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A Phenomenological Approach to Understanding How Women Make Breast Cancer Treatment
Decisions within the Context of Communities

by

Lailea J. Noel

A dissertation presented to the
Graduate School of Arts & Sciences
of Washington University in
partial fulfillment of the
requirements for the degree
of Doctor of Philosophy

August 2016
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*But to do good and to communicate,
forget not: for with such sacrifices God is well pleased
~ The Bible, Hebrews 13:16 KJV*

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Lailea Noel

Washington University in St Louis

August 2016

ABSTRACT OF THE DISSERTATION

A Phenomenological Approach to Understanding How Women Make Breast Cancer Treatment

Decisions within the Context of Communities

by

Lailea J. Noel

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Professor Sarah Gehlert, Chair

Nationally, African American women have 40% higher mortality from breast cancer than White women. While many factors contribute to this disparity, the timely initiation of treatment is a growing area of interest. Certain treatment is associated with increased survival for women with a breast cancer diagnosis yet evidence suggests that African American women use treatment less frequently, and in some cases do not use treatment at all, compared to White women with similar tumor characteristics. As one solution, the Institute of Medicine suggests moving from provider-centered care and towards patient-centered care as a means of engaging patients in their care, improving treatment initiation, and enhancing health outcomes (Barry & Edgman-Levitan, 2012; Elwyn et al., 2014; Epstein & Street, 2007). An under-explored area of attention for scientific studies on breast cancer treatment initiation and health decision-making is how to identify and engage in care women who do not follow up with treatment. To date these women have not been included in research focused on understanding treatment decisions and patient engagement in care decisions. Often these are among the most marginalized women of our society who have some of the highest rates of mortality from many different health related conditions. This study helps to fill this gap by identifying and engaging this community in

research thus providing a wealth of information on potential points of intervention leading to improved timely treatment initiation.

Using a phenomenological qualitative approach, this study explored the lived experience of African American women living in a socially and economically isolated environment in a large metropolitan area who did not begin a recommended treatment plan within six-months following the identification of a breast abnormality. The research questions for this study were: (1) What are the lived experiences of African American women who had not followed up with care for a diagnosis of breast cancer for 6-months or more following a breast abnormality? (2) How do women apply meaning to the process of deciding whether or not to initiate treatment for breast cancer? and (3) Under what circumstances does the phenomenon (treatment for breast cancer was not initiated) persist beyond 6-months?

In-depth interviews were conducted with eight women between the ages of 37 and 78 years of age. In all cases, the initiation of treatment was delayed for more than 6-months following a breast abnormality. The delay was more than a year in three of the eight examples in the dissertation study and more than two years in one of the eight examples. In accordance with phenomenological methodology, the interviews were open-ended, allowing for rich, in-depth data to emerge relatively unencumbered by the assumptions and expectations of the investigator.

Key findings suggest that engaging patients in health care decision making necessitates a better understanding of the processes involved in treating breast cancer, the impact the side-effects may have on quality of life, and knowledge and access to patient support services to counter these side-effects in communities. Also, the findings from this study highlight that most of the communication about treatment initiation occurred at the primary care level, prior to initiating contact with cancer-specific services. Primary care proved to be the most important

provider-patient relationship for these women. The primary care setting is where these women go with concerns about their breasts and where they return for information about treatment and support for side effects. Therefore, it is important to engage women in conversations about treatment initiation earlier in the process than is currently done.

The analysis revealed that women's descriptions of experiencing health decision making included five thematic areas: pride, self-efficacy, demystifying the treatment process (especially radiation therapy), knowing your body, quality of life. Furthermore, the context within which they experienced the phenomenon is structured by underlying conceptualizations of chronic traumatic events coupled with resource deserts. Finally, many of the women reported keeping their illness to themselves and described social and cultural barriers to utilizing available support systems to assist with unmet needs. These situations taken together allowed the delay in the initiation of treatment for breast cancer to persist.

These results indicate that future interventions aimed at engaging women in care decisions and improving time to treatment for breast cancer should take place between PCPs, oncologists, and their patients and focus on de-mystifying the process of treatment. Incorporating this information as a type of barrier-focused community-based intervention or improved case management services to assist cancer patients in the primary care setting would increase a patient's self-efficacy and ultimately impact cancer mortality outcomes.

1: CONTEXT AND INTRODUCTION

1.1. Introduction

African American women have a 40% higher mortality rate from breast cancer than White women and this disparity is widening over time (DeSantis et al., 2016; DeSantis et al., 2015; Siegel, Miller, & Jemal, 2015). While this difference in mortality rates is likely a combination of biologic and non-biologic factors (Gehlert, et al., 2008; Siegel, Ward, Brawley, & Jemal, 2011), one understudied area is disparities in the initiation of treatment. Additionally, there exist a lack of clarity in the literature on whether these observed disparities are primarily an influence of race or socio-economic status (SES). Certain treatment is associated with increased survival for women with a breast cancer diagnosis yet evidence suggests that African American women use treatment less frequently, and in some cases not at all, compared to White women with similar tumor characteristics (Fedewa et al., 2011; Sheppard, Adams, Lamdan, & Taylor, 2011). Furthermore, differential rates of diagnostic follow-up by race after a breast abnormality may also produce disparities (Tejeda et al., 2013). Conversely, scientist have found, while not clinically significant, there is a statistical significance in breast cancer mortality in the status of breast cancer subtype estrogen (ER)/ progesterone (PR) across levels of SES and not across race (Andaya et al., 2012; Dunnwald, Rossing, & Li, 2007). The investigators found that geographic areas with high-SES showed higher levels of ER+/PR+ than low-SES areas (H-SES 62.9; M-SES 57.7; L-SES 53.4 $p < .01$). While low-SES geographic areas were shown to be associated with higher levels of ER-/PR- than areas with high-SES (H-SES 17.7; M-SES 19.7, H-SES 21.9 not statistically significant) (Andaya et al., 2012). This is important because there are fewer treatment options for ER-/PR- than for ER+/PR+. This multi city study had a sample size of 184,602, with %15 being African American and %70 White women.

Models of health behavior have been used successfully to predict health decision making, including the Health Belief Model, the Theory of Reasoned Action, the Theory of Planned Behavior and the Social Cognitive Theory (Glanz, Rimer, & Viswanath, 2008). One of the greatest challenges for investigators concerned with behavior change is how to determine the degree to which a theory or model fits a particular phenomenon. While existing health behavior theories have been widely used to increase participation in breast cancer prevention, including screening and self-breast exam, they have not been applied in the area of engaging women in health care decision making and treatment initiation. Additionally, while they have been used within low-SES African American communities in the area of HIV/AIDS research, initiating treatment for breast cancer may entail a different set of constructs for a similar population.

The present study helps to fill the above mentioned gap by identifying and engaging in research African American women who had not followed up with care for over 6-months after identification of a breast abnormality. This approach thus provides a wealth of information on potential points of intervention leading to increased rates of timely initiation of treatment for breast cancer. All of the women included in this study lived in North St Louis City and North St Louis County, predominantly African American neighborhoods characterized as having high rates of mortality from breast cancer. This dissertation captured their individual voices as well as a collective narrative of experience with health decision making. This study was as much about (if not more) illuminating the lived experience of treatment decision making for this vulnerable group of women as was about identifying potential supports and barriers to treatment initiation (Vagle, 2014). This study engaged in research and gave a voice to women who are under-represented in previous scientific studies and added knowledge to existing models of health decision making between such patients and their healthcare providers.

1.2. Research Questions

The research questions for this study are:

- 1) What are the lived experiences of African American women who had not followed up with care for a diagnosis of breast cancer for 6-months or more following a breast abnormality?
- 2) How do women apply meaning to the process of deciding whether or not to initiate treatment for breast cancer?
- 3) Under what circumstances does the phenomenon (treatment for breast cancer was not initiated) persist for more than 6-months?

1.3. The Specific Aims

It is worth noting that prior to conducting the study, I sought out to recruit women who had a confirmed diagnosis of breast cancer or who had received an abnormal mammogram but had not initiated treatment. However, based on participant interviews, I discovered that treatment decision making began for these women much earlier. In many cases the delay in treatment for breast cancer took place between identification of a breast abnormality and confirmation of a breast cancer tumor. Therefore, the specific aims for this study were altered from their original presentation to included the initiation of follow up care for a breast abnormality.

The specific aims for this study are:

- 1) To collect the lived experiences (individual narratives) of African American women who did not follow up with care *for a breast abnormality* or after an abnormal clinical breast

exam or an abnormal screening mammogram, that is classified as suspicious finding or a diagnostic biopsy or a diagnostic test classified as C4 (most likely cancer) or C5 (cancer).

- 2) To illuminate elements of how a woman applies meaning to the process of deciding whether or not to initiate treatment.
- 3) To analyze the collective narratives of a cohort of women who have not initiated timely breast cancer treatment to articulate the common experiences of the phenomenon (health decision making process as it relates to follow up care for breast cancer)

1.4. Prior Research Experience

This research is very important and has implications for oncology social work practice and community-based social work interventions. I have spent the past 20 years working in the area of cancer care administration and program management. While working in the field I met and spoke with women who faced breast cancer and also knew many women who died from the disease. Many of those women were young African American women.

During my time over the past 5 years at the Brown School of Social Work I had the privilege of working with my advisor, Dr. Sarah Gehlert, in North St Louis City and North St Louis County, an area of the city that is characterized as having some of the highest rates of mortality in the region as compared to other areas of the region. Our research area covered eight ZIP codes which were predominately African American. During my time serving this area we interviewed 96 women in a study focused on decreasing barriers to treatment initiation by first exploring the system level barriers (Noel, Connors, Goodman, & Gehlert, 2015). The study was conducted in partnership with Barnes Jewish Hospital, and the findings from that study led to

many interventions within the community. My dissertation research is a follow-up study to this original scientific study.

I wanted to identify and interview women who had not sought follow up care to hear their stories directly. The results from this study complement what we heard from the women in the previous study. Key findings suggest that an understanding of the processes involved with treating breast cancer has more of an impact on the initiation of treatment than learning of the diagnosis itself. These findings suggest that we need to improve interventions in the community and in the primary care setting that target de-mystifying the process of treatment. My hope is that for those reading this dissertation, you will not only agree with me that this is a critical issue needing our attention, but also that you will experience a little of the lived experience of health decision making among women living in geographically isolated, low-SES neighborhoods and facing a diagnosis of breast cancer.

1.5. Plan for Dissertation

The purpose of this study is not to compare different racial/ethnic groups but rather it is to examine the specific aspects of breast cancer treatment decision making in vulnerable and medically marginalized populations, in particular the importance of paying close attention to the specific socio-environmental issues that could help explain disparities. For this study that is African American women who live in North St Louis City and North St Louis Country, and area plagued with poverty and high rates of breast cancer mortality. Identifying factors within this social environment that highly influence a woman's breast cancer treatment initiation can help tailor future research studies and interventions for other vulnerable and medically marginalized groups.

This dissertation is presented in two parts. The first part, chapters 2 and 3, is a literature review of the current state of the research field including gaps and how the current study fills those gaps while the second part, Chapters 4 through 7, presents the current study and the next steps. Chapter 2 is a review of the scientific literature on racial disparities in breast cancer mortality rates. The chapter also reviews the common approaches to addressing these disparities and proposes decreasing the disparities in treatment initiation as an alternative approach gaining attention in the scientific community. Chapter 3 is a review of the current theoretical foundation on health behavior research and how these theories have been used in the area of breast cancer research. The chapter will end with a summary of the gaps in the literature and how the current study fills those gaps. Chapter 4 outlines the study design and methods of the current study. The chapter will also offer an overview of the sample for this study and the context within which they reside. Chapters 5 and 6 give an overview of the lived experience of the phenomenon including the common themes and findings from the collective examples. Chapter 7 concludes the dissertation with a discussion of the significance to research and practice and the next steps.

2: BACKGROUND AND SIGNIFICANCE

2.1. Racial Disparities in Breast Cancer Mortality Rates

Breast cancer is the second most commonly diagnosed cancer for US women, excluding skin cancers, with an estimated 232,000 new cases of invasive breast cancer annually, and 60,000 new cases of in situ breast cancer annually (DeSantis et al., 2016). It is the second leading cause of cancer death for US women, second to lung cancer, with 40,000 deaths reported annually (DeSantis et al., 2016; Siegel et al., 2015). African American women have the highest mortality rate from breast cancer (31.0 per 100,000) compared to other racial groups (Figure 2.1) (DeSantis et al., 2015).

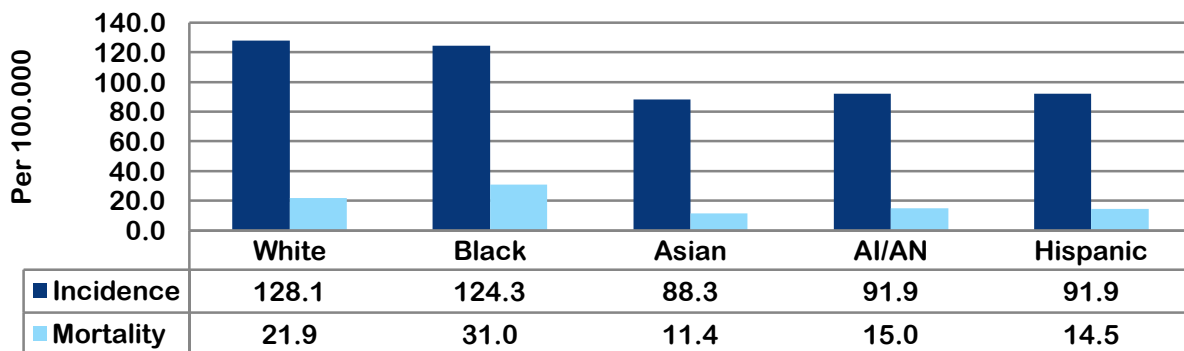


Figure 2.1 Breast Cancer Incidence and Mortality Rate by Race/Ethnicity, US Age Adjusted Surveillance, Epidemiology, and End Results (SEER) Program data (2008-2012). Adapted from “Breast Cancer Statistics, 2015” by C. DeSantis, et al., 2015, *CA: A Cancer Journal for Clinicians*. Doi: 10.3322/caac.21320. Available online at cancerjournal.com.

With an increase in screening mammography, the addition of a growing focus on targeted therapies for subtypes of breast cancer, and an increase in financial resources, the mortality rate for breast cancer has decreased for both White women and African American women. The 5-year relative survival rate for White women is 91% and for African American women is 80% (DeSantis et al., 2016). However, as Figure 2.2 demonstrates, the trend in mortality from 1991 to

the present has decreased much faster for White women than for African American women. Furthermore, this mortality disparity is widening over time (DeSantis et al., 2015; Whitman, Orsi, & Hurlbert, 2012). African American women have a 40% greater chance of dying from breast cancer than White women (DeSantis et al., 2016; DeSantis et al., 2015; Siegel et al., 2015). Even when women have equal access to insurance, such as in military and Veteran’s Affairs facilities and managed care organizations, higher rates of mortality among African American women compared to White women persist, indicating a social component to these observed racial disparities (Brawley, 2002; Bigby & Holmes, 2005; Fedewa et al., 2011).

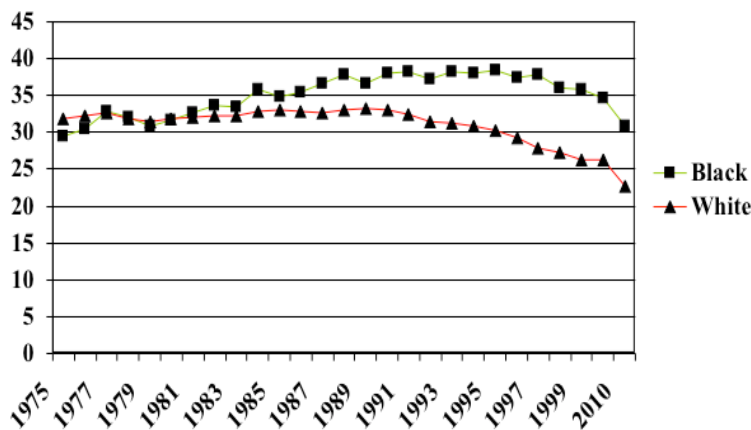


Figure 2.2 Disparity in Breast Cancer Mortality Rate by Race, US Age Adjusted SEER data (1975-2012). Adapted from “*Addressing the African American and White breast cancer mortality disparity in St Louis*” by S. Gehlert, et al., [unpublished White Paper] and “Breast Cancer Statistics, 2015” by C. DeSantis, et al., 2015, *CA: A Cancer Journal for Clinicians*. Doi: 10.3322/caac.21320. Available online at cacancerjournal.com.

It is also well documented that African American women are more likely than White women to present at diagnosis with late-stage disease, with less well differentiated or poorly differentiated tumors, and to have less favorable outcomes (DeSantis et al., 2016; Fayanju, Jeffe, Elmore, Ksiazek, & Margenthaler, 2013; Sheppard et al., 2011; Warner et al., 2012; Yu, 2009). Advanced-stage disease is associated with higher rates of recurrence and lower rates of survival (Fayanju, et al., 2013). As Figure 2.3 illustrates, 43% of African American women present with

distal or regional tumors, compared to 33% of White women. This is important because the survival rate when diagnosed with a localized tumor is 96% for White women and 93% for African American women but drops dramatically for regional tumors (White 87%; African American 78%) and distal tumors (White 34%; African American 24%).

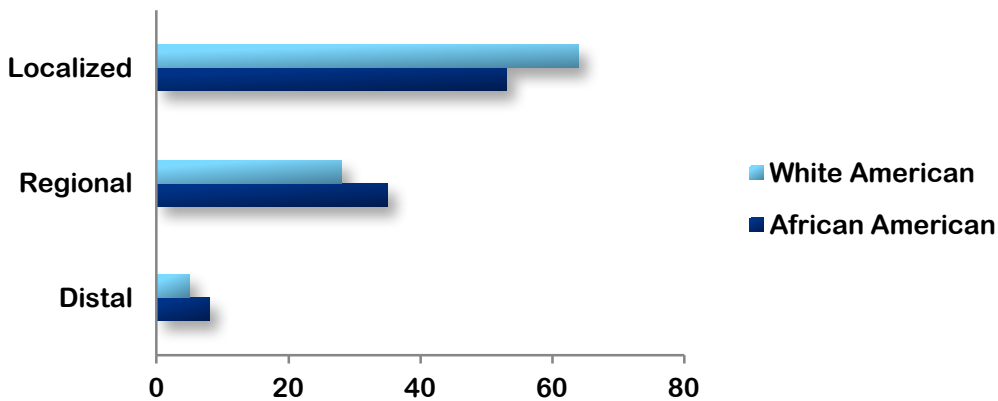


Figure 2.3 Breast Cancer Stage Distribution by Race, US 2005-2012 Adapted from “Breast Cancer Statistics, 2015” by C. DeSantis, et al., 2015, *CA: A Cancer Journal for Clinicians*. Doi: 10.3322/caac.21320. Available online at cancerjournal.com.

Not only do African American women present with later stage tumors than White women, which are more difficult to treat, but African American women also present with higher rates of basal-like tumors, which tend to be more refractory to treatment (DeSantis et al., 2016; Wheeler, Reeder-Hayes, & Carey, 2013). No longer considered a single disease, scientists have identified 21 histologic subtypes and four molecular subtypes of breast cancer, each associated with a specific set of risk factors, treatment options, and responses to treatment (DeSantis et al., 2016). African American women are over represented in categories of subtypes with fewer available targeted therapies, such as HR-/HER2- and triple negative (DeSantis et al., 2016; Kohler et al., 2015; Warner et al., 2015; Wheeler et al., 2013).

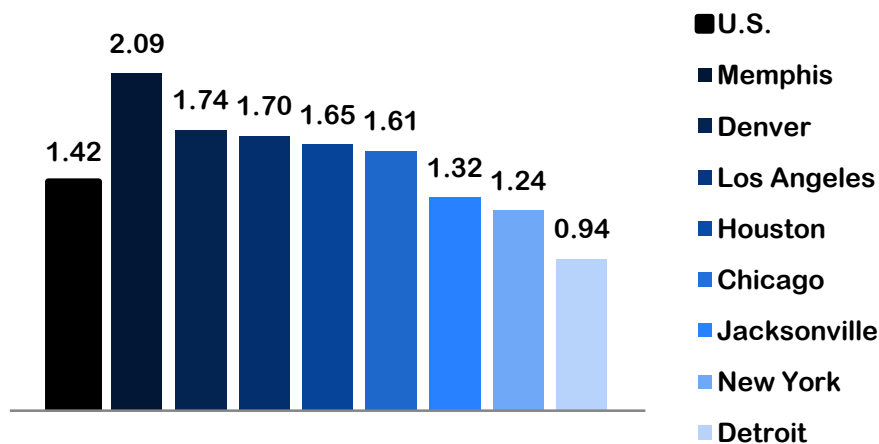


Figure 2.4 Three Year Estimates of Breast Cancer Mortality Relative Risk Non-Hispanic African American and Non-Hispanic White Women by City 2005-2007. Data adapted from “The racial and ethnic disparity in breast cancer mortality in the 25 largest cities in the United States” by S. Whitman, J. Orsi, & M. Hurlbert, 2012, *Cancer Epidemiology*, 36(2), e147-e151. *Note: The reference category is White women.*

While breast cancer affects women in all neighborhoods, the mortality rate from breast cancer is higher for women in more densely populated urban environments (Polacek, Ramos, & Ferrer, 2007; Tannenbaum, Koru-Sengul, Miao, & Byrne, 2013; Yu, 2009) and more rural settings (Bettencourt, Schlegel, Talley, & Molix, 2007; Nguyen-Pham, Leung, & McLaughlin, 2014) than suburban areas and less dense city environments. However, substantial relative risk varies across densely populated cities. For example, in Chicago (RR 1.61, 95% CI 1.42 – 1.83), Houston (RR 1.65, 95% CI 1.42-1.92), and Memphis (RR 2.09, 95% CI 1.64-2.67), the gap is greater than the national average whereas in New York (RR 1.24, 95% CI 1.15-1.34) and Jacksonville, Florida (RR 1.32, 95% CI 1.06-1.65), the gap is smaller than the national average (Figure 1.4) (Whitman et al., 2012).

Poverty, lower levels of educational attainment, and a lack of health insurance are also associated with decreased breast cancer survival (DeSantis et al., 2016). The states in which poverty rates are at 20% or greater are located predominantly in southeastern United States,

specifically, Mississippi, Louisiana, Kentucky, South Carolina, Georgia, Arkansas and Alabama (Housing Assistance Council Rural Research Note, 2012). As shown in Table 2.1, these are also states with high breast cancer mortality disparity by race as outlined by DeSantis et al. (2015).

Table 2.1
Age Adjusted State Variation in Female Breast Cancer Incidence and Mortality Rates by Race for States with Highly Concentrated Rural Communities 2008-2012 (per 100,000)

	White American				African American			
	% IN SITU	% Regional/ Distant	Incidence	Mortality	% IN SITU	% Regional/ Distant	Incidence	Mortality
Alabama	18.0	34.0	117.5	20.4	18.0	43.0	125.9	30.7
Arkansas	*	*	107.7	21.4	*	*	106.1	31.4
Georgia	20.0	33.0	125.8	21.2	20.0	44.0	124.1	29.5
Kentucky	17.0	34.0	121.6	22.1	20.0	39.0	133.2	32.7
Louisiana	18.0	35.0	121.2	21.9	17.0	45.0	130.0	34.8
Mississippi	16.0	35.0	113.9	20.4	16.0	47.0	124.0	33.3
Missouri	18.0	35.0	124.6	22.6	19.0	47.0	135.6	33.7
South Carolina	19.0	33.0	125.9	21.1	19.0	45.0	125.1	29.2
Wisconsin	20.0	34.0	126.5	20.7	24.0	49.0	126.0	32.1
United States	20.0	33.0	128.1	21.9	20.0	43.0	124.3	31.0

Note. Adapted from “Breast Cancer Statistics, 2015” by C. DeSantis, et al., 2015, *CA: A Cancer Journal for Clinicians*. Doi: 10.3322/caac.21320. Available online at cancerjournal.com.

* Statistics could not be calculated because data on stage distribution was not available during analysis

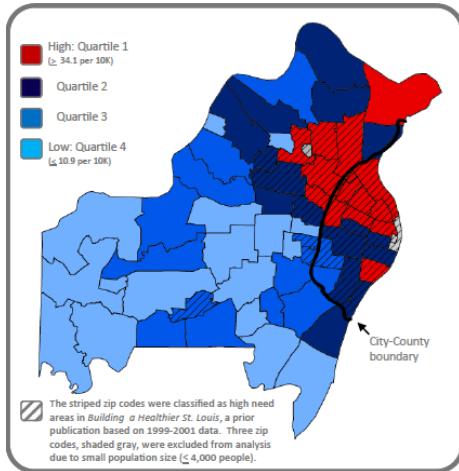
According to DeSantis et al. (2015), the percentage of regional and distant tumors ranges from 28-38% for White women and 35-49% for African American women. African American women in the states of Wisconsin (49%), Missouri (47%), and Mississippi (47%) have the highest percentages of regional and distal tumors in the country (DeSantis et al., 2015). This is

particularly interesting in light of the fact that African American women received screening mammography at the same or at higher rates than White women in these same state: Wisconsin (African American 88% White American 80%); Missouri (African American 84% White American 75%); Mississippi (African American 70% White American 70%) (DeSantis et al., 2015).

2.2. The Context for this Current Study: North St Louis City and County, Missouri

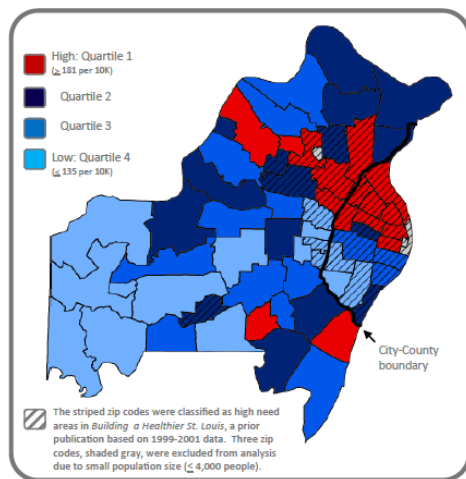
The focus geographical area for the present study is North St Louis City and North St Louis County. Despite some improvements in the overall health of the St Louis region, racial disparities in breast cancer mortality persist. Residents of North St Louis City and portions of North St Louis County, predominately African American communities and neighborhoods experience the worst social and health indicators in the St Louis region. Figure 2.5 highlights just three areas (diabetes, heart disease, and mental health), however, the maps of other health outcomes look very similar. Each map highlights the prevalence of health disparity for North City and North County.

According to a report published by the St Louis Regional Health Commission (2012), the number of people living in poverty in the St Louis region increased by 26% from 2000 to 2010, with 30% of the African American population living in poverty in 2010 compared to 10% of the White population. According to that same report, the North City and North County areas have some of the highest rates of victims of violence across the region (ex. a north city ZIP code 63136 at 73.1 per 10,000 compared to a south city ZIP code 63114 at 26.2 per 10,000). This is important to the study of breast cancer treatment initiation, because neighborhoods that have a high level of violence can negatively affect residents' likelihood to engage in physical activity, coalesce with their neighbors, and can increase social isolation.

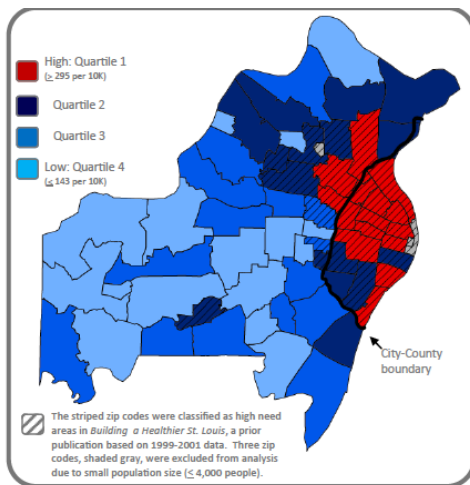


Note: Red areas represent highest hospitalization rates for the St Louis region, light blue represents the lowest rates for the region; black line represents county-city line.

A. Hospitalizations from Diabetes



B. Hospitalizations from Heart Disease



C. Behavioral Health Hospitalizations for an Acute Mental Disorder Event

Figure 2.5 Maps of St Louis City and County Displaying Health Disparities by ZIP code; retrieved from St Louis Regional Health Commission Decade Review of Health Status Report for St Louis City and County, (2012); <http://www.stlrhc.org/work/decade-review-health-status-report/> on April 2, 2016

The Commission further reports that high rates of acute mental health disorders that are highly concentrated in areas of North City and North County, a population that tends to be highly medically marginalized. Also, the Commission reported approximately 30% of the City and County population is obese. While this percentage is lower than the national percentage (35.7%), it remains high. This is important because obesity has been linked to many adverse health outcomes, including the development of breast cancer and poorer outcomes among obese women with breast cancer (Gillespie et al., 2009).

As Figure 2.6 displays, the rate of breast cancer mortality for African American women is similar to observed nationwide trends (2010 African American US 30.8 African American STL 30.2). The St Louis Regional Health Commission reports the relative risk of breast cancer mortality for African American women in St Louis region as 1.20 when compared to White women. However, there is great geographical variation in breast cancer mortality rates by ZIP code with the North City and North County ZIP codes experiencing the highest mortality rates (see Figure 2.7).

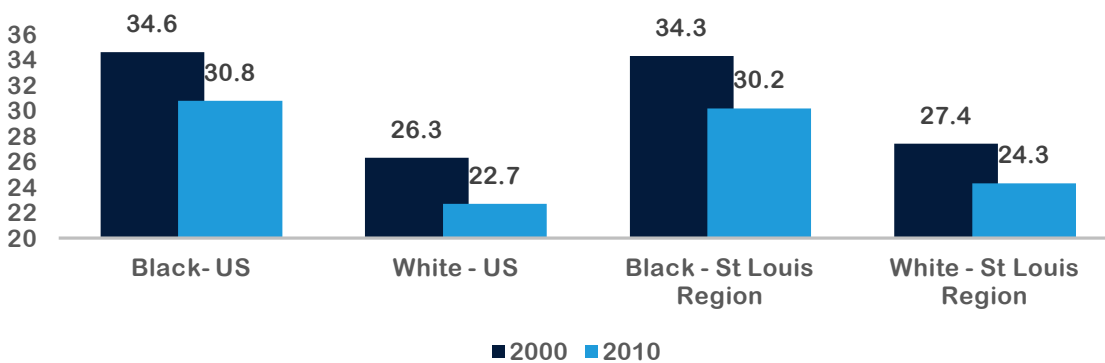


Figure 2.6 US and St Louis Region Breast Cancer Mortality Rate by Race, 2000 and 2010; retrieved from St Louis Regional Health Commission Decade Review of Health Status Report for St Louis City and County (2012), <http://www.stlrhc.org/work/decade-review-health-status-report/> on April 2, 2016 and DeSantis et al., 2015 using SEER Cancer Statistics Review data. *A Cancer Journal for Clinicians*. Doi: 10.3322/caac.21320. Available online at cacancerjournal.com.

Cancer Mortality Rate by Zip Code, 2008-09

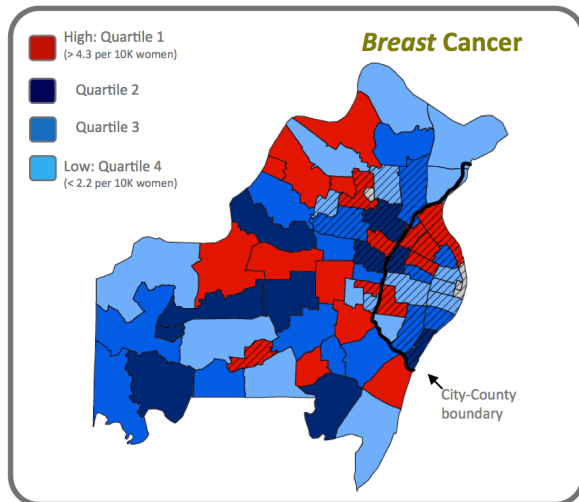


Figure 2.7 Map of Breast Cancer Mortality Rate by ZIP Code for St Louis Region; retrieved from St Louis Regional Health Commission Decade Review of Health Status Report for St Louis City and County, (2012); <http://www.stlrhc.org/work/decade-review-health-status-report/on> April 2, 2016

The Regional Health Commission reports that the regional area healthcare safety net system, a system of community-based PCPs who offer health services to low income people, serves a population of 336,000 individuals in 2011 (26% of city and county population) (SLRHC Report, 2012). Primary care is composed of adult medical care, pediatric care, obstetrical and dental care.

2.3. Common Approaches to Decreasing Disparities in Breast Cancer Mortality

In an effort to address breast cancer racial disparities, a growing body of research has focused on breast cancer prevention (Colditz & Bohlke, 2014; Hewitt, Byers, & Curry, 2003). While a variety of intervention approaches address prevention, the following sections highlight a small selection that has been shown in the literature to have a high impact on breast cancer outcomes.

Smoking and Obesity. Social scientists have found links between smoking and cancer outcomes, and more recently, obesity and cancer outcomes (Colditz et al., 2002; Hewitt, et al., 2003; Lorincz & Sukumar, 2006). Smoking has been linked with at least 16 types of cancers as

well as other chronic conditions; making it the single preventable risk factor associated with cancer death (Colditz, Wolin, & Gehlert, 2012).

Obesity itself affects the development and growth of cancer cells (Lorincz & Sukumar, 2006). This is important because among American adults over the age of 20 years, 65.1% are overweight or obese, 30.4% are obese, and 4.9% are extremely obese (Hedley et al., 2004). Furthermore, in almost every age and racial/ethnic group, the prevalence of overweight or obesity surpasses 50% (Hedley et al., 2004). The links through which obesity is associated with breast cancer have yet to be precisely defined. However, scientists have begun to investigate the influence of more advanced disease at presentation, systematic underdosing of adjuvant chemotherapy, and higher rates of diabetes and hypertension (Braithwaite et al., 2009; Gillespie et al., 2009; Griggs, Sorbero, & Lyman, 2005; Lipscombe, Goodwin, Zinman, McLaughlin, & Hux, 2008; Loi et al., 2005). For example Wolf and colleagues (2006) found that higher rates of diabetes is associated with higher likelihood of ER- tumors, which have fewer treatment options.

Stress. On the biological level, scholars also consider physiological pathways such as the link between postmenopausal hormone therapy and estrogen plus progestin (Colditz & Rosner, 2000) and the link between cortisone levels and stress (Gehlert et al., 2008). For example, high levels of ongoing environmental stressors associated with residing in isolated urban areas have an impact on health outcomes. There is evidence that increased likelihood of aggressive, high-grade tumors occur more frequently in women who are lonely and isolated and living in stressful social environments (Gehlert et al., 2008).

Neighborhood effects. Investigators have also identified a variety of neighborhood-level phenomena that seem to play a role in higher mortality rates from breast cancer, such as food deserts/swamps, and social isolation. The lack of access to healthy foods, supermarkets, and

fresh fruits and vegetables in urban inner city neighborhoods has been well documented in the literature. Specifically, inner city neighborhoods contain 2-4 times more fast-food outlets and convenience stores and 3 times fewer large supermarkets (Block, Scribner, & DeSalvo, 2004; Kwate, 2008; Morland & Filomena, 2007). Equally important, research suggests that the high levels of neighborhood violence and features such as vacant lots and abandoned buildings that are not maintained, also lead to higher incidence rates of cancer (Gerend & Pai, 2008, Williams & Collins, 2001; Williams & Jackson, 2005). Areas in which residents do not feel that it is safe to leave their homes, such as those found in many urban settings, lead to less physical activity. This is important because the lack of healthy food options, increased access to fatty food choices, coupled with an increased presence of neighborhood isolation and violence will only serve to increase the prevalence of obesity and subsequent incidence of breast cancer.

Facilitating access to affordable care. Important national reforms have occurred in coverage of breast cancer screening and treatment since the 1990s, including expansion of the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), which provides care for lower income women (Lantz, Weisman, & Itani, 2003). The NBCCEDP was established in 1991 with the purpose of increasing the number of women screened for breast cancer. However, the program inadvertently created a treatment gap because it did not cover all needed diagnostic services, nor any treatment costs (Lantz et al., 2003), thus producing a subset of the population diagnosed with cancer that could not afford treatment. Therefore, the NBCCEDP was adapted and expanded in 2000 to extend Medicaid coverage to any uninsured woman under 65 diagnosed with breast or cervical cancer or pre-invasive cervical disease when screened through the NBCCEDP. The new program, called the Breast and Cervical Cancer Prevention and Treatment Act (BCCPTA) (October 24, 2000) was originally adopted by 12 states and now is in all 50

states. Services coverage, provider payment rates, co-pays and length of coverage vary by state. For example, states have the option to adopt one of three coverage models. According to a report by the Susan G. Komen Foundation for the Cure (2008), 21 states and the District of Columbia have adopted the most restrictive of the three options in which women are considered eligible for Medicaid treatment only if their screening services were provided by the state's BCCPTA - funded program. The second option, adopted by 15 states, provides Medicaid treatment coverage for women even if their particular clinical service was not provided by the State's BCCPTA-funded program, but the service was within the scope of a grant, sub-grant or contract under the BCCPTA state program. Finally, option three, adopted by only fourteen of the fifty states, is the least restrictive in that under this option, women qualify to receive Medicaid treatment regardless of where they were originally screened (Susan G. Komen for the Cure, 2008). However, this option does not cover treatment for follow up care following surgery or treatment, such as treatment for lymphedema.

On March 21, 2010, President Obama signed into law the Patient Protection and Affordable Care Act and the Health Care and Education Reconciliation Act (known together as the Affordable Care Act, or ACA) (Albright et al., 2011). The ACA was created to generate opportunities for health insurance coverage for individuals who were not previously covered by any health plan. If a woman is enrolled in the ACA she is no longer eligible for coverage under the BCCPTA. She can only be enrolled in one federal program at a time. Because of this rule, some women are inadvertently ending up without breast cancer coverage. While the ACA provides additional coverage for individuals who lacked services for conditions such as diabetes, heart disease or pulmonary disease, the provisions in the ACA that effect cancer care delivery and reimbursement are more complicated (Albright et al., 2011). According to Albright et al.

(2011), the ACA calls for a delivery and reimbursement system based on a bundle of services.

Bundled payments generate a single payment for all services related to a treatment or condition.

Such that,

cancer centers and programs currently within hospital networks or academic medical centers that provide a wide range of health services, including primary care, will be able to collaborate within their existing networks. Larger independent cancer centers will need to develop partnerships with other networks providing a full range of health services, including primary care (Albright et al., 2011, p. 1568).

However, the coverage is administered on the state level and the amount and type of coverage varies by state. This new way of delivering and reimbursing for care has some insurance companies associated with cancer centers concerned about the high cost of providing care. Some of the insurance companies that have historically provided care to women under the BCCPTA program are considering not accepting the ACA for reimbursement. Therefore, if a woman obtains insurance from the health exchanges, while she will have coverage for diabetes, she will in essence have no coverage for her cancer care if she wants to be treated at one of these comprehensive cancer centers (Albright et al., 2011). Yet if she does not sign up for the ACA she will not have coverage for other comorbid diseases. As such, a treatment gap may result for this subgroup of women.

2.4. Increasing Timely Treatment Initiation as an Approach to Decreasing Disparities

Based on evidence that diagnostic mammography rates are similar for both African American and White women, and insurance is available through the BCCPTA, racial and ethnic differences in timely treatment initiation have become a greater focus of attention for studies focused on breast cancer mortality disparity (Bish, Ramirez, Burgess, & Hunter, 2006; Richardson et al., 2010; Warner et al., 2012). Specifically, while certain treatment is associated

with increased survival for women with a breast cancer diagnosis, evidence suggests that African American women use treatment less frequently, and in some cases not at all, compared to White women with similar tumor characteristics (Allen, Shelton, Harden, & Goldman, 2008; Fedewa et al., 2011). As such, the initiation of treatment may be a very important and overlooked factor in observed racial and ethnic disparities in breast cancer mortality. However, very few published studies capture data on women who are diagnosed with a malignant breast tumor and do not initiate primary first course treatment.

2.4.1 Standardized Guidelines for Breast Cancer Treatment

First, in order to investigate timely treatment initiation for breast cancer, it is important to understand that the recommended treatment of breast cancer is individualized and varies from woman to woman. Providers consider many factors when developing a treatment plan for a breast cancer, such as the tumor biology, age of patient, and presence of comorbidities. However, according to standardized guidelines, the status of estrogen (ER+), progesterone (PR+), HER2 human epidermal growth factor (HER2) receptors, and stage are the most significant indicator in the choice of recommended treatment modality (Aebi, Davidson, Gruber, & Cardoso, 2011).

The discovery that breast cancer is not one disease but instead composed of a growing number of subtypes (such as luminal A, luminal B, basal-like, HER2+/ER-, & ER-/PR-/HER2-negative also called “triple-negative”) refined treatment decision-making for women with breast cancer and increased the rate of survival for a profile of each subtype (Wheeler et al., 2013) (See Table 2.1). This is important for this project because the subtypes in which African American women are over-represented have fewer options for treatment. Luminal A tumors have the highest incidence among all races/ethnicities and the lowest mortality, yet African American

women present with higher rates of basal-like and HER2-type tumors than White women (Warner et al., 2015). Fewer treatment options are available for these subtype than for Luminal A tumors. In the Warner et al. (2015) study, African American and White women with basal-like tumors were 40% and 70%, respectively, more likely to die from breast cancer than women of the same race with luminal A tumor.

Table 2.2

Hazard Ratios for the Effect of Race on Breast Cancer-Specific Mortality by Immunohistochemical Subtype in the Carolina Breast Cancer Study

Breast Cancer Subtype	HR for race (AA vs. WA) adjusted for age at diagnosis, year of diagnosis, socioeconomic factors and tumor characteristics	
Luminal A like	1.78	(1.12 to 2.86)
Luminal B like	1.58	(1.16 to 2.15)
HER2 type	1.00	(0.57 to 1.73)
ER negative	1.14	(0.90 to 1.45)
Triple-negative	1.04	(0.79 to 1.37)

Note: HR = hazard ratio; AA = African American; WA = White American (control group); N = 17,268 women diagnosed with stage I to III between 2000-2007. ER= estrogen receptor and HER2 =human epidermal growth factor receptor.

Adapted from “Racial and Ethnic Differences in Breast Cancer Survival: Mediating Effect of Tumor Characteristics and Sociodemographic and Treatment Factors” by E.T. Warner et al., 2015, *Journal of Clinical Oncology*, 33(20), 2254-2263.

Most common profile for each subtype taken from the Susan G. Komen for the Cure website <http://ww5.komen.org/BreastCancer/SubtypesofBreastCancer.html> on July 19, 2014

2.4.2 Standard Definitions of Treatment Initiation

Many investigators chose to define treatment initiation in the literature as surgery completed. For example, Russell and colleagues (2012), who examined surgical outcomes using a national sample of 22,088 women diagnosed with breast cancer, found that African American

women were much less likely to have had surgery (any surgical type) than White women (9.0% versus 4.4% respectively, $p < .001$). Similarly, African American women were more likely than White women to have had no surgery (adjusted OR = 1.62; 95% CI 1.11 to 2.37) in a study of 5,719 women diagnosed with breast cancer in Michigan (Bradley, Given, & Roberts, 2002).

While surgery is not the only treatment option, it is the first course of recommended treatment in the vast majority of cases with the exception of women who present with locally advanced or nonresectable disease or women with distant metastases at the time of diagnosis.

2.5. Chapter Summary

This chapter established the urgency of addressing the growing racial disparity in African American and White female breast cancer mortality rates. Based on past trends and a growing incidence rate for breast cancer for both African American women and White women, this disparity will likely continue to widen over time (DeSantis et al., 2016). The time period between the identification of a suspicious finding and the initiation of treatment has an impact on the mortality rate. Knowing how to engage women in conversations about treatment decisions during this time is imperative. There are proven models of health behavior used to predict health decision making, such as the Health Belief Model and the Theory of Reasoned Action and the Theory of Planned Behavior and the Social Cognitive Theory (Glanz, Rimer, & Viswanath, 2008). The next chapter will outline some of these models and discuss their usage in the field of breast cancer prevention and treatment initiation.

3: THEORETICAL FOUNDATION

3.1. Predictors of Health Decision Making

This chapter reviews theories that are in use today that focus on health behavior and health promotion practice. Some theories focus on the individual as the unit of change, such as the Health Belief Model and the Theory of Reasoned Action and Planned Behavior. Others emphasize the contribution of families, institutions, communities and social norms, such as the Integrated Behavioral Model, the Social Cognitive Theory and social ecological models. One of the greatest challenges for investigators concerned with behavior change is learning to analyze how well a theory or model fits a particular phenomenon. Some of these theories have been widely used in the area of breast cancer to increase the use of prevention methods including screenings but have not been applied in the area of treatment initiation. Additionally, while they have been used within low-SES African American communities in the area of HIV/AIDS prevention and screening, initiating treatment for breast cancer may pose a different set of constructs for a similar population.

This chapter will begin with an overview of some of the more prevalent theories and their application in breast cancer research and practice. This overview will begin with individual-level theories (Health Belief Model and the Theory of Reasoned Action and Planned Behavior) followed by a review of three theories that are from an ecological and more interactive approach to behavioral change (Social Cognitive Theory, the Integrated Behavioral Model of Behavior, and the Social Ecological Model). The chapter will then discuss the limitations of theory development in this research area and will conclude with the contribution of the current study.

3.2. The Health Belief Model

The Health Belief Model (HBM) was developed in the 1950's by social psychologists working in the US Public Health Services, Hochbaum and Rosenstock, and has remained one of the most widely used conceptual frameworks to help explain health behavior (Hochbaum, 1958; Rosenstock, 1974). According to Champion and Skinner (2008), when this theoretical model was developed, the investigators were concerned with increasing the use of prevention and early detection services. In this way the HBM was used to help target messages that would in turn improve the outreach efforts of the US Public Health Services. Although the model has been further refined in recent years, the constructs of the model are still based on the original two learning theories, Stimulus Response Theory and Cognitive Theory.

Stimulus Response theorists are concerned with how reinforcement of behavior leads to an increase in behavioral response. In this case social psychologists believe that the act of an immediate reward is enough to reinforce a positive behavioral response from the receiver. A person learns to enact new behaviors, change existing behaviors, and reduce or eliminate behaviors because of the consequences and rewards of their actions. According to Champion and Skinner (2008), behavioral response is a basic learned behavior, requiring no act of reasoning or thinking on the part of the receiver.

Whereas Stimulus Response theorists are not concerned with reasoning or thinking on the part of the receiver, the constructs of reasoning and thinking are a fundamental part of Cognitive Theory. Cognitive theorists emphasize the role of the subjective expectations held by the person, such as beliefs, attitudes and desires. According to Champion and Skinner (2008), cognitive theorists believe that reinforcement of these subjective beliefs and expectations about a particular situation rather than the behavior itself drives behavior change. For example, it was assumed by

these theorists that the value of avoiding illness along with the expectation that a specific health action would help to prevent illness would be enough to alter a behavioral outcome (Champion & Skinner, 2008).

The HBM combines both of these theories to posit a model that includes six constructs presented to predict why individuals enroll in health behavior activities: perceived susceptibility; perceived severity; perceived benefits; perceived barriers; cues to action; and self-efficacy (Figure 3.1) (Champion & Skinner, 2008).

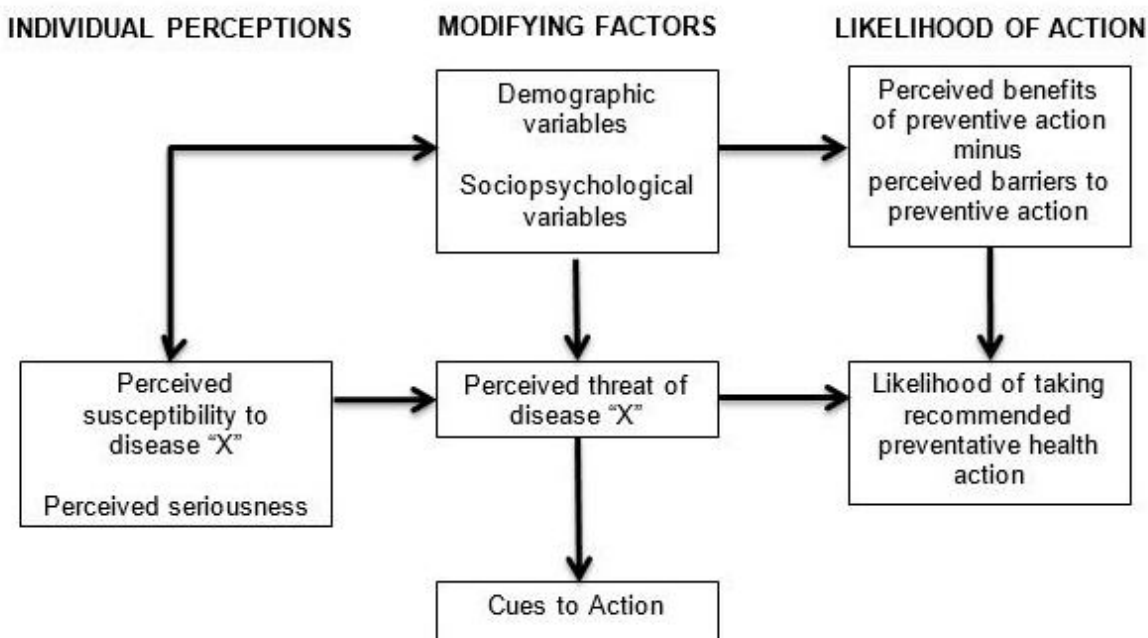


Figure 3.1 Health Belief Model retrieved from Perceptions of successful cues to action and opportunities to augment behavioral triggers in diabetes self-management: qualitative analysis of a mobile intervention for low income Latinos with diabetes. Burner, et al., 2014, 16(1): e25

The HBM has been widely used to help explain the psychosocial variables involved in breast cancer screening and prevention. A scoping review of the CINAL database using the terms “health belief model” and “breast cancer” produced 97 peer-reviewed scholarly manuscripts in academic journals between 2000 and 2016. The overwhelming majority of those

articles were focused on increasing screening mammography. Another sizable portion was focused on increasing physical activity amongst breast cancer survivors. A third and smaller group of manuscripts focused on increasing the use of breast self-examination. Many investigators choosing to use a scale developed and validated by a scale created by Champion in 1984 specifically for the HBM constructs related to breast self-examination is widely used in prevention research (Champion & Skinner, 2008). The scale was revised in 1997 to add mammography-barrier constructs (Champion & Scott, 1997). The revised scale was validated with a population of 344 low income African American women recruited into a mammography-promotion intervention study (Champion & Skinner, 2008). The scale has since been translated into other languages and validated with other ethnic groups. According to Champion and Skinner (2008), the construct of “perceived susceptibility” (the likelihood of getting breast cancer) displays the highest internal consistency reliability across studies. They also found that mammography screening is higher when women perceive barriers to screening as lower than perceived benefits and when self-efficacy is high (Champion & Skinner, 2008).

3.3. The Theory of Reasoned Action and the Theory of Planned Behavior

The Theory of Reasoned Action and the Theory of Planned Behavior are often applied to interventions as a unit (see Figure 3.2) and add the concept of behavioral intentions to health behavior research (Montano & Kasprzyk, 2008). This aggregated model assumes an individual’s intention is the most important determinant of behavior, and thus if barriers and supports to intention can be identified and addressed, the outcome will be behavioral change.

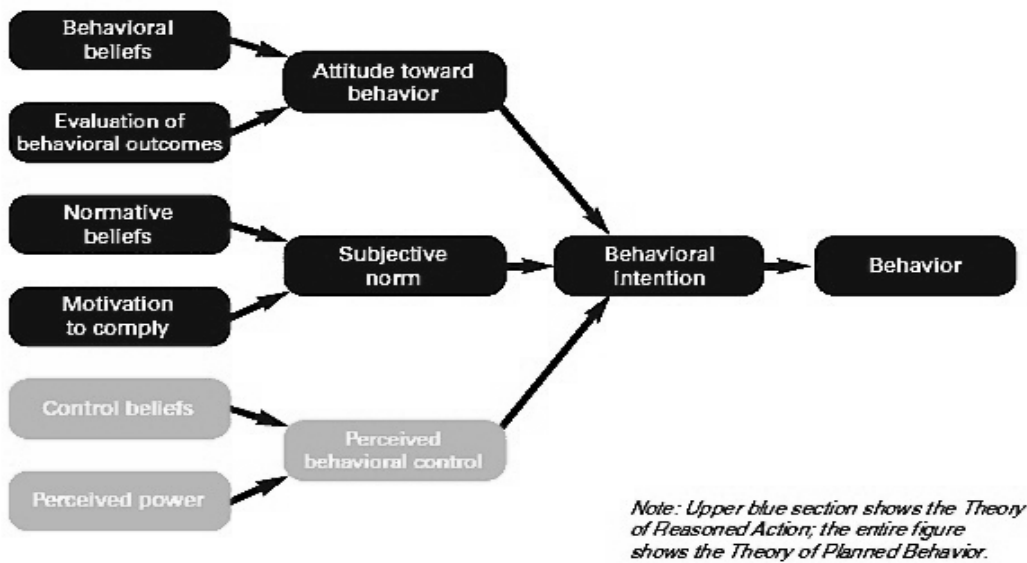


Figure 3.2 The Theory of Reasoned Action and the Theory of Planned Behavior Model. Accessed at Theory at a glance: a guide for health promotion practice, 2nd ed. Bethesda, MD: National Institutes of Health; 2005:18, http://cancercontrol.cancer.gov/brp/research/theories_project/theory.pdf on May 21, 2016.

Before I explain the aggregate model, I will explain the individual models. The Theory of Reasoned Action (TRA) was first developed by Fishbein in the late 1960s (Fishbein & Azjen, 1975). This theory is focused on behavioral intention, the likelihood that an individual will behave in a certain way given a particular situation, not the actual behavioral outcome (Montano & Kasprzyk, 2008). The basic premise of this model is the belief that behavioral intention is influenced by a person's attitude towards performing a behavior and by the perception of whether the people close to them will approve or disapprove of the behavior (subjective norm). TRA contributes eight constructs to the model: behavior, behavioral intention, attitude, behavioral belief, evaluation, subjective norm, normative beliefs, and motivation to comply (Montano & Kasprzyk, 2008). TRA was modified by Fishbein and Azjen (1975) to include the Theory of Planned Behavior (TPB) in the 1970's. TPB is an extension of TRA and adds perceived control over the performance of the behavior as an additional construct (see Figure

3.2). Proponents of TPB posit that the presence or absence of factors that will make a behavior easier or harder to perform affect perceived behavioral control.

One difference between the HBM and the TRA/TPB model is an added focus on what others in the environment would think about the behavior and how that might influence the woman's health behaviors. So for example, a hypothetical study of mammography screening focused around HBM would examine an individual woman's beliefs and attitudes about breast cancer and screening. On the other hand, a similar hypothetical study of mammography screening focused around TRA/TPB would examine how much influence a group's opinion of breast cancer and screening has on the woman's attitudes and beliefs about screening. The first study may show that most women have a positive attitude about avoiding breast cancer, and yet the second study might find that women's positive attitude about avoiding breast cancer does not always translate into positive attitudes about screening because of messages from her family and friends.

TRA/TPB has been used less frequently in breast cancer research than HBM. A scoping review of the CINAL database using the terms "theory of reasoned action" and "theory of planned behavior" and "breast cancer" produced only 4 manuscripts in academic journals between 2000 and 2016. Three papers, focused on increasing physical activity amongst cancer survivors, were published in nursing journals and written by the same research team at a nursing school in Canada. This group found a high correlation between the constructs of the TRA/TPB model and intention to exercise. Specifically, one of the studies, using a survey of 83 breast cancer survivors and regression analysis reported that attitude, subjective norm, and perceived behavioral control explained 45% of the variance in exercise intention, with each construct adding a unique contribution (Blanchard, Courneya, Rodgers, & Murnaghan, 2002).

The fourth paper through the CINAL search focused on predicting mammography screening intention. This paper was also completed by a team of investigators from a nursing school, Louisiana State University who surveyed 302 rural women from Southeastern Louisiana without a prior history of breast cancer to test the TRA/TPB model. Using regression analysis, they found that the TRA/TPB model explained 24% of the variance found in screening mammography intention and that the construct “perceived control” was the strongest predictor (Steele & Porche, 2005).

These results support evidence that the TRA/TPB model has positive implications in helping understand intentions and motivations behind behaviors. Understanding whether or not a person feels empowered to control a behavior is important because it is an actionable item. It is a place where interventions can have a strong impact, at least in theory. Yet the focus remains on individual motivation and does not include interpersonal, group and community factors to any great extent, such as poverty, access issues, or educational attainment. People cannot always act on their perceived control and good intentions. Therefore, a model is needed that includes an interaction with the person in environment. The next set of theories, the Integrated Behavioral Model, the Social Cognitive Theory and the Social Ecological Theory is a step in that direction.

3.4. The Integrated Behavioral Model

In an effort to deemphasize the differences between the various models of health behavior, the National Institutes of Mental Health convened a working group in 1992 of leaders in the field of behavioral health theory, including Fishbein, Ajzen, Kasprzyk, and Montano, to develop an integrated model of health behavior (Fishbein, Cappella, Hornik, Sayeed, Yzer., & Ahern, 2002).

This model attempts to demonstrate how environmental and individual factors interrelate to impact behavior.

According to the integrated Behavioral Model (IBM), four major components affect behavior: intention, including the influences thereof from the TRA/TPB model; knowledge and skills to carry of behavior; the saliency of the behavior to the individual; and environmental constraints (See Figure 3.3) (Fishbein & Yzer, 2003). This model is similar to the TRA/TPB model in that intention to perform the behavior is the central construct, but this model also expands and renames the constructs that influence attitudes and normative behavior and redefines the control elements to include self-efficacy. The IBM postulates that a particular behavioral outcome is most likely to occur if: (1) a person has strong intentions to perform it and the knowledge and skills to do so, (2) there is a lack of environmental constraints preventing the person from following through on their intentions and (3) the act of the behavior is salient, or seen as important to the individual performing the behavior (Fishbein & Yzer, 2003).

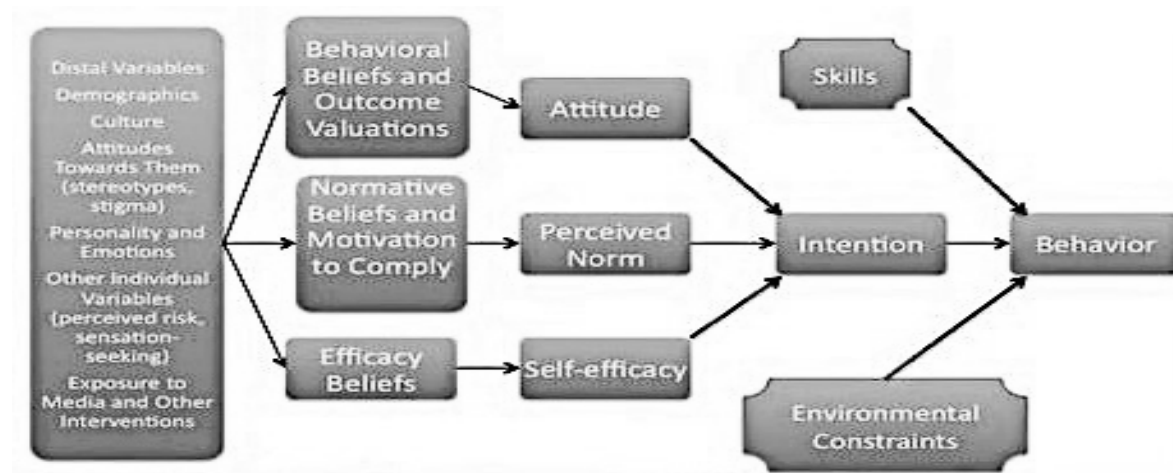


Figure 3.3 An Integrated Model of Behavior Prediction. Retrieved from M Fishbein & MC Yzer, 2003, Using theory to design effective health behavior interventions. Communication Theory, 13:164-183.

In the IBM, the constructs “attitudes” and “perceived norms” are similar to those of the TRA/TPB model. Attitude measures an individual’s positive emotional reaction to performing the behavior, such that those with strong positive emotional reactions are more likely to perform the behavior (Montano & Kasprzyk, 2008) while perceived norm refers to the social pressure she may feel to carry out the behavior (Montano & Kasprzyk, 2008). Perceived norms include what others in her circle of influence thinks should be the behavioral response as well as the motivation to comply with those individuals (Montano & Kasprzyk, 2008). Additionally, the actual actions of others in the person’s environment may influence her decision to perform the behavior (Montano & Kasprzyk, 2008). In the IBM, perceived behavioral control (from the TRA/TPB model) has been renamed as self-efficacy (Fishbein & Yzer, 2003). Whereas perceived behavioral control is an individual’s perceived amount of control over the behavioral performance, self-efficacy is the individual’s degree of confidence in her ability to perform the behavior in the face of various obstacles and challenges (Montano & Kasprzyk, 2008).

The relative importance of the three theoretical constructs –namely attitude, perceived norm and self-efficacy – in determining behavioral intention may vary for different behaviors and for different populations, specifically with the degree to which environmental factors make it easy or difficult to carry out the behavior (Montano & Kasprzyk, 2008). Thus it is important first to determine the degree to which that intention is influenced by attitude, perceived norm and personal agency to design effective interventions to influence behavioral intentions. The IBM provides a theoretical basis from which to understand behavioral intention and identify specific beliefs for targeted interventions (Fishbein, Von Haefen, & Appleyard, 2001; Guilamo-Ramos, Jaccard, Dittus, Gonzalez, & Bouris, 2008; Jaccard, Dodge & Dittus, 2002; Lindsey, Chambers, Pohle, Beall, & Lucksted, 2013). A quick search of the CINAL database using the terms

“integrated behavioral model” and “breast cancer” did not produce any peer reviewed scholarly manuscripts in academic journals.

3.5. Social Cognitive Theory

While individual-level theories are useful in many respects, as demonstrated above, their ability to explain social phenomena is limited because they lack the ability to capture the impact of the social environment over the course of a person’s life. Social norms such as messages within isolated communities, access to adequate health care resources, and environmental stressors that increase isolation may also influence health behavior. Whereas HBM and TRA/TPB explain how to predict health behavior, they do not address the mechanisms that influence behaviors such as relationships within the individual’s social environment. Social Cognitive Theory (SCT) has been used by social scientists to understand health care disparities. SCT suggests, “human behavior is the dynamic interplay of personal, behavioral and environmental influences” (see Figure 3.4) (McAlister, Perry, & Parcel, 2008, p. 170). SCT is a psychological model of social learning and development whose principal proponent is U.S. psychologist Albert Bandura (Bandura, 1986; McAlister et al., 2008).

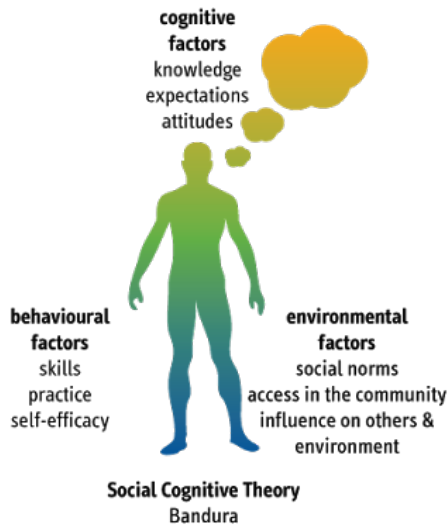


Figure 3.4 Bandura’s Model of Social Cognitive Theory. Source of Image <http://ahmadasim.blogspot.com/p/constructive-perspectives.html> accessed May 21, 2016

Bandura initially focused on observational learning or modeling (social learning theory) and later developed this theory further into SCT (Bandura, 2005). In the social cognitive theoretical view, individuals are neither solely controlled by internal forces nor do they automatically respond to factors from their external surroundings. Instead, they engage in a reciprocal process in which behavior is the product of a dynamic, reciprocal interchange between personal/cognitive factors, behavior factors, and the social environment (Bandura, 1986).

Bandura supported the concept that individuals’ behavior is influenced by the environment with which they interact on a regular basis. However, Bandura (1986) indicated that an individual’s behavior also influences the environment in which the individual dwells. The mutual effect and interactions shared between an individual and the environment is known as “reciprocal determination” (McAlister et al., 2008). Numerous key concepts are incorporated in the SCT model. For purposes of this study, three specific constructs will be discussed: (1) psychological (cognitive) determinants of behavior, (2) behavioral factors, and (3) environmental determinants of behavior.

Psychological (cognitive) determinants of behavior. Psychological determinants of behavior include intra-personal and social outcome expectations. Outcome expectation is defined as “beliefs about the likelihood and value of the consequences of behavior choice” (McAlister et al., 2008, p. 171). This concept, similar to the Health Belief Model, is grounded in the principle that people are motivated to maximize benefits and minimize costs (Gehlert & Bollinger, 2012). For example, the strength of a perceived threat of a cancer diagnosis can be offset by the strength of the perceived benefit of screening, and therefore the outcome could be increased screening and prevention practices. How a woman perceives a threat, and her ability to process the outcome will influence her health decision-making.

Interventions often rely on interactive patient decision aids and decision support counseling to better equip a patient to weigh a perceived threat versus a perceived benefit for a given situation in order to make better informed healthcare decisions. For example, to help address barriers to informed decision-making during the provider-patient interaction, Vidal and colleagues at Dartmouth-Hitchcock Medical Center developed interactive patient decision-making aids to help equip patients with the information needed to make better-informed decisions (Ubel, 2012). These aids included free use of an online library of videos that are downloadable. Patients also had the option to request pamphlets and booklets on several topics, including breast cancer screening and prevention. The Center also provided free one-on-one decision support counseling to help patients understand the material. This intervention resulted in higher health literacy rates. Patients reported a better understanding of the information given during a medical encounter.

A team of investigators completed a systematic review of the use of decision-making aids for patients who were facing a screening decision (Stacey et al., 2009). They reviewed 86

randomized controlled trials involving 20,209 participants and found that decision aids increased a patient's involvement in decisions about their health, and improved understanding and perceived risk and benefits of outcomes (Stacey et al., 2009). However, many of these interventions are limited in scope in the sense that the provider-patient relationship is not an equal partnership. The patients had very little self-efficacy to communicate with their doctors (Sheppard et al., 2010). Increasing the health knowledge of the patient did not address this power differential.

Behavioral Capacity. Central to this group of SCT constructs is the concept of perceived self-efficacy, or the extent to which the individual believes she can control expected benefits and costs. Behavioral capacity is the result of an individual incorporating the necessary knowledge and skills into practice, thereby performing and mastering a desired behavior. The performance of many behaviors is a direct result of both outcome expectations and self-efficacy working together (McAlister et al., 2008). Perceived self-efficacy affects a woman's investment in performing a behavior (such as breast cancer treatment initiation), her behavioral decision-making, her perseverance and affective state when trying to perform a behavior in challenging situations, and her engagement in positive or negative thinking while trying to perform the behavior (Bandura, 1986). Self-efficacy is essential in understanding how individuals can overcome barriers to a behavior. Lacking self-efficacy decreases the likelihood that the behavior will be performed, especially in challenging situations, even if one has the skills, knowledge, and resources to perform it.

Like all SCT constructs, perceived self-efficacy is influenced by both internal and external forces and therefore varies as a function of the individual's environment as well as her intrapersonal state (Bandura, 1986). Intrapersonal state can influence perceived self-efficacy

through changes in mood, which can be altered by failed attempts to accomplish the behavior. For example, if a woman has tried to obtain treatment in the past for another illness and failed, she may be less likely to feel empowered to be able to obtain the treatment needed in the current state of affairs. Similarly, environmental factors can also influence perceived self-efficacy through social norms and social support, which can enhance perceived self-efficacy by providing positive or negative affirmation of a person's ability to perform the behavior. For example, if the same woman receives information from a neighbor about their personal experience with receiving treatment, the woman may feel more empowered to seek treatment. To date no study could be found that considered the association between perceived self-efficacy and treatment initiation in breast cancer. Yet social peer norms have been strongly associated with sexual behavior interventions in diverse high-risk populations, with direct links and indirect links through self-efficacy being found to explain this relationship (Latkin, Sherman, & Knowlton, 2003; Miner, Peterson, Welles, Jacoby, & Rosser, 2009).

Environmental determinants of behavior. Environment entails factors external to the individual that influence a person's behavior. One concept, which may prove central to this study, is observational learning. Observational learning is defined as "learning to perform new behaviors by exposure to interpersonal or media displays of them, particularly through peer modeling" (McAlister et al., 2008, p. 171). The social learning theory and social cognitive theory postulated by Bandura (1971) provide a model to establish the connection between social norms, observational learning, and modeling and social learning as it relates to the sample population. For example, social norms (such as fatalism and spirituality) have been shown to influence breast cancer screening behaviors (Champion et al., 2008; Peek, Sayad, & Markwardt, 2008; Russell, Monahan, Wagle, & Champion, 2007). Fatalism is defined as "the belief that the future is

predetermined and that action or inaction will not influence outcomes...because it is believed that action will not change outcomes, one will be better off not knowing about the disease” (Sheppard et al., 2011, P. 1311). These interactive concepts have had some success when incorporated in interventions aimed at increasing screening and prevention practices. It stands to reason that they may also influence treatment initiation practices as well.

3.6. Social Ecological Models

The Social Ecological Model (SEM) is a theory-based framework for understanding the multifaceted and interactive effects of ‘person in environment’ and the factors that determine behavioral intent (Sallis, Owen, & Fisher, 2008). Ecological models highlight the interaction between individuals, social relationships, community, institutions and society factors. Proponents of ecological models of health view health behavior as a byproduct of the interaction of these levels. The pioneer of the ecological model is Bronfenbrenner (1979). However, the model has been adapted by many different scholars and disciplines since 1979. For instance, McLeroy, Steckler, Bibeau and Glanz (1988) presented their ecological approach which included the following constructs: interpersonal, interpersonal processes and primary groups, institutional factors, community factors, public policy.

A national transdisciplinary group of investigators attempting to understand the factors that contribute to cancer have identified factors at multiple levels of influence from the biological level to the neighborhood level and vice versa (see Figure 3.5) (Gehlert et al., 2008). This group of scientists theorize that by investigating these factors simultaneously, it might be possible to identify what contributes to the disparities found in cancer outcomes. A fundamental component of this model is the inclusion of social determinants of health. Social determinants of health (SDOH), as defined by the World Health Organization Health Commission on Social

Determinants of Health, are those “circumstances in which people are born, grow up, live, work and age, and the systems put in place to deal with illness” (Kaplan & Galea, 2014, p. 90). SDOH are connected with the life course and over time may impact every aspect of a person’s life, from cell growth, to the pursuit of jobs, to interaction with neighbors, to mortality. Characterizing the associations between SDOH and health outcomes is complex. Many of the concepts (such as discrimination, race, social isolation, and mobility) are difficult to measure; yet it is imperative to uncover these associations in order to move closer to addressing the fundamental causes of health outcomes.

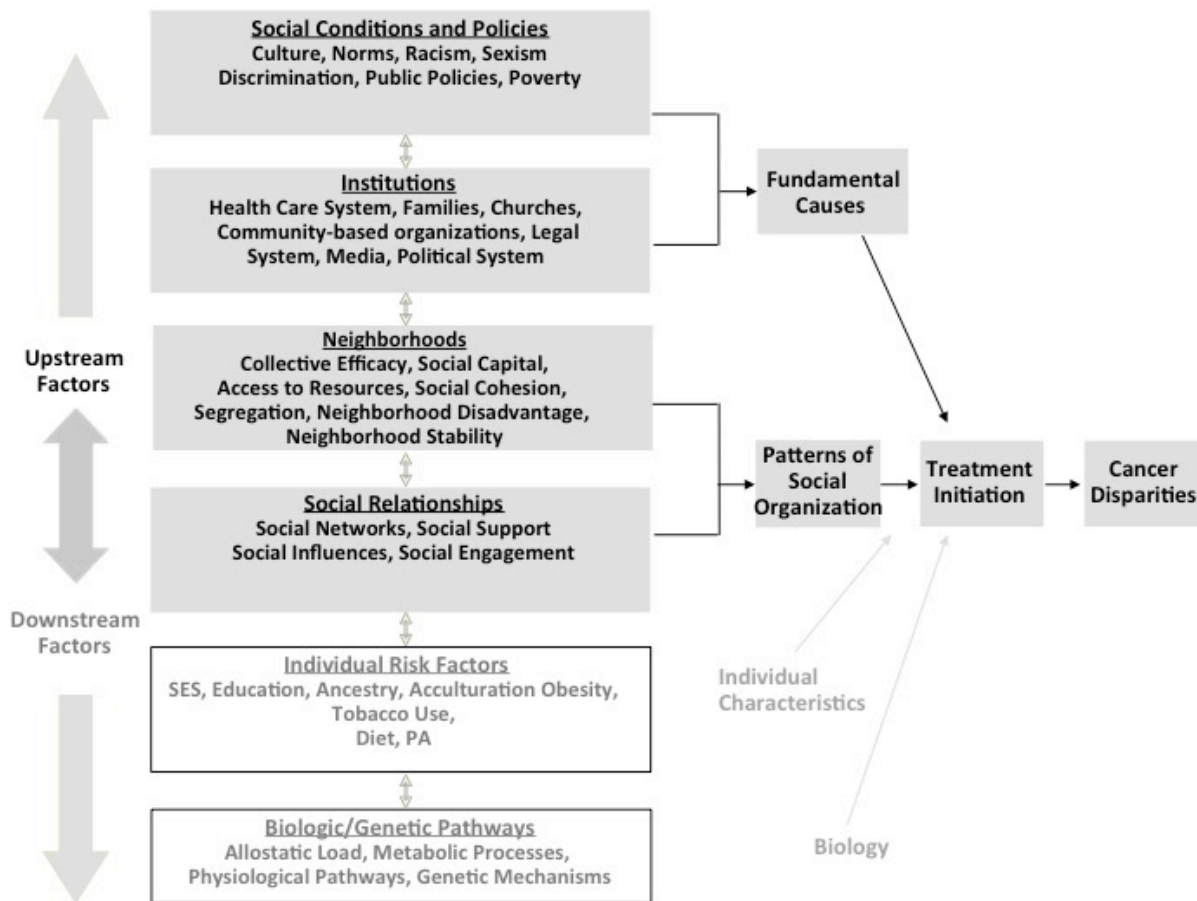


Figure 3.5 Factors at Multiple Levels that Contribute to Cancer Disparities. Adapted from “Targeting health disparities: A model linking upstream determinants to downstream interventions” by S. Gehlert, D. Sohmer, T. Sacks, C. Mininger, M. McClintock, & O. Olopade, 2008, *Health Affairs*, 27(2), 339-349.

Although delineating these associations presents social scientists with challenges, examples exist of studies that have connected SDOH and breast cancer mortality. An example comes from the results of a qualitative study by Sheppard and colleagues (2010) that included data from interviews with 34 African American breast cancer survivors in Washington DC in developing messages for a treatment decision support intervention. This study explored social, behavioral and spiritual attributes that influenced African American women's treatment decisions. The authors found that treatment decisions were influenced by cultural messages (such as hope, determination and faith in God) as well as fear of treatment side effects (such as hair loss and nausea). Decisions were also influenced by common myths that drug therapies were experimental and that physicians want to use people as 'guinea pigs' in research (Sheppard et al., 2010). As a result, these women chose not to begin treatment (Sheppard et al., 2010).

My colleagues and I (Noel et al., 2015) found similar attributes for 96 low-income African American women in North St Louis in a recent interview-based study. Women in this study were averse to beginning chemotherapy and radiation therapy based on the negative experiences of people they knew or stories they had heard. For example, when asked if she understood the diagnosis and recommended treatment, one participant responded:

Somewhat, I had friends with breast cancer and they suggested I research on the internet. I was recommended to have a mastectomy. I got a little upset. I didn't want that and was given an option. Mastectomy with no chemotherapy or radiation or lumpectomy with chemotherapy and radiation. My friend had breast cancer the previous year and recommended that I have reconstructive surgery. I went on several interviews with plastic surgeons and got a saline implant. My friend and my daughter convinced me to get a mastectomy.

Another participant who was concerned about the effects of chemotherapy did not receive treatment following her mastectomy, stating:

I did not want to do chemotherapy because my friend had suffered so from chemotherapy. Nor did I want reconstruction surgery. The doctor really wanted me to do this.

These examples show the importance of including social and environmental constructs in health behavior models.

3.7. Chapter Summary and Contribution of This Study

As outlined in the first part of this chapter, application of health behavior theories in breast cancer research has been limited in focus to increasing the use of breast self-examination, mammography screening as prevention efforts, and physical activity among breast cancer survivors. However, little is known of how these theories would enhance the rate of breast cancer treatment initiation, especially among medically disenfranchised African American women. For instance, are there additional constructs to consider? Do some of the relationship directions and/or strengths change based on the influence of the social environment? Further illuminating the relationships between the constructs of these models of health decision making and the rate of increasing treatment initiation for breast cancer will allow interventions to be better tailored for optimal health outcomes.

Also, an under-explored area of attention for scientific studies on breast cancer treatment initiation and health decision-making is how to identify and engage in research women who do not follow up with treatment for a breast cancer diagnosis or other life threatening diseases. Often these are among the most marginalized women of our society, confronting homelessness, drug dependency, fear or shame, comorbidity or disabilities, being underinsured or uninsured, and living in areas characterized by low-SES and disenfranchised medical services. These women are often under-represented in research studies yet they have some of the highest rates of

mortality from many different health related outcomes. Including them in a research study will add to the scientific knowledge base.

In addition, despite a growing theoretical literature on health decision-making, few have explored the meaning lower SES African American women apply to breast cancer treatment decision-making. Yet identifying and characterizing the people, places and treatment messages within the social and cultural environment that highly influence the initiation of treatment can help to help tailor interventions to optimize health outcomes. Most research on breast cancer disparities has focused on the biological/genetic pathways and individual risk factors (e.g., smoking, cancer screening and diet) to the exclusion of social relationships, neighborhoods, institutions, and social conditions and policies. The lack of empirical work in this area, combined with the need to comprehend in greater detail this experience from the woman's perspective, requires a focus on this vulnerable group of women.

This study adds to the scientific literature by engaging in research and giving a voice to women who are under-represented in previous scientific studies. It is a retrospective exploration of the lived experience of African American women, living in a socially and economically isolated environment in North St Louis City or North St Louis County, who had not started a recommended breast cancer treatment plan for more than six-months following a finding that required follow-up care. The next chapter will outline the research design.

4: STUDY DESIGN AND METHODS

4.1. Research Approach- Transcendental Phenomenology

The qualitative research approach, of phenomenology, is used to determine and describe what an experience means for those who live that experience (Cohen, Kahn, and Steeves, 2000; van Manen, 1990). The method involves the use of thick description and close analysis of *lived experience* to capture the meaning and common features, or “essence,” of an event or phenomenon (Groenewald, 2004; Starks & Trinidad, 2007; Moustakas, 1994; Vagle, 2014). This study provides thick, rich descriptions of the lived experience(s) of a cohort of African American women with breast cancer and their treatment decision-making processes that foster a unique understanding of this phenomenon. This type of research dictates a sustained interaction with people within their own surroundings (Creswell, 2013; Van Manen, 1990). Phenomenological research thus focuses on the whole experience rather than solely on objects or parts, obtaining descriptions of lived experience in first person accounts (Moustakas, 1994; Starks & Trinidad, 2007).

Discussions of phenomenology first appeared in the eighteenth century, written by philosophers such as Kant, Hegel and Descartes (Dowling, 2007; Giorgi, 2009). According to van Manen (1990), one of these eighteenth century philosophers, as a philosophical construct, phenomenology was defined simply as a sense of the lifeworld. The application phenomenology from a descriptive science is associated with Edmond Husserl and is often referred to as descriptive phenomenology or more commonly transcendental phenomenology (Giorgi, 2009; Levinas, Cohen & Smith, 1998; Moustakas, 1994; van Manen, 1990). Transcendental phenomenology necessitates the investigator step out of her own experiences in order to hear and illuminate how the participants apply meaning to the phenomenon (Dowling, 2007). Husserl

describes phenomenology as “descriptive doctrine of the essence of transcendently pure experiences” (Husserl & Dahlstrom, 2014, p.134). According to van Manen (1990), Husserlian transcendental phenomenology “does not study the ‘what’ of our experience but the ‘experience’ of the what – the experience of the intentional object, thing, entity, event as it appears in consciousness” (van Manen, 1990, p.91). Husserl presented a scientific model based on what he coined “phenomenological reduction” that would illuminate how objects are experienced and subsequently interpreted in the human subconscious (Cohen et al., 2000; Levinas et al., 1998; Sloan & Bowe, 2014). Consider the following example: a young lady is walking across the campus of Washington University and encounters a large and beautiful oak tree. For an instant she is transcended to a time when she and her father spent time in a treehouse in a similar tree. She feels an overwhelming sense of warmth and security in this moment. She sits under the tree and reflects on the past experience with her father, her current experience with the University and the future hope that lies in opportunities that await her. The importance of this scenario is not the tree itself but her experience with encountering the tree. In this way, transcendental phenomenology is not the study of the outcome of a phenomenon but rather it is the study of someone’s experience of the phenomenon.

Current phenomenological practitioners divide into two camps, Husserl’s transcendental, also referred to as descriptive phenomenology, or Heidegger’s interpretive phenomenology, also referred to as hermeneutic or existential phenomenology (Dowling, 2007; Giorgi, 2009). Hermeneutic phenomenology was developed after Husserl’s descriptive phenomenology because Heidegger did not believe it was possible for the investigator to bracket or set aside their experiences during the study process (Sloan & Bowe, 2014). Transcendental phenomenology holds that the investigator “could transcend the phenomena and meanings being investigated to

take a global view of the essences discovered” (Sloan & Bowe, 2014, p. 1294). Husserl believed the investigator could remain objective. Heidegger on the other hand disagreed and held the view that the investigator would be a natural part of the process and as such would experience the phenomena along with the participants. Interpretive phenomenology, therefore, includes the investigator’s perceptions and experiences of the process along with the participant’s (Van Manen, 1990). Husserl’s transcendental phenomenology is intended to be more of a bird’s eye view of the participant’s description of their experience with the phenomenon with the ultimate goal of gaining a better understanding of the essence of the phenomenon. Transcendental phenomenology includes the technique of “bracketing” out influences outside of those brought to the table by the participant in order to get at the essence of the phenomenon (Cohen et al., 2000). Hermeneutic phenomenology is, on the other hand, concerned with the process of how the participant is actively processing and illuminating the experience of the phenomenon to the investigator, such as language, smells, touch, verbal and non-verbal clues, and how the person interacts with the investigator (Sloan & Bowe, 2014). As such, hermeneutic phenomenology does not bracket out the perspective of the investigator.

This study uses the principles of Husserl’s transcendental phenomenology, with the purpose of gaining a better descriptive understanding of how African American women in a region of North St Louis City and North St Louis County experience treatment decision making after the identification of a breast abnormality that is most likely breast cancer and where treatment was delayed for more than 6-months. This study hopes to illuminate the experiences of this vulnerable group of women whose voices and experiences are underrepresented in the research. Because I have a background in practice and research in this area, I come to the table with many preconceived ideas and theories. Therefore, as principal investigator (PI), bracketing

was used in order to remain open to new themes that may illuminate the unique nature of the experiences of this group of women from other women who initiate care within 6-months thus adding to the scientific research base.

4.2. Research Questions and Specific Aims

Research Questions

- 1) What are the lived experiences of African American women who had not followed up with care for a diagnosis of breast cancer for 6-months or more following a breast abnormality?
- 2) How do women apply meaning to the process of deciding whether or not to initiate treatment for breast cancer?
- 3) Under what circumstances does the phenomenon (treatment for breast cancer was not initiated) persist for more than 6-months?

Specific Aims

- 1) To collect the lived experiences (individual narratives) of African American women who did not follow up with care for a breast abnormality or after an abnormal clinical breast exam or an abnormal screening mammogram, that is classified as suspicious finding or a diagnostic biopsy or a diagnostic test classified as C4 (most likely cancer) or C5 (cancer).
- 2) To illuminate elements of how a woman applies meaning to the process of deciding whether or not to initiate treatment.
- 3) To analyze the collective narratives of a cohort of women who have not initiated timely breast cancer treatment to articulate the common experiences of the phenomenon (health decision making process as it relates to follow up care for breast cancer).

4.3. Participants

The present study helps to a gap in the literature by identifying and engaging in research women who have not started a treatment plan for a diagnosis of breast cancer for more than 6-months following a breast abnormality, women who live in low-SES communities and African American women. This would allow me as the primary investigator to engage in research and give a voice to women who are under-represented in previous scientific studies and to enhance existing models of health decision making.

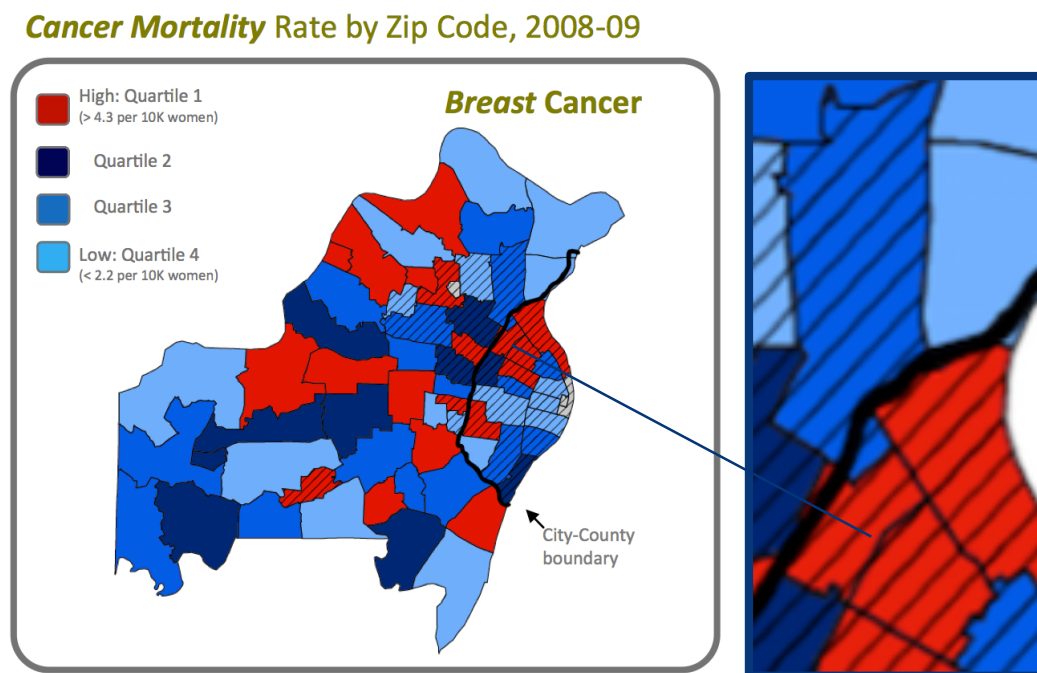


Figure 4.1 Map of Geographic Area Where Participants Live; retrieved from St Louis Regional Health Commission Decade Review of Health Status Report for St Louis City and County, 2008-2009; <http://www.stlrhc.org/work/decade-review-health-status-report/> on April 2, 2016

The women who participated in this study reside in a small geographic area which includes North St Louis City neighborhoods and portions of North St Louis County including Jennings and Ferguson (ZIP codes 63115, 63120, and 63136) (see Figure 4.1). This area was targeted

because it is characterized by predominately African American communities and neighborhoods and the high rates of adverse social and health outcomes in the St Louis region. Table 4.1 highlights some of these disparities. This study is as much about (if not more) illuminating the lived experience of treatment decision making for this vulnerable group of women as it is about identifying potential supports and barriers to treatment initiation (Vagle, 2014).

Table 4.1

Selected Health and Social Outcomes for Participant ZIP Codes (rate per 10,000)

	Breast Cancer Mortality Rate 2008-2009	Heart Disease Hospitalization 2009-2010	Diabetes Hospitalizations 2009-2010	Victims of Violence 2000-2009
63115	4.2	250.8	60.2	73.1
63120	6.0	234.1	55.8	79.8
63136	2.9	195.3	48.4	60.8
St Louis City & County Mean	3.3	161.9	24.7	30.7

Source: St Louis Regional Health Commission Decade Review of Health Status Report for St Louis City and County

4.3.1 Inclusion and exclusion factors

Inclusion:

- African American
- Over age 18
- Lived in St Louis City or St Louis County
- Diagnosed with breast cancer or received an abnormal mammogram which was most likely breast cancer

- Had not followed up with care for 6 or more months following a breast abnormality

Exclusion:

- Non-English Speaking
- Incarcerated

4.3.2 Enrollment

Although the targeted number of examples was 8-15, I was only able to recruit eight. This was due to the fact that this group of women is very isolated and does not participate in the more common sources of recruitment, such as churches and beauty salons. They are also not participating in the usual sources of preventive care, so utilizing our contacts at community based clinics did not yield any women. Therefore, the study was promoted among community-based breast patient navigators, the State Health Department's Show Me Healthy Women coordinators county-wide, homeless shelters, women's shelters, community health centers (such as Planned Parenthood), and other community locations who serve women. A substantial amount of time was needed to develop trust within the community and with each participant. Participants then referred the study to other women they knew met the inclusion and exclusion criteria.

To reach the number of examples needed to properly describe this phenomenon the study featured two sampling techniques: criterion and snowball. The recruitment started with criterion sampling, because it allowed for women to be identified who have experience with the phenomenon and are able and willing to share their story (Creswell, 2013; Vagle, 2014). Criterion sampling was coupled with snowball sampling. The snowball method expanded the number of examples through participants' recruitment through social networks. I did not set out

to incorporate snowball methodology in this study. What I found instead was that every woman knew someone who had waited longer than she did or did not follow up on care at all. Furthermore, these women reported not sharing their own experience with anyone, so the fact that they were willing to recommend me to someone whom they knew was a testament to our ability to achieve a high level of comfort and trust within the interview relationship.

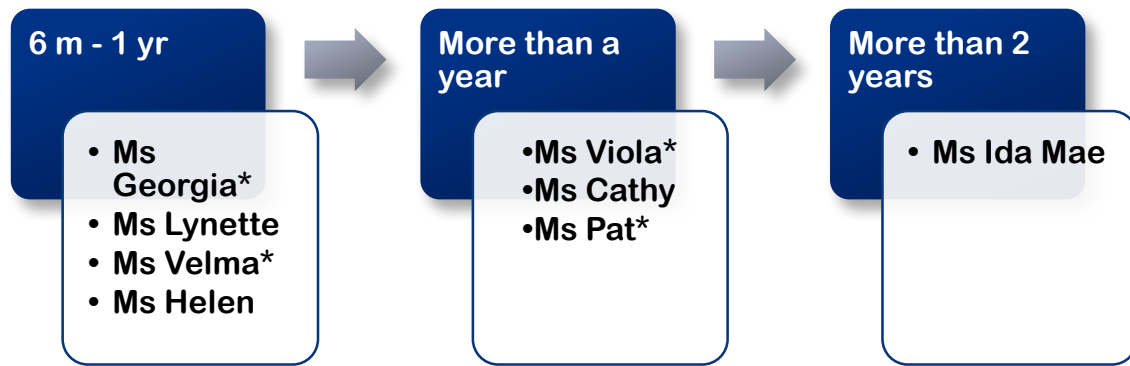


Figure 4.2 Recruitment Progress – Criterion and Snowball Techniques
 * Indicates a woman who recommended the study to another woman

Figure 4.2 represents the flow of recommendations during recruitment. As shown in the Figure and indicated by an (*), four of the eight women recommended the study to another woman. Recruitment and interviewing lasted for five months (November 2015 through March 2016). It took much longer to build rapport with women where treatment had been delayed for close to two years or more than for women closer to 6-months. It is possible that, had I spent a year in the field, I may have been able to interview more women at the 2-year mark or even women who had never started treatment. However, even with eight examples, I collected enough information to illuminate the essence of this phenomenon.

While the number of examples is small in comparison to that of other methods, the same size is appropriate for phenomenological studies (Eatough & Smith, 2007; Groenwald, 2004; Starks and Trinidad, 2007). The goal of phenomenological research is not to generalize but to illuminate in-depth characteristics, themes, and content that shine a light on the “what” and “how” of a lived experience (Starks and Trinidad, 2007; Van Manen, 1990). The unit of analysis is not the individual but rather the phenomenon (Dukes, 1984; Vagle, 2014). In general, a phenomenological investigator seeks as many examples as needed to provide a rich account of the experience of this phenomenon as it is lived by this group of women (Van Manen, 1990, Wertz, 2005). Experts in the field of phenomenology state that as few as one and as many as 25 participants could be used to provide examples of the lived experience of a phenomenon, with the majority citing between 3 and 10 examples as the norm (Dukes, 1984; Moustakas, 1994; Polkinghorne, 1989; Starks and Trinidad, 2007; Wertz, 2005). For example, Dukes (1984) recommends including three to 10 participants for one phenomenological study in order to provide extensive study of a small group of examples. Starks and Brown Trinidad (2007) report a typical number of examples include between one and 10. Finally, I referred to five dissertations as a point of reference for the structure of this dissertation and the number of examples within those dissertations were 4, 6, 8, 10, and 15 (Ismail, 2012; Gavin, 2016; Jacob, 2002; Milligan, 2014; Van Alst, 2012)

4.4. Sources of Data

4.4.1 Open-ended interviews

Data collection consisted of in-depth interviews over a 5-month period of time (November through March). Data collection for this study employed the use of an in-depth open-

ended interview with participants with the option of a second follow-up interview as needed (Marshall & Rossman, 2008). The method of phenomenology essentially involves allowing narratives of lived experience to emerge as naturally as possible. I concentrated on what is given as experience before following up with more specific questions about the phenomenon (Hycner, 1985). According to the literature on phenomenological methodology, data is gathered around two general questions: (1) What have you experienced in terms of the phenomenon (health decision making process as it relates to follow up care for breast cancer)? (2) What contexts or situations have typically influenced or affected your experiences of the phenomenon (health decision making process as it relates to follow up care for breast cancer)? (Creswell, 2013; Groenewald, 2004). The interview guide for this study focused on these 2 questions along with additional probes (see Appendix 3 for interview guide).

As the PI of this dissertation study, I conducted all interviews. Initial contact with the women was made by telephone. The women called the study cell phone to opt into the study. The interviews took place in the woman's home with two exceptions. One was at a library and one was held at a community center. The interviews were audio recorded and I transcribed all interviews verbatim. Each initial interview lasted approximately 90 minutes in length, and I conducted a second interview with two women for further clarification and exploration of identified themes. The second interviews were shorter in length, lasting only approximately 30 minutes. They were conducted over the telephone as a point of clarification only. Transcripts and field notes produced during the analysis were stored electronically in password protected Word files. Microsoft Word 15.22.1 and NVivo 10.0 was used to organize the data during the analysis phase (Gibbs, 2008).

4.4.2 Socio-demographic information

Socio-demographic information was obtained at the time of the face-to-face interview. The information collected captured socio-economic characteristics of the participant and their home environment (see Appendix 2). The items were adapted from the demographic questions used in the University of Chicago's Center for Interdisciplinary Health Disparities Research study of women newly diagnosed with breast cancer while living on the south side of Chicago (Gehlert, et al., 2008). Data were stored electronically in password protected Word files.

4.5. Data Analysis: Adapted Version of Van Kaam's Method of Analysis

The analysis of data for this study followed Van Kaam's method of analysis as outlined by Moustakas (1994) (see Appendix 5). This method was chosen because it is a rigorous and highly organized systematic approach to analyzing data. Also, the approach is well-accepted by other qualitative research scientists familiar with transcendental phenomenology (Creswell, 2013; Giorgi, 2009; Groenwald, 2004; Hycner, 1985; Jacob, 2002; Moustakas, 1994). The steps of the model are summarized in Appendix 5. This process is comprised of four steps: (1) engaging in epoche; (2) applying phenomenological reduction; (3) using imaginative variation; and (4) synthesis of a composite description of the essence of the phenomenon (Moustakas, 1994). The following sections describe the four steps of this methodological process in more detail.

4.5.1 Epoche

The first step of the study process comprised engaging in the practice of epoche, or the practice of "bracketing" previous experiences with the phenomenon (Creswell, 2013; Marshall & Rossman, 2011; Moustakas, 1994; van Manen, 1990). Epoche is specific to phenomenology. As

mentioned earlier in the chapter, Husserl's transcendental phenomenology is intended to be more of a bird's eye view of the participant's description of their experience with the phenomenon with the ultimate goal of gaining a better understanding of the essence of the phenomenon. Transcendental phenomenology includes the technique of "bracketing" out influences outside of those brought to the table by the participant in order to get at the essence of the phenomenon (Cohen et al., 2000). Epoche is defined as a suspension of current a priori assumptions, theory and expectations in an attempt to describe the participant's accounts of the meaning making behind an event or experience (Owen, 1994; Vagle, 2014). The nature of phenomenological research requires that the investigator sets aside their assumptions, theories, and former experiences to capture and explain the phenomenon from the perspective of the participant (Starks & Trinidad, 2007). I have extensive personal and professional experience with breast cancer research and oncology social work program management in both clinical and community-based settings. As a result, I entered this study with predisposed biases that need reflection and bracketing, or setting aside during the course of data collection.

Epoche occurs at two points of the data collection process. It is carried out first, before the study begins, when there is a point of personal reflection and journaling that the investigator engages in. This is an opportunity for the investigator to reflect on the study questions and their biases. Dowling (2007) argues that in order to set aside one's preconceived perspectives and thoughts on an experience, a person has to first make them overt. Because I have written on the subject of breast cancer disparities and interviewed women in the past during other research projects, it was important for me to reflect on how I thought women would answer the questions. I also reflected on the life circumstances I thought the women might be encountering and how those circumstances influence their treatment decisions. I also reflected on the many questions

and comments I receive when I am speaking on this subject at national and local conferences and meetings. Everyone has a story they want to share with me about an aunt, a friend, or a personal experience with breast cancer. This information is important to my own personal experience with this phenomenon and therefore needs to be set aside for future analysis after the data collection phase.

The second point at which one incorporates epoche is during the data collection process. Before each interview, it was helpful to journal expectations of the interview and the expected participant. This is a critical part of the process, because phenomenology is as interested in the individual experiences with the phenomenon as it is with the collective narrative. Phenomenology celebrates the unique example of the phenomenon unlike other methods that searches for commonality (Vagle, 2014) allowing the investigator the opportunity to re-examine a phenomenon with each interview as if seeing and experiencing it for the first time.

It also became important before and after interviews to journal about the physical surroundings of the participant's home environment. This became increasingly important because I have been conditioned to notice my surroundings. I think it is important to make note of the environment but not let it lead to expectations of the upcoming interview. Altogether, the practice of epoche helped me experience the phenomenon from a renewed perspective.

4.5.2 Phenomenological Reduction

Phenomenological reduction is the systematic process of condensing information and exploring the data to develop a textual description of the participants' narrative example of 'what' was experienced, and 'how' the experience transpired (Creswell, 2013). The overall intent of phenomenological reduction is to provide the investigator with a systematic and rigorous model for analyzing the data. This process involved transcribing and scrutinizing the data for

significant phrases, defining meanings, and common themes (meaning making statements), and presenting a comprehensive textural composite of the data that accurately depicts the phenomenon. See Appendix 5 for a more detailed list of steps.

4.5.3 Imaginative Variation

Upon completion of the phenomenological reduction phase, which results in a composite experienced, the next phase is imaginative variation, or the crafting of the structural composite (under what circumstances does the phenomenon occur). Again the adapted version of Van Kaam's approach as outlined by Moustakas (1994) was used for this study (see Appendix 5). Imaginative variation encourages the investigator to "imagine the appearance of the phenomenon against the backdrop of various horizons in an attempt to see what the total phenomenon means" (Keen, 1975, p. 39).

The investigator applies analytic thought to the individual narratives to explore the hypothetical world of the lived experience through the lens of various universal structures (Moustakas, 1994). Universal structures are those elements of society that shed light on aspects of the phenomenon that make it unique (Dowling, 2007). This stage helps to illuminate the universal structures that led to how participants experienced delay in the initiation of treatment: under what circumstances does the lived experience persist? The process involves returning to the original transcripts to uncover common universal structures that help explain how women arrived at a delay in treatment initiation. The investigator accomplishes this by asking the question "is this phenomenon still the same if we imaginatively change or delete this theme (universal structure) from the phenomenon?" (Van Manen, 1990, p. 107). From universal

structures, individual structural composite descriptions of the experience are crafted for each woman followed by the crafting of a composite structural description.

4.5.4 Crafting the Essence of the Phenomenon

The final step of data analysis involves the synthesis of a composite combining both the textural and structural composites. This composite highlights the unique qualities of the phenomenon that is common to the collective of participant examples of lived experience. The composite description illuminates a plausible scenario of the lived experience of the phenomenon which may be used to inform future interventions.

A visual representation of the process is illustrated in Figure 4.3 and 4.4 and 4.5.

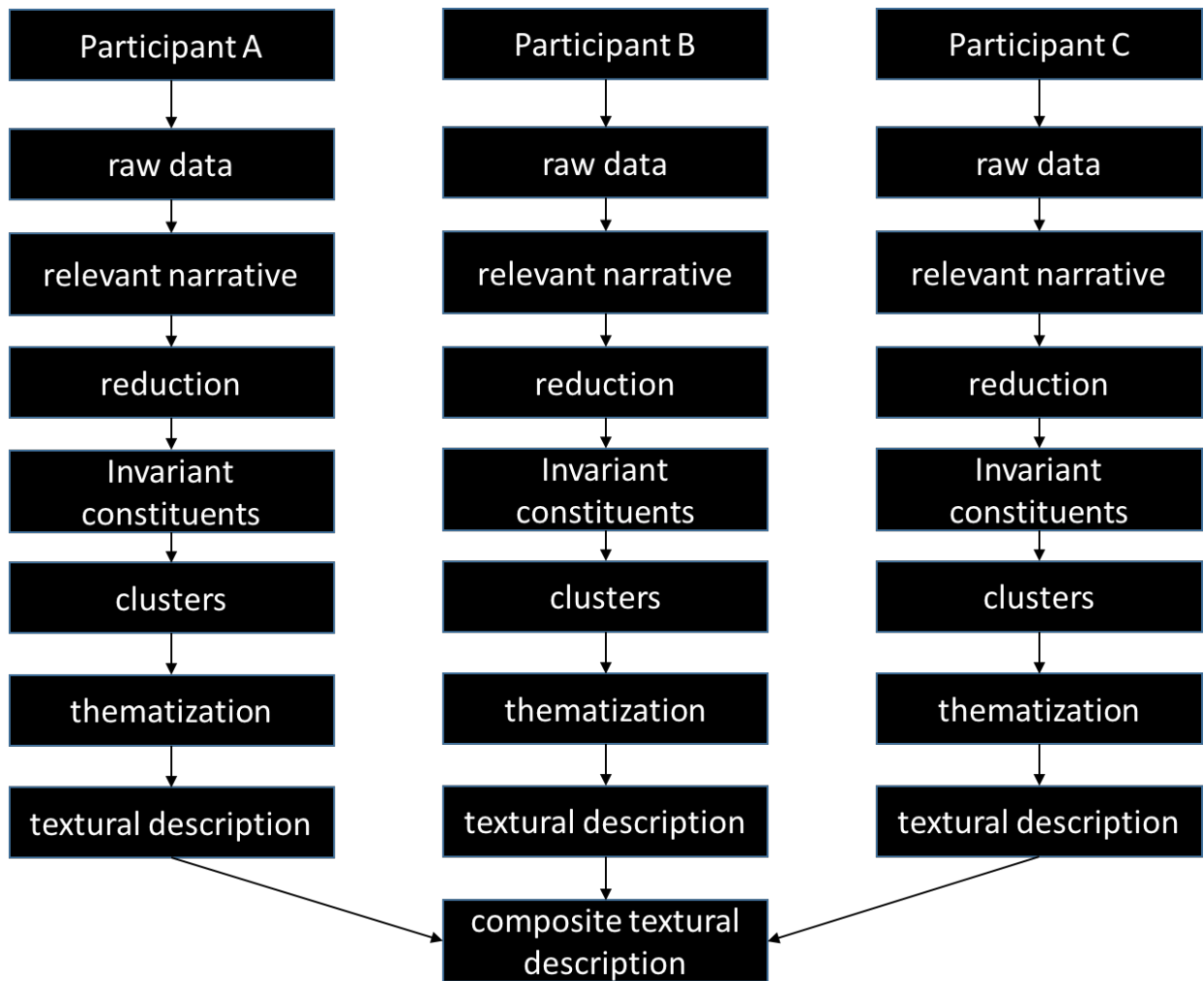


Figure 4.3 Data Analysis Step I: Phenomenological Reduction

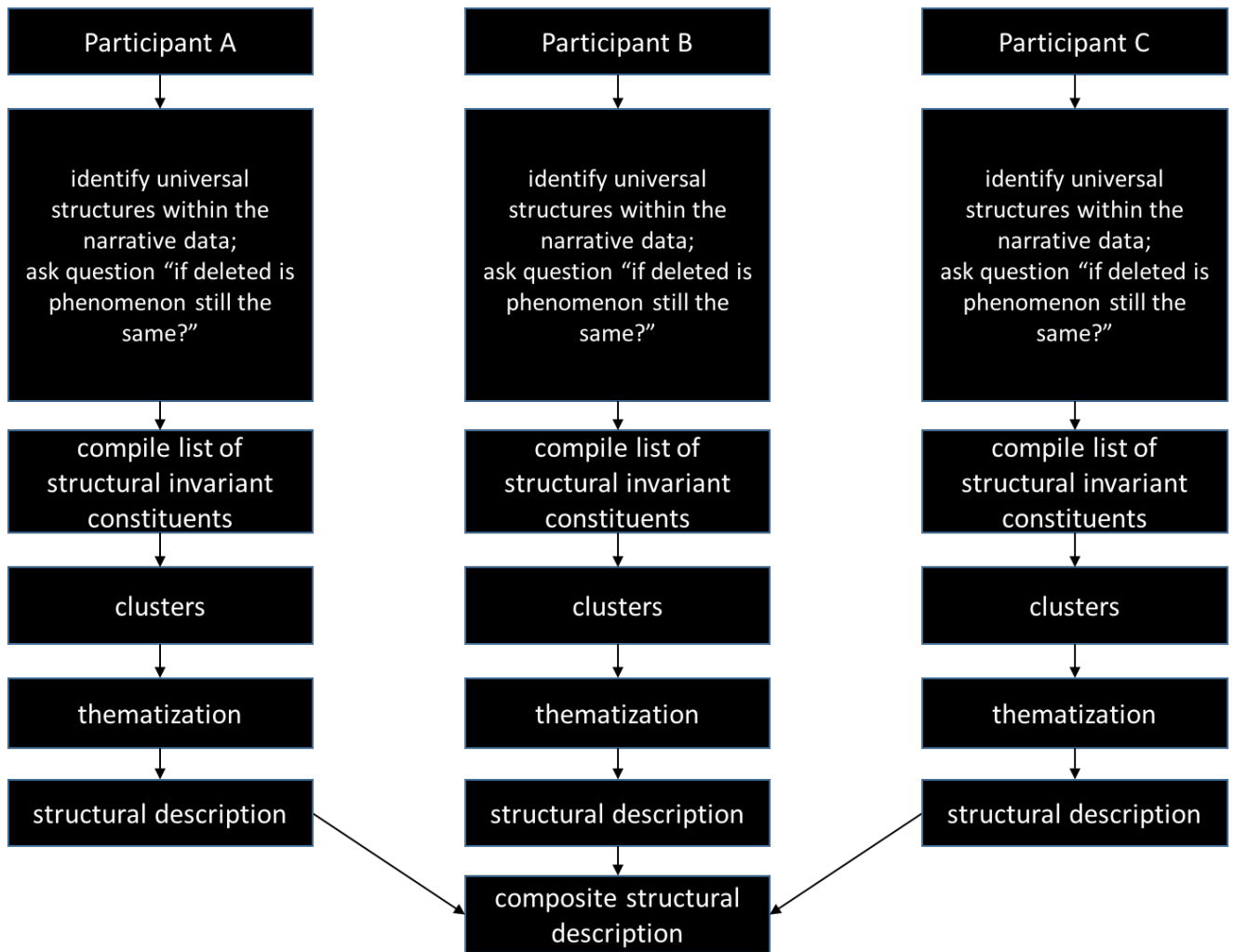


Figure 4.4 Data Analysis Step II: Imaginative Variation

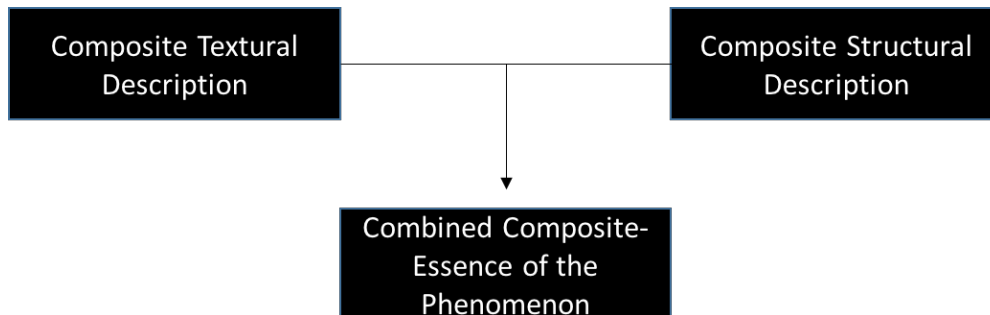


Figure 4.5 Data Analysis Step III: Crafting the Essence of the Phenomenon

4.6. Data and Safety Monitoring Plan

4.6.1 Informed Consent

The approval of the Washington University's Institutional Review Board (IRB) was obtained prior to the start of the study as well as the Human Research Protection Office (HRPO), and the Siteman Cancer Center Protocol Review and Monitoring Committee (PRMC) Breast Cancer Subcommittee. The approved consent document was read to the participants during the pre-screening phone call with the PI (see Appendix 4 for Consent document). The participants were asked to provide a verbal consent over the phone at the time of the initial phone screening, followed by a written consent at the time of the face-to-face interview.

4.6.2 Risk versus benefits

The risk to the participant was minimal. It was explained during the consent phase that the participant might experience potential discomfort with discussing personal matters involving health or socioeconomic factors related to their health. As PI, I conducted all interviews personally. I am a trained qualitative social worker, skilled at conducting interviews of a sensitive nature. I had also drawn up and kept on hand a referral protocol for additional information regarding treatment decision-making, as per a request from the Siteman Cancer Center's PRMC. The referral protocol starts by referring the women to their personal physician or healthcare clinic. Also the consent document informed participants that research is voluntary and that they may skip any questions and/or withdraw from the study at any time. No women withdrew their participation during the course of this study. While there were many tears, all women participated freely and openly in the dialogue.

4.6.3 Confidentiality and Record Keeping

To help protect the participant's confidentiality and the confidentiality of the interview responses, all interviews, field notes journal entries and participant information were stored in a password secured file on the PI's computer; and each of the interview documents was individually password protected per the instructions of Washington University's IRB. Participant identifying information was stored in separate files from any of the interview guides and audio records of their responses. Records linking individuals with data were assigned a unique numeric identifier and the information used to link records will be only accessible to the PI and the faculty sponsor/chair of the dissertation committee. The dissertation chair has been added to the IRB file for this study. The results of this study may be presented to the funder, the American Cancer Society, the dissertation committee faculty members, in neighborhood forums, conference presentations, and journals, but participant-identifying information will not be used in these reports or the final dissertation. The names of the participants are changed in the dissertation to protect their privacy.

4.7. Strategies for Rigor

Strategies of rigor are pursued during a study to achieve high levels of credibility. Credibility is defined as how accurately the results represent the participants' realities of the social phenomena and is considered credible to them (Creswell, 2013). Three factors were incorporated into this study design in order to ensure overall credibility: bracketing, transferability, auditability.

I enhanced the trustworthiness of my analytical process by striving towards an objective perspective through the use of personal journals and phenomenology's method *bracketing*. As

explained in detail earlier in this chapter, the nature of phenomenological research requires that the investigator adopt an approach that is free of value judgments from an external frame of reference and instead focuses on the meaning of the situation purely as it is given in the participant's experience. The investigator sets aside their presuppositions, biases, assumptions, theories, or previous experiences to capture and describe the phenomenon from the perspective of the participant (Gearing, 2004). I have extensive personal and professional experience with breast cancer, and as a result I enter this study with predisposed biases. Therefore prior to the start of this study and during the course of the study, I engaged in reflexive bracketing by recording my thoughts in a journal. I attempted to record my thoughts before and after every interview and some-times in between if I was thinking about the interview conversation. I did not process my biases with anyone. But what I found was that by doing this reflective writing, I was able to hear elements of their stories I was not expecting.

Transferability captures the extent to which the results established in one context can be applied to another context (Padgett, 2012). I strove to establish transferability in the writing phase of analysis through the use of "thick description." Uncovering concepts involved with quality of life of daily tasks that offer insight into barriers or supports to care could be transferable to other geographical areas or other ethnic groups. It just may display itself in a slightly different manner. For example, the women in this study spoke about the pride they had in providing stability for their family. I would imagine that this concept is also important in other communities and with other ethnic groups as well.

Establishing an audit trail increased the dependability of the study procedures. The process does not need to lead to the same conclusions but should allow another investigator to use a similar process to conduct a study of this kind (Padgett, 2012). Documents created during this

study included transcripts, field notes, data analysis steps, notes and memos that were preserved and stored using password protected Word files.

5: FINDINGS - EIGHT PROFILES OF LIVED EXPERIENCE

*“I’ve learned that people will forget what you said,
people will forget what you did.
But people will never forget how you made them feel.”
~ Maya Angelou*

5.1. Introduction

This is the first of two chapters outlining the findings for this study. In this chapter, I present the eight profiles that illuminate the lived experience of the phenomenon, African American women who lived in North St Louis City or North St Louis County who experienced treatment decision making following a breast abnormality which was most likely breast cancer. During the conversation, we spoke about health care decisions in general, but especially about breast cancer and the decision to initiate follow up care for a breast abnormality and recommended treatment.

In this chapter I will highlight the demographic profile of the group of women who provided these examples of this phenomenon, followed by a brief vignette of each woman’s story. I tried to pay particular attention to what sets this group of women apart from women who have initiated breast cancer treatment within 6-months of a breast abnormality; specifically, these women are less educated and have a lower family household income than the average population of breast cancer survivors, and they live in a geographical area that is more isolated, and have lower SES and higher health mortality rates than the other areas of St Louis City and County.

5.2. Participant Profile

Eight women shared their experiences as examples of this phenomenon, the lived experience of African American women where timely treatment for breast cancer was not initiated within 6-months following a breast abnormality. As noted earlier in chapter 4 most

phenomenological experts believe 3-10 is a typical amount of examples for a thorough investigation of a phenomenon (Starks and Trinidad, 2007). Table 5.1 and Table 5.2 outline a few demographic characteristics of the women. Most of the women were single/never married with an annual self-reported household income between \$30,000 and \$39,000. There were three women that reported a household income below \$30,000. Three of the women reported not completing high school, with two later completing a GED. Two more completed high school. An additional two reported some college or technical training, with one reporting completing a four-year college program.

Participants also reported living in the same neighborhood all of their lives and in the same home for more than half of that time (Table 5.2). The one person who reported only 3 years in her current residence, reported living in her previous residence for 25 years. All but one of the homes I entered was a single family home. The one person who lived in an apartment building was a woman who had recently lost her job. All but one of the women are single. Most have either raised children in the neighborhood or are still raising children.

Table 5.1

Participant Profile - Demographics

	Age	ZIP Code	Years in current home	Highest level of education	Current Marital Status	Current Employment Status	Current annual household income
Ms. Viola	61	63115	35	high school graduate	married	retired	\$30-39,000
Ms. Georgia	78	63120	41	GED (10 th Grade)	widowed	disability	\$10-19,000
Ms. Lynette	59	63136	23	technical school	widowed	employed	\$30-39,000
Ms. Velma	68	63115	3	GED (11 th grade)	single never married	retired	\$30-39,000
Ms. Cathy	37	63115	15	College grad	Single never married	employed	\$30-39,000
Ms. Pat	68	63136	11	Some college	Single never married	employed	\$30-39,000
Ms. Helen	60	63115	11	High school graduate	Single never married	employed	\$20-29,000
Ms. Ida Mae	70	63115	49	Less than 9 th grade	Single never married	retired	\$20-29,000

As Table 5.2, further outlines, all but two of the women found the breast lumps themselves. The following vignettes will supply more details on the discovery of the breast lumps. However, it is worth noting here that the time to treatment is an estimate based on the interview transcript. Many of the women had no idea how long they had the breast abnormalities prior to seeking care. Therefore, as the primary investigator, I summarize the time to treatment

initiation based on my conversation with each woman as either (1) between 6-months and a year, (2) between one year and two years, or (3) more than two years.

Table 5.2

Participant Profile – Treatment Initiation Factors

	Breast Lump Discovery	Time to follow Up Treatment *
Ms. Viola	Felt lump but thought it was a cyst which runs in her family	1 – 2 years
Ms. Georgia	Discovered blood in bra over the span of many months	6-months – 1 year
Ms. Lynette	Mammogram	6-months – 1 year
Ms. Velma	Felt lump; first primary care physician said it wasn't a concern; she went for a 2 nd and 3 rd opinion; biopsy showed it was breast cancer	6-months – 1 year
Ms. Cathy	Could not lift her arm to take off her pajama top	1 – 2 years
Ms. Pat	Turned over one day and had major pain in her breast	1 year – 2 years
Ms. Helen	Mammogram	6-months – 1 year
Ms. Ida Mae	ER doctors found out she had been packing her breast with gauze	More than 2 years

* Note: Time to treatment is an estimate based on self-reported information from the participants, many of whom had no idea how long the breast lumps were present before seeking care.

5.3. Participant Vignettes

The following vignettes have been assigned pseudonyms to protect the confidentiality of the study participants. All names were assigned at random by the PI. The formal “Ms.” is used

before each of the names to align with the cultural practices of the African American community in which the interviews were conducted.

Ms. Viola

“I’m never going back”

Ms. Viola is a 61-year old woman who lives with her husband and occasionally a grandchild or two. She has not worked outside the home since her husband was injured on the job and had to go on disability. She has lived in the same duplex for 35 years. She and her husband own the duplex and rent out the upstairs apartment to her sister. Ms. Viola wanted to tell me her story because she was adamant she “was not going to let them cut on her” or “put un-normal things in her body.” She eventually did have surgery but only after her daughter pleaded with her. But she wanted me to make sure I understood that she “was never going back.”

Ms. Georgia

“The whole time I’m thinking should I tell someone? I just kept it to myself”

Ms. Georgia is a 78-year old widow. She reported that she fell off the back porch and had to stop working. She is now on disability. The week before I met with her, her house was outfitted with fall prevention equipment. She now has new staircase rails, new shower rails, a walker and other gadgets in the kitchen to help with daily household chores. The year before she was diagnosed with breast cancer, both her husband and one of her daughters died. Her daughter died of breast cancer. Even though she lives alone, she has three adult children who provide ongoing support and check on her daily.

Ms. Georgia reported feeling confused, frustrated and distressed throughout the diagnosis and treatment phases. While she found blood in her bra every day for weeks, her primary care

doctor couldn't find anything wrong. "She (the doctor) said, 'Well maybe that was from the fall.' She did a breast exam and said everything seemed normal and my mammogram from a few months earlier was normal. But this one spot of blood was on the bra in the same spot for weeks." Ms. Georgia did not tell anyone about the blood in her bra, the conversations with the primary care doctors, or her feelings of distress. She reported keeping it to herself. "So trying to go to bed and every time pulling off a bra. I go through that and I say do I tell somebody that I saw some blood in my bra. I'm thinking the doctor missed it. But it could be a blood clot, I have been falling. I don't want to get them (her family) upset." So she kept it to herself.

Ms. Lynette

"Some people don't want to [get treatment]. Some people are embarrassed and ashamed and scared and don't want no body to know. Cause I did. Your self-worth is gone. I really felt like that. I'm not that *beautiful black queen* I use to be. It (cancer) is going to change your life and some people don't want change."

Ms. Lynette is a single woman raising two teenage boys, her son and her little brother, in Ferguson, MO. She reports being very active with her local government and was recently appointed as an Alderwoman. "I just wanted to make a difference. I can't sit back and watch what's going on and not do something. I have my boys to think about and all the other kids in this neighborhood." She also reports struggles with depression following her breast cancer treatment experience, and is taking an antidepressant. "You can't play with yourself. I know I need it. I keep saying I'm ok but I'm not. And I do not know how long it is going to take me but I get into that little depression. So yes I do need that." Ms. Lynette wanted to share her story with me because no one shared their story with her. She reported feeling alone as she made these decisions, only to find out later that several members of her family also had surgery and treatment for breast cancer. "No one talked about it. No one said anything."

Ms. Velma

“The doctor said I had it. I don’t claim any illness. The more you talk about things that are bothering you or hurting you physically the more it presents itself. But if you don't make mention of it before you know it the situation would be gone.”

Ms. Velma is a single 68-year old woman. She wanted to share her experience with me because she wants women and health care providers to understand that a positive attitude is a vital part of the process. “I think the medical profession should have a positive approach. I don’t care what the condition is or what they are treating the person for. I think they should give the person the best hope that they can. Your mind is key. The doctor should know this and the doctor should give the person encouragement. So I don’t think anybody a doctor or a medical person should ever tell someone well you have just. Let a person be determined. Let them live.” Ms. Velma does not say she had cancer, instead she says she had “a procedure.”

Ms. Cathy

“So I went to those appointments still not feeling well. I thought it might have been stress and all that I had to deal with on a daily basis... I never thought it was cancer.”

Ms. Cathy was 32-years old when she was diagnosed. She is a single mother of three. She also cares for her grandmother. She reported working two jobs to provide for her family and she was proudest of the fact that she was home every night to feed her children, do homework with them and put them to bed. She also mentioned how well her children were performing in school. She was very proud of the home environment she has been able to sustain. Yet at the same time, Ms. Cathy was diagnosed with several tumors in her breast, tumors that were, in the words of her doctors as reported by Ms. Cathy “protruding from her breasts.” She stated that the doctors could not understand how she could wait so long before seeking help. She said she did not notice the change in her breasts because “by the time I got in the bathroom to take a bath it would be after

10:00. I would jump in, shower and literally almost pass out being so tired... I didn't pay any attention to my own health because I was responsible for four other people.”

Ms. Pat

“I was laying [sic] on the sofa watching TV and I rolled over and something said get up off of me. I felt it. Then I went to my primary.”

Ms. Pat is a 68-year old single woman. She works part time and cares for her elderly mother. She stated that she was working and didn't have a lot of time to think about it. She stated during her interview that she didn't know what to do or what questions to ask. “I guess you could say I went into this kind of blindly. I didn't ask enough questions. I found out by chance about reconstruction. I didn't know I could afford it. No one around me every talked about it.” She spoke extensively about how messages about ways of paying for treatment and patient support services following treatment do not get out into the community. “There needs to be better ways of getting the word out about what's available.”

Ms. Helen

“I am very secretive. I didn't want anyone to know. Then I was ashamed... that it had happen to me.”

Ms. Helen, a 60-year old single woman, met with me with her daughter present. She experienced a closed head injury in the past and has trouble processing questions and responses. However, she really wanted to share her story, so her daughter was present to assist her. Ms. Helen has worked part time at Goodwill for 30 years. She spoke with pride that she has held a job at the same company for 30 years. Like the other women in this study, she didn't tell anyone about her diagnosis. She only told one friend who took her in for her appointments. She stated,

“I am very secretive. I didn’t want anyone to know. Then I was ashamed... that it had happen to me.” She said she was worried about who was going to take care of her kids and grandkids and how she would pay for the services.

Ms. Ida Mae

“I felt like I didn’t have any control over the situation any more. My hands were tied. In order to live I had to do what the doctors said.”

Ms. Ida Mae was the least forthcoming of the study participants. She keeps her feelings and experiences very private. “There are members of my family that still do not know I had cancer. I’m not comfortable talking about it.” Ms. Ida Mae was referred to me by her sister, another study participant. Her sister’s trust in me was the only reason she agreed to meet with me. She is a 70-year old single woman. She has been battling diabetes for many years and it was because of an emergency room visit due to the diabetes that her breast cancer was uncovered. Once admitted to the ER, healthcare professionals found that she was packing her breasts with gauze. They ran tests and determined it was breast cancer and encouraged her to seek treatment.

5.4. Selected Individual Textural and Structural Descriptions of Phenomenon

This section highlights the individual descriptions of three of the women in the study. The individual descriptions for each woman are combined and used to craft the essence of the phenomenon. The following vignettes of three of the participants were chosen because they present three varying perspectives on the phenomenon which covers many of the key themes identified in the next chapter.

Individual Description – Ms. Georgia

For Ms. Georgia her experience with breast cancer treatment decision making was one of frustration, mostly with herself. She expressed a lack of empowerment to get her doctors to hear her. She describes the experience as such:

When I went to wash my bra I noticed blood was on my bra. I started looking at them and every one of the bras had that spot. I thought maybe that was a mole and I was on Coumadin and I thought maybe I did have a little blood clot. I go to my primary care doctor every month. So when I went and I told her can you do a breast exam on me? She said sure why? I say I saw some blood on my bra. She said really but you had your mammogram. I said yes she said well maybe that was from the fall. She did a breast exam and said everything seemed normal. I'm looking to see something big or whatever. But this one spot of blood was on the bra in the same spot. I go through that and I say do I tell somebody that I saw some blood. I'm thinking the doctor missed it. I don't want to get them upset. So I kept it to myself.

She expressed feelings of never really feeling a part of the decision making process:

I just went along with what the doctors said. I was in a daze really. I didn't understand what was happening. I was blank. I didn't know how far it [referring to the tumor] was, how far it had spread, so I didn't say go on and take the whole thing off [referring to her breast] instead of half of it or whatever. Because something was telling me that if it was in the one it may be in the other.

There was a duality persisting between her need to care for herself and her medical needs and not having enough trust in her own knowledge to speak up about her needs. She shared:

I didn't get the answers I needed because I didn't trust myself. That I knew what I was talking about. I know I saw it (blood spots on her bra). But they didn't.

She also had a hard time with the radiation so much so that she was so afraid she'd have to go through it again when diagnosed with kidney cancer immediately following breast cancer treatment. She shared:

Then I ended up with kidney cancer and was afraid I'd have to have radiation all over again. You know going through radiation is not the easiest thing and knowing that you have to possibly go through this all over again. Because I wasn't told that once they take the kidney out that I wasn't going to have to have radiation.

She mentioned that she knows many people who have said that they don't want that medicine put in their body.

They don't want the medicine because the medicine makes you sick. Women hide it. They act worse with that than gonorrhea. They are ashamed. They think it is taboo to have it.

Ms. Georgia experienced health decision making for her breast health in the wake of the death of her husband and her daughter (her daughter passed away from breast cancer) within the same year. She expressed some apprehension as she aged and found herself living alone. Most of her life she had someone else around who could help nudge her forward. But her children were adults and she felt she should be able to care for herself.

Like when I fell one day. My son had just left and I did not want to bother him. So I scooted my but up on my steps and then I pulled myself up. When my son found out I had fallen and had not called him, he said mom why didn't you call me? I could have been just right around the corner. I said because I was going to work it out and get myself up off the floor. It's one of those things.

Ms. Georgia had been falling a lot over the past year. In fact, it was because of these falls that she believed the primary care doctor that perhaps the issue with her breast was a blood clot from the fall. It made sense to her.

So trying to go to bed and every time pulling off a bra. I go through that and I say do I tell somebody that I saw some blood in my bra. I'm thinking the doctor missed it. But it could be a blood clot, I have been falling. I don't want to get them (her family) upset. We were still dealing with the death of my husband and my daughter. So she kept it to myself.

Ms. Georgia experienced a lack of self-efficacy and her expressed concern to minimize some of the chronic stress in her family. As such she did not tell her children about her issues with her breast.

It took months before they ran further tests. I still didn't tell anyone. So trying to go to bed and every time pulling off a bra. I'm lookin'. My nipple looked really funny...I said maybe I did have a blood clot or bruised it when I fell...Still holding it to myself.

Individual Description – Ms. Cathy

Ms. Cathy is a proud single mother of three. She also cares for her grandmother. She approaches health care decision making as an informed participant. She wants to be a part of the conversation. However, as she shared with me, she felt she was talked to and not included in the decision making.

So they shared with me what they found and then they had a plan of action. But that is not what I wanted to do. I said no disrespect but you guys don't know everything. And they were like "Oh." And so I said I'm going to get a second opinion. So that is what I did. So in this amount of time that I need to make these decisions what I felt I should do was have surgery first and if I decided to do chemo then I would. I was definitely not doing radiation. It's not about what decisions I ultimately make. I still had chemotherapy. I just didn't want them dictating to me.

She reported working two jobs to provide for her family and she was proudest of the fact that she was home every night to feed her children, do homework with them and put them to bed. She also mentioned how well her children were performing in school. She was very proud of the home environment she has been able to sustain. Yet at the same time, Ms. Cathy was diagnosed with several tumors in her breast, tumors that were, in the words of her doctors as reported by Ms. Cathy "protruding from her breasts" at the time of diagnosis. Ms. Cathy stated that she woke up one day and could not lift her arm to take off her pajama top. She went to her primary care doctor. "I still remember going to the doctor that morning with my pajama top on." Her primary care doctor referred her to oncology for further testing.

She examined me and then she told me she wanted me to have a mammogram and where to go. And so I followed up with that. She was pretty assertive. She wanted me right now to go. But she didn't indicate anything, just seemed concerned.

Ms. Cathy further shared:

I scheduled things and went to those appointments still not feeling well. I thought it might have been stress and all that I had to deal with on a daily basis. I knew something was wrong because you walk into this room and there are all of these boxes of tissue and a

whole staff of different individuals came in and they introduced themselves. I knew it was something but I never thought it was cancer.

Ms. Cathy was diagnosed with multiple tumors in her breasts. Still Ms. Cathy was determined to remain in control of her own body and what goes into it.

No one wants to go through chemo but I wasn't going to do anything I thought I was pressured to do and I felt the staff, just because they are experts and they do these things on a daily basis, they had a plan of action for the stage that I was in. But that's not necessarily what I wanted to do. So I gave them a little bit of a push back. So I went (to another hospital). The doctor at that time agreed with what I wanted to do and said that would be ok. So I transferred.

It was very important to Ms. Cathy to remain in the conversation because as she stated it:

I had little kids to take care of. So I needed to know what was my best option to be around to take care of them... even your attitude and your approach to your own health, I think you need to take control... I wanted to have clarity of thought and direction. Even though I didn't have the MD initials behind me, I wanted to be able to communicate with the doctors that I knew some of the things that they were sharing with me...and asking them about their approach to my health. It's my health.

Ms. Cathy was 32-years-old when she was diagnosed. She is a single mother of three.

She also cares for her grandmother. She reported working two jobs to provide for her family and she was proudest of the fact that she was home every night to feed her children, do homework with them and put them to bed. She also mentioned how well her children were performing in school. She was very proud of the home environment she has been able to sustain. "I always meet their bus from school or my neighbor does if I'm working." Yet at the same time, Ms. Cathy was diagnosed with several tumors in her breast. Tumors that were, in the words of her doctors as reported by Ms. Cathy "protruding from her breasts." She stated that the doctors could not understand how she could wait so long before seeking help. She said she did not notice the change in her breasts because:

By the time I got in the bathroom to take a bath it would be after 10:00. I would jump in, shower and literally almost pass out being so tired... I didn't pay any attention to my own health because I was responsible for four other people.

Ms. Cathy was just one of two participants that wanted to meet with me somewhere other than her home. We met just a few blocks away at the public library. She said there was too much going on at her house. Too many distractions. I think she wanted me to see her through her eyes and through her story and not through her physical surroundings. This is also her approach with health care providers. She takes a lot of pride in being informed and having a voice during health care decisions for herself and her family. She expressed that while it was hard to identify the proper resources it was also important to her to try. Additionally, she told no one.

Even to this day there are members of my own family that don't know I had cancer. Even if people are talking about it around me, I don't tell them. At work one day a lady was talking about being diagnosed with breast cancer. I may lend some advice, but I never tell them it is because I went through it.

I asked her who took care of her children during the surgery and subsequent treatment? She said she told her parents, who live in Wisconsin, that she was having a procedure and asked if her children could spend a few weeks with them. It was summer break from school.

Individual Description – Ms. Velma

My conversation with Ms. Velma caught me off guard at first because our opening went as follows. I asked her if she was diagnosed with breast cancer and her response was, “Well the doctor says I had it. But I don't.” It was only later in the conversation that I started to understand what her initial statement meant to her. For Ms. Velma the experience of health decision making involves positive thinking. She believes strongly that what you dwell on in the mind is what your body will respond to physically. So she refers to her experience as a procedure not surgery and treatment for breast cancer.

I don't claim any medical condition. I'm not claiming anything in my body that don't belong in my body. The doctor said I had cancer. I respect the medical profession but I don't claim things.

She added:

At first I was like I don't have cancer. Because I am this type of person. I don't speak nothing into my body that don't belong there and I'm being honest with ya. So on the natural side of things I was emotional at first. When I got back to work that day, I was all nervous. I know the higher power concerning my life that I seek out and I seek out the God almighty because he is "THE" physician not "A" physician. Then from that point if a person really believes, then you can strengthen your own body to endure anything. I'm serious you have to forgive me if I become teary. I'm serious. You make the decisions on how far you are going to go and how you are going to endure. If you constantly talk about something negative, then that negative situation is going to continuously present itself but if you speak about something positive it turns that negative all the way around.

Ms. Velma found it difficult in the beginning to get her primary care physicians to agree with her that there was a breast lump.

I was going for a pap. I told the doctor to check my breast again and he was like I don't find nothing. But I could feel it. So I told him I'm going to go to another doctor for a second opinion and he said ok and I think he gave me the name of this other doctor to go to. He did a tissue removal and he said it came back that it was cancer.

Ms. Velma also believed very strongly that the medical profession should convey this positive attitude during the patient-provider interaction.

I think the medical profession should have a positive approach. I don't care what the condition is or what they are treating the person for. I think they should give the person the best hope that they can. Who are you to say I give you six months. Who are you? You are a human being just like I am. You might be gone tomorrow and I'm still here. God is in control of our lives. You are not in control of our lives. Death is not based on sickness. I've never read in the Bible that you have to be sick to die. I think it is unfortunate for a doctor to say I give you six months. You might be cheating a person out of a little more longevity and a person might give up just like that. So I don't think anybody a doctor or a medical person should ever tell someone well you have just. Let a person be determined. Let them live...I wish we could communicate better to people who have conditions that seem like everybody earmarks as fatal. And it is unfortunate I believe a lot of people have cheated themselves out of life naturally so by hearing from medical people and the community well you are going to get sick.

Ms. Velma approached her treatment decisions in total isolation. She asked a co-worker for a ride to the hospital because she was going in for a procedure. She shared this with me:

I already know the mindset of the people on the street, its negative...I do not discuss my health issues. I am very discrete and very mindful of who I discuss my health issues with you know what I'm saying because in situations like this people give you such negative hopes and my hopes are not focused on what you say because as a human being you are not the one that is going to determine how things are going to progress with me I determine that because that is between me and God.

She continued:

There are certain members of my family today that don't know I had the surgery because when you hear people talk about well so and so had it. How can you speak and say this condition is so this and that and so traumatic and so incurable how do you know that if you have never been through it and I don't want to hear well Mary Jane had it and this happen to her well I'm not Mary Jane? I don't know what Mary Jane did do or didn't do. I don't know Mary Jane's mindset. I don't know what her thought pattern was. I don't know what her strengths were or what her weaknesses were. So I don't want to hear that.

She made her treatment decisions within the primary care setting.

I was going (to my primary care doctor) for a pap. I told the doctor to check my breast again and he was like. "I don't find nothing." But I could feel it. So I told him I'm going to go to another doctor for a second opinion and he said ok and I think he gave me the name of this other doctor to go to. He (the second doctor) did a tissue removal and it came back that it was cancer.

6: FINDINGS – CRAFTING THE ESSENCE OF THE PHENOMENON

*“...phenomenologists are not primarily interested in what humans decide, but rather in how they experience their decision making”
~ Vagle, 2014, p.21*

6.1. Introduction

The goal of a phenomenological study is to illuminate features of the lived experience of a phenomenon (Starks & Trinidad, 2007). The results from this study illuminate the lived experience of treatment decision making for a group of African American women where the initiation of treatment for breast cancer was delayed for more than 6-months following a breast abnormality. In this chapter, I outline the essence of this phenomenon by providing an overview of the meaningful textural statements and themes describing what was experienced and the meaningful structural universal concepts that led to how participants experienced delay in the initiation of treatment and under what circumstances does the lived experience persist.

6.2. Textural Themes

Key findings suggest that a greater understanding of the processes involved with treating breast cancer and their effects on quality of life has more of an impact on the initiation of treatment than learning of the diagnosis itself. Much of the reported delay in the initiation of treatment occurred prior to and during the identification of a problem. Identification of an issue with their breasts predominantly occurred by the woman noticing a problem. Only two of the eight women had a screening mammogram that led to a biopsy. Five women reported a problem with their breasts involving pain, blood or a lump to their primary care doctor, and lastly, breast cancer was discovered in the eighth woman when she was admitted to the emergency room for an unrelated issue (diabetes). The results identify three scenarios each having its own set of

supports and barriers to treatment initiation: (1) Women who had breast lumps protruding from their breasts for months, even years, before seeking care, (2) women who noticed issues with their breasts and sought out care only to have communication issues with their health care providers, and (3) women who received a confirmed biopsy but were uncertain about following through on treatment. In all three scenarios, the analysis revealed five thematic textural clusters of what was experienced: (1) pride; (3) self-efficacy; (5) demystifying treatment process, especially radiation therapy; (4) knowing their bodies; (5) impact on quality of life. These themes are further described in this section.

6.2.1 Pride

Throughout the course of the interviews, these women never portrayed themselves as victims. Rather, they were strong, confident and very much in control of their homes, their bodies and their families. This shone through in statements such as “You make the decisions on how far you are going to go and what you are going to endure,” “I don’t quickly go along with what a doctor says because this is my body. I know my body better than anybody,” and “I wasn't going to do anything I thought I was pressured to do. I felt the staff thought just because they are experts and they do these things on a daily basis that they had a plan of action for the stage that I was in, but that's not necessarily what I wanted to do.”

As a result, one of the key thematic areas to emerge is what I am calling pride. The women I interviewed were proud of the quality of the home environment they had been able to establish and maintain in spite of social and economic conditions. Most were mothers who had either raised children successfully or are currently in the process of raising their children. Ms. Viola mentioned in the course of her interview, “I am so into children and their upbringing. I want them to get the best out of life as they can,” followed by, “This baby (at the park) looked

like the environment that she is coming up in. You know how you can look at a child and see that she isn't being cared for.... That was never going to be my children." While Ms. Lynette mentioned that her boys "have never been in trouble with the law. They are good boys."

Yet while their pride in their accomplishments has led to resiliency against adverse environmental conditions, it has posed some barriers within the provider-patient interaction that threaten timely treatment initiation for breast cancer. Women reported that their accomplishments in the home are important to the stability of their families and treatment for breast cancer pose obstacles to this stability. The women reported that healthcare professionals do not acknowledge these obstacles during the provider-patient interaction. According to Ms. Cathy:

They (the doctors) wanted to know from me how could you take a bath every day and not notice that you had tumors protruding through your skin. But my children were fed, I took care of my grandmother who is living with me, I worked two jobs to make the rent and helped the kids with their homework. By the time I got in the bathroom to take a bath it would be after 10:00. I would jump in, shower and literally almost pass out being so tired because I worked full time so I didn't pay any attention to my own health because I was responsible for four other people.

Ms. Lynette expressed her pride in being able to raise her son and her younger brother in Ferguson with all of the unrest going on in their community. The boys are in school and doing well. She also mentioned being proud of paying her mortgage on her home and not wanting to take her boys somewhere else because she would have to start over. Yet after being diagnosed with breast cancer, she felt defeated. She stated, "I'm all they have. What if something happens to me?" She describes the feeling of shame she felt and depression and not having anyone to talk to who would understand. In a conversation about why some women are hesitant to follow through on care for a breast cancer, Ms. Lynette stated:

Some people don't want to. Some people are embarrassed and ashamed and scared. And don't want no body to know, cause I did.... Your self-worth is gone. I really felt like that. It is going to change your life and some people don't want change.

In contrast, women who felt a sense of respect from their providers were more likely to report following through on care. In most cases it was just a show of acknowledgment of their circumstances from the provider. Ms. Velma shared:

If you don't have a good bedside manner as a doctor your patients won't come to you and tell you secret things. How they are feeling or what hurts. Sometimes they will just blow it off. But if you have a good bed side you'll be able to get all kinds of stuff out of them. I think a good relationship with your doctor is just like your relationship with God. You need that. You need that respect from your doctor and he needs to know that you need that and he needs to be there for you and give you what you need when you are going through and afterwards.

6.2.2 Self-efficacy

Another area that prevailed across interviews was self-efficacy or being equipped with the knowledge and the confidence to not only represent oneself in conversations with health care providers but also to know when to seek help. Women who navigated through life with health conditions that they did not feel empowered to say anything about, end up in situations with many other symptoms, sometimes worse than when she first noticed the signs. Ms. Viola shared:

I knew I had a lump but I thought it was a cyst. My sisters have had those in the past... I mean if it is cancer or something like that, that is so scary. You know. I have to really search and find out what's going on with it what would happen if I do not do this, or how long it will be before I have it done or if I should let them. Because I have been told so many times that if you have cancer and they open you up it is going to spread so quick. That's scary. So I may just want to go on even though I have cancer and do the best with it.

Ms. Pat shared that she thought it was stress. She works and cares for her elderly mother who is sick. "There was just not a lot of time to think about it".

In this study women either reported positive connections of self-efficacy with active coping, such as Ms. Velma, “the doctor couldn’t find it, but I could feel it. I went for a second opinion” or a less constructive connections of self-efficacy with passive coping, such as Ms. Georgia, “the doctor couldn't find anything wrong so maybe I do have a blood clot from a fall.” The latter increased the time to treatment.

The women who I interviewed earlier in the interview process, those with time to treatments closer to 6-months or a year, were more likely to report more self-efficacy in their discussions with physicians. Ms. Lynette, Ms. Pat and Ms. Velma all spoke extensively about pushing the doctors for a diagnosis and getting second opinions. While those who were closer to a year or two years before seeking care for a breast abnormality were less likely to seek the opinion of a health care provider and more likely to self-monitor her own health care, such as Ms. Cathy, Ms. Georgia, Ms. Ida Mae, and Ms. Viola. The discussion of trust in the health care system did not explicitly stated in the interviews. However, I believe that it was implicit in their response to care seeking behavior and self-monitoring of their health.

6.2.3 Demystifying the Treatment Process, Especially Radiation Therapy

Most of the literature leads you to believe that the problem for women who do not pursue treatment is the fear of the “C”-word or hearing that cancer equals a death sentence. This was not the case with these women. Instead it was the vague and unpredictable nature of the process involved with treating breast cancer that caused the most worry and impacted help seeking behavior. Fear and confusion over the anticipated effects of the process of treating breast cancer on their physical body and on their quality of life caused the most concern and delay in treatment initiation.

Most of the conversation revolved around radiation, sometimes referring to mammograms and other times referring to radiation therapy. Ms. Viola stated emphatically she never went for mammograms.

Another thing I don't like; they push that radiation in you too much. They want to take too many pictures. And they are steady shooting radiation in you. I don't believe in all that. Adding, "I never believed in radiation going into my body period, for real. I didn't have my first mammogram until, how old am I, 61, until I was about 58. I only did it because my mother asked me to do it before she passed away (from pancreatic cancer). Just like I would not have had this surgery if Ashley [daughter] had not asked me to go on and do it.

Women referred to radiation (and chemotherapy to a smaller degree) as "a foreign substance" or "unnatural." Referring to radiation as research, Ms. Viola stated, "You never want anything put in your body. It wasn't normal. I thought it was research. I'm not really into that." Ms. Pat added, "I have a sister who gets a shot for anything. I don't put un-normal things in my body." Ms. Georgia who faced kidney cancer after dealing with treatment for breast cancer teared-up when she spoke to me about the fear she felt when she thought she would have to go through radiation therapy again.

I also had a hard time with the radiation. And then I ended up with kidney cancer and was afraid I'd have to have radiation all over again. You know going through radiation is not the easiest thing and knowing that you have to possibly go through this all over again. Because I wasn't told that once they take the kidney out that I wasn't going to have to have radiation. I didn't understand why they couldn't do it all at once.

Concern over the effects of radiation on their bodies caused some women to delay initiated treatment. Other women were concerned about the effects of radiation on their daily lives.

Women stated, "How am I going to keep working... If I don't work, how will I pay my bills." "I was so afraid my boyfriend would move out and my boys need him.... He was a good male role model."

To some extent the women spoke of treatment for breast cancer as something they cannot visualize. Ms. Georgia believes that if women could picture the impact treatment would have on a tumor, and even more important the impact not receiving treatment would have on a tumor, then they would be more likely to seek care. She compared a diagnosis of breast cancer to a diagnosis of diabetes in this way:

Because comparing it to diabetes people go through dialysis and then some of them loose their feet, their limbs, and whatever. I'm listening to people who say, 'I need to go to the doctor and see about my feet. Because I am not letting anyone cut off my toes. Because I'll lose my foot'. They have seen that. They know what that looks like. No treatment equals no toes. You can put anything down on paper and read it but when you see it they may say I don't like to see that.

6.2.4 Knowing their Bodies

The women who participated in this study had a keen sense of their bodies and took satisfaction in closely monitoring what goes into it.

I always believed in starting young with yourself and staying on a schedule so you can know what's going on with yourself and if there is a change you will know when it happens. So you won't have to ask yourself I wonder how long this has been going on. I pay so close attention to my body I already knew that something was wrong with my body. You can really tell the difference if you know your body.

Many women mentioned eating fruits and vegetables as if to assure me they take care of themselves. "Every day when I arrived at work I'd stop by the cafeteria for an apple. I always made sure to eat an apple a day." "I found this book that explained how to increase my fruits and vegetables, eat more organic type food not processed food." "Till this day I do not eat a lot of meat or sweets. I found that food is really our medicine. If you eat the right food your body will feel better." "My kids don't eat a lot of sweets; we will splurge every now and then." Ms. Cathy explained the importance of taking control of what goes into your body this way:

I just believe our bodies weren't designed for all these pills because you always have side effects. So I made sure I was informed on my own health options. I sought out information to do something different. You see all the side effects. You know what you

are getting yourself into with chemo and radiation. I had little kids to take care of. I needed to know what was my best option to be around in order to take care of them. I needed to take control over what I put in my body.

Ms. Cathy only trusted herself and her own knowledge of what was needed for her body. She did not trust the physicians. She wasn't alone. Many of the women spoke about knowing what was needed to care for their bodies. Ms. Velma said she tests her physicians to see if they will ask her the right questions needed to get at the proper diagnosis.

I don't quickly go along with what a doctor says because this is my body. I know my body better than anybody. Until I share something with a doctor about what's going on or if there is a thorough examination and he can tell me something and then I can see if I had been experiencing these conditions and that way I can kind of know if this doctor is making the right decision or had made the right decision or know what he is talking about. So I don't necessarily go in telling the doctor what is going on because I want (him) to tell me. I'm going in March for an eye exam and I have been having certain things go on with my vision but I want my eye doctor to say well have you been experiencing blah blah blah and then I can say yes and then I will know he knows what he is talking about. But if I have to tell you everything how do I know for certain you know what you are talking about.

When I asked her how she knows what the right questions are, she responded that she knows how she feels and how she should feel. A couple of the women mentioned the internet, like Ms. Cathy and Ms. Velma mentioned the internet. However, as I mentioned above, these women possessed more self-efficacy than most of the women in the study.

6.2.5 Quality of Life

The results of this study identified a connection between threats to quality of life and the initiation of treatment. It took more than two years for Ms. Ida Mae to receive care for her breast tumor(s). She told no one. She packed her breast with gauze, wore oversized shirts and dresses and continued her daily tasks. Over the years she was increasingly sick from her diabetes, eventually ending up in the emergency room. It was there that health care professionals

identified the cancer and encouraged her to follow through with surgery. When I asked her why she moved forward with treatment, she said:

I didn't feel I had a choice really. I was in so much pain. I knew I would not be able to do anything without it. If I wanted to live, I had to have the surgery.

Ms. Ida Mae was one of the women who delayed care seeking behavior because she didn't want them to cut her open. She believes as many of the women in this study and in the literature have reported that "if you cut me open, it will spread and I will die". I had a hard time reconciling this with the fact that if you do not get treatment for a breast cancer tumor you will also die. However, I believe this speaks to the point made earlier by MS. Georgia that people cannot visualize the impact of non-treatment on a tumor, however, she could visualize being cut open and the tumor spreading.

In many of the stories shared with me, if the pain associated with the cancer interfered with the woman's ability to perform her daily tasks, she sought care.

One mother of an adult daughter, Ms. Velma, shared:

I'm just so into (her daughter). She wanted me to do the surgery. She means so much to me. Our relationship is so wonderful. She is so nervous and everything. She just don't think she can do without me in the world. She just wants me around for as long as she can have me. I can still see that little girl look in her face when she is afraid.

Some women also spoke of the influence of side-effects for treatment on their quality of life. Ms. Lynette was worried about being able to go back to work. "What if I'm too sick to work. How will I keep my job"? She also mentioned burning badly from the radiation and not knowing how to care for her burns in a way that would allow her to return to work. Ms. Cathy was worried about her young children, "I'm a single parent who is going to take care of them if I am too sick." She mentioned that she asked her parents if the kids could stay with them for a couple

weeks over summer break. But she stated that she should have asked for their help a bit longer. Because she found herself too tired or too sick to interact with the kids at times.

6.3. Structural Themes

Wherein this group of African American women experienced treatment decision making in a context structured by the underlying conceptualizations of chronic traumatic events and environments characterized by a lack of resources about making treatment decisions and support services following treatment. Also, women reported keeping their illness to themselves and described social and cultural barriers to utilizing available support systems to assist with unmet needs. Finally, most of the communication or lack thereof about treatment and the initiation of care took place in the primary care setting.

6.3.1 Chronic Traumatic Events

Exposure to chronic traumatic contexts such as urban poverty, life events (such as unemployment or under-employment or caring for a sick parent or child while working full time), or poor quality built environment (neighborhoods with vacant buildings and areas of high crime), increases individual level distress. Individual level distress over time has been linked to mental health, isolation, morbidity and mortality and health (citation). A mechanism less investigated is that of chronic traumatic contexts on psychosocial variables (self-efficacy, pride, quality of life) and their mediating or moderating effects on help seeking behavior.

The first significant underlying structural theme to surface during this study is that women are facing ongoing chronic traumatic events that are persistent and in some cases have been around for most of their lives. Situations such as the ongoing stress that goes along with neighborhood violence and neighborhood poverty, or trying to make treatment decisions when

she is unsure if she is going to be too sick to continue to work or take care of her husband or grandmother who are on disability and rely on her. Keeping her home and her children safe when she is too sick to get out of bed; or not having the time to care for her personal health needs because she is busy holding the pieces together for her family. Ms. Lynette stated,

With all that is going on up here (she lives in Ferguson) who is going to take care of my boys. I'm all they have. I fight for them every day. If I'm too sick to get out of bed who will fight for them.

Ms. Velma, worried about her husband who is disabled, stated, "I can't afford to be sick. I have to take care of him (pointing to the bedroom where her husband is). He is counting on me. I have to think about that. It's not just me." While Ms. Helen, who suffers from a closed head injury and has worked part time at Good Will for more than 20 years, was afraid of losing her job if she started treatment. "I didn't know how I would pay for it. What if I lost my job? It was scary"

6.3.2 Resource Deserts

Women also reported wanting more resources in their communities about breast cancer treatment, side effects from treatment, and patient support services to deal with the side effects, but found none. Women reported having to make these health care decisions with very little information about the side effects of treatment and the availability of resources to help counter these side effects. Ms. Pat stated:

I guess you could say I went into this kind of blindly. I didn't ask enough questions. I found out by chance about reconstruction. I didn't know I could afford it. No one around me ever talked about it.

The women did not mention the internet very often. Only in a couple of instances did the subject arise. Ms. Cathy for example spoke extensively about searching the internet for healthy alternatives to traditional treatment. But most of the women spoke about messages in the community. Ms. Pat spoke extensively about how messages about ways of paying for treatment

and patient support services following treatment do not get out into the community. “There needs to be better ways of getting the word out about what’s available.”

As mentioned earlier, women struggled with feelings of shame. Shame in that “it happened to me. Why me?” Shame that they did not go to the sessions with the physicians prepared: “I was mad at myself for not bringing the bra to show them.” Shame that they do not feel prepared to ask the right questions. Ms. Cathy shared the following:

Even though I didn’t have the MD initials behind me, I wanted to be able to communicate with the doctors that I knew some of the things that they were sharing with me...and asking them about their approach to my health. It’s my health.

6.3.3 Social Isolation

Seven of the eight women reported making these decisions in isolation of their social support from family and friends. They told no one. Not even their adult children or those they consider close friends. Furthermore, many did not tell anyone afterwards either. Many of them shared that people still don’t know. Often women used the word procedure to indicate to their loved ones what they were going through. One of the young women in the study with young children told her parents that she was having a procedure and asked if her children could spend a few weeks with their grandparents. It was summer break from school. Two older women in the study shared that they only mentioned to one friend that they needed a ride to the hospital for a procedure.

Several of the women mentioned that they keep it to themselves because people in the community only have negative messages to share. “You know (Sue) had it and girl she was so sick”; “Girl don’t let them put those chemicals in you. You are just going to get sick and it isn’t going to help”; “you know if they cut you open it will spread.” Ms. Velma said she chose not to tell anyone because, “I already know the mindset of the people on the street, its negative.” While

Ms. Cathy said, “One woman I know said, ‘I saw Cathy and she look so sick. I knew at that moment she couldn’t come around me.’ She could only see where I was and not where I was going to be.”

Many of the women shared that they did not tell their adult children until the day before the surgery and in some cases after the surgery even in situations where they were confused about the diagnosis and needed additional support to speak with the physicians.

Do I tell somebody that I saw some blood? I’m thinking the doctor missed it. I don’t want to get them upset. So I kept it to myself.

There were families that never spoke about it. Ms. Lynette shared that it was only after mentioning the pain she was in following burns from radiation that four of her cousins revealed to her that they had been through treatment for breast cancer. One of her cousins was able to help her with resources for the burns. The women also conveyed that they are listening for the right messages, such as people who are not spreading negative messages but information that equips a person to have productive conversations with healthcare providers. Ms. Lynette stated:

If you have someone that has already been through it and you are looking at a survivor who looks like me and I tell you what I went through and everything is going to be alright trust and believe me, I think she would be more susceptible to going ahead and getting it (treatment) done.

When I asked how we could get positive messages to women who are isolated and not speaking to anyone. Ms. Pat thinks that the local media, especially the TV stations can be helpful in effecting change. “We listen to TV reporters.” She says, “we believe they are well informed”.

6.3.4 The Physician-Patient Interaction in the Primary Care Setting

The fourth universal structural construct identified in this study that allows this phenomenon to persist is that these conversations about breast health are taking place in the primary care setting not the oncologist’s office or a women’s breast clinic. In every case, women

shared their experiences of going to their primary care physician and asking him/her about breast abnormalities. This is in line with other literature. In communities characterized by low SES and marginalized health care services, primary care (including social work, nursing and physicians) becomes the most important provider-patient relationship for many residents. In many cases, residents visit PCPs either at federally qualified health care clinics or at a private clinic. In the case of the women in this study, they visited their PCP with questions about their breasts. Further down the line the women were connected with cancer care teams for diagnostic services and treatment. But this was not the focus of the conversation I had with the women. They spoke mostly about the identification of a breast abnormality and their interaction with their PCP.

The textural themes (pride, self-efficacy, de-mystifying the treatment process, knowing their bodies and caring about what goes into it, and continuing a productive quality of life) are influenced by the primary care setting. It is the first point of contact for women experiencing breast issues and it is where they go back after surgery to seek answers for patient support services to deal with the side-effects of treatment. As such, there is a growing need for primary care to be a part of the conversations aimed at decreasing the time to treatment for breast cancer patients. Only they know what they need to do their jobs more efficiently. In the discussion section I speak about the importance of communication between PCPs and Oncologists to the process of timely treatment initiation.

7: DISCUSSION AND CONCLUSIONS

7.1. Introduction

As a complement to health behavior models, patient-centered care has become a national priority as a means of engaging patients in their care, improving treatment initiation, and enhancing health outcomes (Barry & Edgman-Levitan, 2012; Elwyn et al., 2014; Epstein & Street, 2007). The concept of patient-centered care, as opposed to provider-centered care, was widely circulated by the Institute of Medicine (IOM) report, *Crossing the Quality Chasm*, as an integral component of the delivery of quality care (IOM, 2001). In the report, patient-centered care is defined as "care that is respectful of and responsive to individual patient preferences, needs, and values and [ensures] that patient values guide all clinical decisions"(IOM, 2001, p.3). The findings from this dissertation fit well within the parameters of the IOM definition of patient-centered care and will be further discussed in this chapter.

First, key findings from this dissertation suggest that engaging patients in health care decision making necessitates a space where providers recognize and respect the life experiences of the patients and include this resiliency in the decision making process, as well as a more informed patient. In order for the second part to happen, women need information about treatment for breast cancer, side-effects from treatment and their potential impact on daily routines, and the availability of patient support services to help counter the side-effects. One suggestion from the women in the study is to partner with local media, especially TV news anchors. Ultimately they want the respect of making an informed choice and having their perspective acknowledged. In section 7.2, I will discuss an African American perspective of participatory decision making and its impact of treatment initiation.

Next, the findings from this study highlight that most of the communication about treatment initiation occurred at the primary care level, prior to initiating contact with oncology services. Primary care proved to be the most important provider-patient relationship for these women. It is where women from the study communities go with concerns about their breasts and where they return for more information about treatment and patient support for side-effects. Therefore, it is important to engage primary care physicians, nurses, social workers and administrative staff in conversations about treatment initiation for breast cancer. I will discuss this further in the conclusion, section 7.6.

Finally, it was common for the women to report keeping their illness to themselves and described social and cultural barriers to utilizing available support systems to assist with unmet needs. The women who shared their stories conveyed that they keep their diagnosis of breast cancer and suspicious lumps to themselves because people in the community only have negative messages to share. “I already know the mindset of the people on the street, it’s negative.” They do not want such “negative energy” around them. In section 7.3, I will discuss the role of community-based negative messages about breast cancer treatment on social isolation and treatment initiation.

The findings from this study complement current literature that suggests efforts to improve patient-provider communication within the cancer care continuum must address patient, health care provider, and healthcare system needs (see Figure 7.1) (Epstein & Street, 2007). I would add community needs as well. I argue that a good patient-centered model will include an informed and empowered patient, an accessible, well organized, responsive community environment, and a provider who is willing to listen and incorporate patient preferences and experiences in the clinical encounter. Specific examples of each of these areas are presented in

the following sections. I will follow this discussion with a review of the implications of these findings for oncology social work research and practice. The chapter ends with an overview of my next steps and future research agenda.

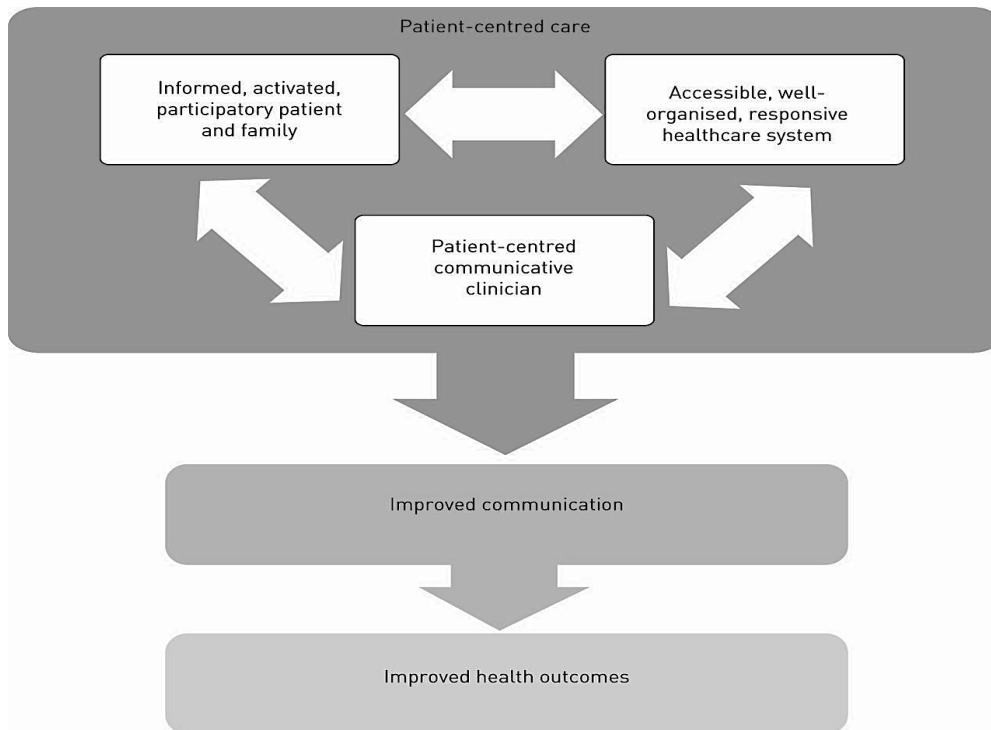


Figure 7.1 Model of Patient-Centered Care. Retrieved from R.M. Epstein & R.L Street Jr., 2007, Patient-centered communication in cancer care: Promoting healing and reducing suffering, p. 2. National Cancer Institute: Bethesda, MD.

7.2. Participatory Decision Making and Treatment Initiation: An African American Perspective

This first part of the discussion suggests that engaging patients in health care decision making necessitates a space where providers recognize and respect the life experiences of the patients and include this resiliency in the decision making process, as well as a more informed patient. Patient's values, preferences and experiences have become more of a focus of clinical interactions as a result of a greater emphasis on patient-centered care (Elwyn et al., 2014).

Current scientific literature suggests evidence that engaging patients in their care decisions improves medication adherence, and while less studied, could also contribute to treatment initiation (Liu, Malin, Diamant, Thind, & Maly, 2013; Sheppard et al., 2011). The findings from this dissertation are in agreement with this literature. Patients seek a clinical environment which promotes the sharing of information on treatment which has been tailored to their experiences, and in a way that they can understand. Failure to provide information in a way that meets the patient's needs could damage the relationship and decrease time to treatment. Since each situation has different psychosocial, cultural, and medical implications, gaining a better understanding of the communities served will help to improve practice in a variety of clinical settings. This study contributes to this literature by illuminating the preferences of a group of African American women who have engaged in provider-patient communication about diagnosis of a suspicious breast lump and treatment for breast cancer.

A racial disparity persists in the breast cancer mortality rate in spite of a high incidence of mammography screening for both White and African American women, improvements in targeted therapies for subtypes of breast cancer, and increased financial resources (Brawley, 2002; Bigby & Holmes, 2005; DeSantis et al., 2016; Fedewa et al., 2011). This suggests a social component to these observed racial disparities. Therefore, considering a woman's community and social influences on her treatment decision making is important. A better understanding of these factors can help tailor interventions targeting low-SES African American cancer patients.

Exploring how women engage in treatment decision making with providers within the context of communities is not new. In fact, at some level many treatment decisions are made by women who are facing environmental influences, regardless of race, ethnicity or SES. However, low-SES African American women are under-represented in research studies and yet have the

highest rates of breast cancer mortality of any other demographic group. What this study adds to the scientific research base is an in-depth discussion of how community and social influences impact help seeking behavior.

As outlined in the first part of this dissertation, application of health behavior theories in breast cancer research has been limited in focus to increasing the use of breast self-examination, mammography screening as prevention efforts, and physical activity among breast cancer survivors. However, little is known of how these theories would enhance the rate of breast cancer treatment initiation, especially among medically disenfranchised African American women. Although further research is needed, this dissertation adds information to the scientific research base on the lived experience of the study respondents as it relates to the constructs in the Integrated Model of Behavior Prediction (IBM) (Figure 7.2).



Figure 7.2 An Integrated Model of Behavior Prediction. Retrieved from M Fishbein & MC Yzer, 2003, Using theory to design effective health behavior interventions. Communication Theory, 13:164-183.

In this study, I found that women wanted to seek care for the most part but either lacked the knowledge or perceived self-efficacy to maintain the well-earned stability and security in

their homes if care was initiated. The women in this study, who have been coping with persistent adverse circumstances for most of their lives, are resilient and competent. The experience of making decisions about their health involved a need for the same level of control and efficiency they had experienced in their homes. Exposure to chronic traumatic contexts such as urban poverty, stressful life events, or poor quality built environment, increased their resiliency and determination to succeed. Yet while their pride in their accomplishments has led to resiliency against adverse environmental conditions, it has posed some barriers within the provider-patient interaction that threaten timely treatment initiation for breast cancer. Women reported that their accomplishments in the home are important to the stability of their families and treatment for breast cancer pose obstacles to this stability. The women reported that healthcare professionals do not acknowledge these obstacles during the provider-patient interaction. Women who felt a sense of respect from their providers were more likely to report following through on care. In most cases it was just a show of acknowledgment of their circumstances from the provider.

Another important component to having an informed and engaged participatory patient (see Figure 7.1) is providing women with knowledge about treatment options, especially side-effects and their impact on the woman's quality of life. Most of the literature leads you to believe that the problem is the fear of the "C"-word or hearing cancer equals a death sentence. This was not the case with these women. Instead it was the vague and unpredictable nature of the process involved with treating breast cancer that caused the most worry and impacted help seeking behavior. Fear and confusion over the anticipated effects of the process of treating breast cancer on their physical body and on their quality of life caused the most concern and delay in treatment initiation.

Most of the conversation revolved around radiation. Women referred to radiation (and chemotherapy to a smaller degree) as “a foreign substance” or “unnatural.” Referring to radiation as research, one participant stated:

You never want anything put in your body. It wasn't normal. I thought it was research. I'm not really into that.

Other women were concerned about the effects of radiation on their daily lives. This is in line with findings from a previous study my colleagues and I conducted in the St Louis area in 2012 (Noel et al., 2015). We found similar attributes for 96 low-SES African American women in North St Louis in a recent interview-based study. Women in this study were averse to beginning radiation therapy based on the negative experiences of people they knew or stories they had heard. They saw radiation as more of an elected service as opposed to part of the treatment process.

This first part of the discussion suggests that engaging patients in health care decision making necessitates a space where providers recognize and respect the life experiences of the patients and include this resiliency in the decision making process, as well as a more informed patient. The next section presents a discussion on the importance of engaging primary care physicians, nurses, social workers and administrative staff in conversations about treatment initiation for breast cancer.

7.3. The Role of Community-based Negative Messages about Breast Cancer on Social Isolation and Timely Treatment Initiation

The final group I would like to include in this discussion is that of the role of the community in patient-centered care. In order to ensure an informed empowered patient and a provider who is trained and willing to listen and incorporate patient preferences and experiences

in the clinical setting, a good patient-centered model will also include an accessible, well organized, and responsive community environment. One of the psychosocial barriers that allows delay in treatment initiation to persist is that of social isolation. Seven of the eight women in this study reported keeping their illness to themselves and described social and cultural barriers to utilizing available support systems to assist with unmet needs. They told no one. Not even their adult children or those they consider close friends. Furthermore, they did not tell anyone afterwards either. Many of them shared that people still don't know. In this study women reported two primary reasons for not sharing this experience with anyone, not wanting to burden their families and negative messages in the community. The latter has direct implications on community-based interventions.

Women also reported wanting to find support and information that was designed to empower them and provide them with the information they needed to make informed treatment decisions. They wanting more resources about breast cancer treatment, side effects from treatment, and patient support services to deal with the side effects, but found none. Women reported having to make these health care decisions with very little information about the side effects of treatment and the availability of resources to help counter these side effects.

I guess you could say I went into this kind of blindly. I didn't ask enough questions. I found out by chance about reconstruction. I didn't know I could afford it. No one around me every talked about it.

Ms. Pat spoke extensively about how messages about ways of paying for treatment and patient support services following treatment do not get out into the community. "There needs to be better ways of getting the word out about what's available."

As mentioned earlier, women struggled with feelings of shame. Shame in that "it happened to me. Why me?" Shame that they did not go to the sessions with the physicians

prepared “I was mad at myself for not bringing the bra to show them.” Shame that they do not feel prepared to ask the right questions. By partnering with community organizations, PCPs and programs can help to improve the resources available to women in the community.

7.4. Implications for Research

Future research implications following the results of the current study include further qualitative research to explore some of the themes presented by the lived experience of this group of women in more detail with women who have not started treatment, testing the Integrated Behavioral Model with low-SES women facing treatment decisions for a breast cancer diagnosis, exploring the PCP perspective of breast cancer treatment initiation.

7.4.1 More Qualitative Research

This study presented an in-depth view of the lived experience of women from a medically marginalized and low-SES community who were faced with making health care decisions about a suspicious breast lump. The themes that were illuminated provided an overview of what is experienced, how it is experienced and under what circumstances this phenomenon is allowed to persist. Future qualitative research would go into more detail on some of the key themes that emerged, such as the concepts of pride and patient provider communication and that of shame and not feeling empowered to incorporate treatment into their quality of life. Future studies could utilize a more structured interview guide to seek saturation on some of these more salient issues. It would be helpful to see if the same themes emerge with a similar community in another area of the country. Additionally, interviewing primary care professionals (physicians, nurses, social workers) about their experiences working with this population and with oncologist as well as identification of their needs would also add to the literature.

7.4.2 Exploring the relationships between chronic traumatic events, psychosocial variables and help seeking behavior

Another area of interest for future research is to explore the model fit between the constructs of the Integrated Behavioral Model and breast cancer treatment initiation (see Figure 7.2). Since the results of this phenomenological study provided evidence that the constructs of this model are in fact experienced by this group of women, a natural next step would be to conduct a study to explore these constructs in more detail. A large part of this future study would be to identify important moderators and mediators between chronic traumatic events and help seeking behavior (see Figure 7.3). Teasing out some of these relationships would improve future interventions aimed at increasing time to treatment. As mentioned earlier in this dissertation this model has not been used in the area of breast cancer research. So identifying the model fit with this population would add important knowledge to the scientific research base on cancer disparities.

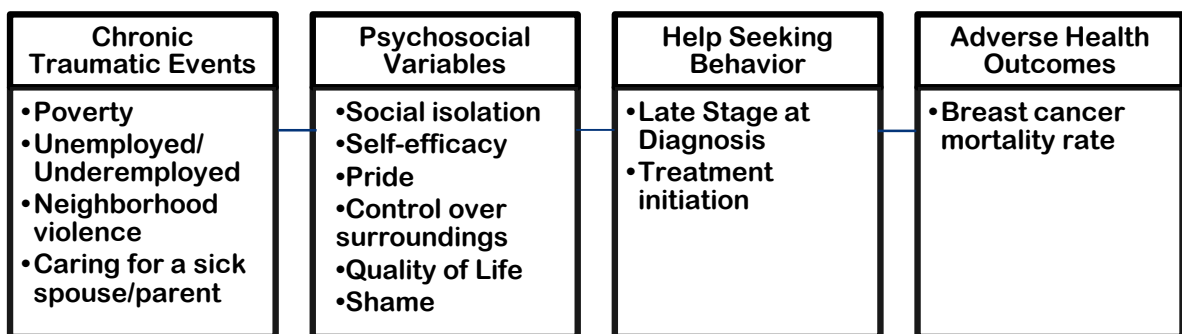


Figure 7.3 Proposed Construct of Relationship Between Psychosocial Variables and Help Seeking Behavior

7.4.3 Exploring the Provider Perspective

Another implication for research would be to explore these concepts from the PCPs perspective. The current study and previous studies by this author and her advisor have been conducted from the patient perspective and the health care system perspective. A useful next step would be to conduct a study exploring the perspectives of the provider, the PCPs. Findings from such a study could then be compared to that of patient experiences to help identify areas of overlap and areas of discourse.

7.5. Implications for Practice

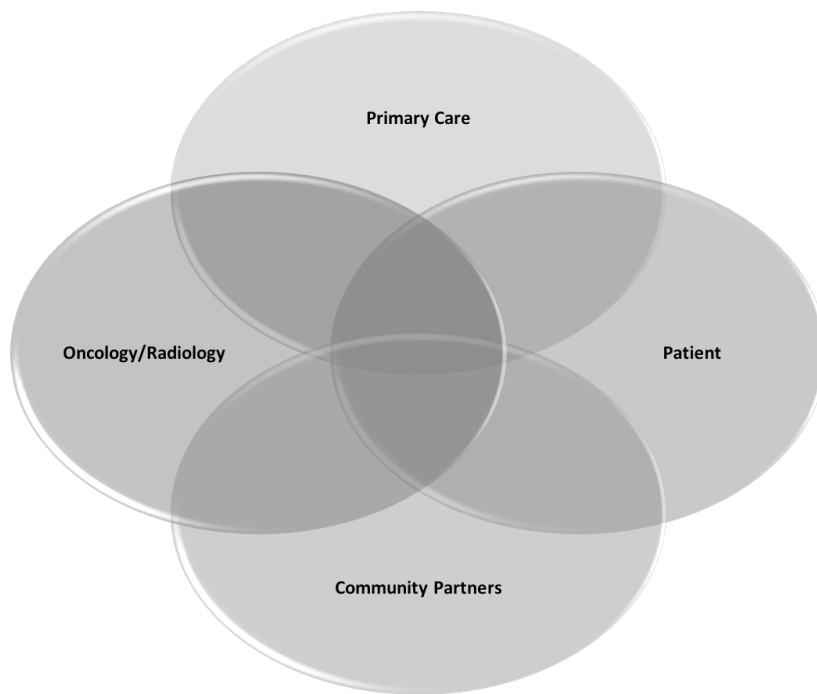


Figure 7.4 Proposed Community-based Collaborative Model of Intervention Practice

7.5.1 Community-based Collaborative Model of Intervention Practice

These results indicate that future interventions focused on improving the initiation of treatment for breast cancer should take place between PCPs, oncologists, and their patients and should focus on de-mystifying the process of treatment. These interventions would benefit from partnerships with the community. This might include community organizations that serve women who are more marginalized in our communities, such as Planned Parenthood, women's shelters, homeless shelters and domestic violence safe houses. Existing services could be expanded to offer women information about treatment options, side-effects, and available resources. Incorporating this information, as a type of barrier-focused community-based intervention, or improved case management services to assist cancer patients in the primary care setting, would increase a patient's self-efficacy and ultimately impact cancer mortality outcomes.

7.5.2 Patient Navigation

It would be interesting to see if breast patient navigators or community health workers could be used to provide more resources in the community about treatment for breast cancer and patient support services following treatment. The Patient Navigator Program was designed in 1990 by Dr. Harold Freeman to address issues with continuity of care for breast cancer patients (Davis, Darby, Likes, & Bell, 2009, Pedersen & Hack, 2010, Wujcik, 2011). A patient navigator program is described in the literature as a type of barrier-focused intervention or case management to assist cancer patients in context of their environments as they navigate through the health care system (Hendren, & Fiscella, 2014; Ko et al, 2014). Patient navigators provide culturally-sensitive coordination of resources for patients and providers by serving as a bridge between patients' unmet needs and health system provision of services (Pedersen & Hack, 2010).

However, very little research has been conducted to explore the effective use of lay patient navigators to introduce appropriate messages concerning breast cancer treatment into socially and economically disadvantaged neighborhoods and the subsequent impact on the number of women who initiate prescribed treatment. With proper training, the program could allow lay navigators to decrease time to treatment.

7.6. Conclusion

One of the universal constructs identified in this study which allows this phenomenon to persist is that these conversations about breast health take place in the primary care setting, not the oncologist's office or a women's breast clinic. In every case, women shared experiences with communicating with primary care physicians. This is in line with other literature. In communities characterized by low SES and marginalized health care services, PCPs (including social work, nursing and physicians) become the most important provider-patient relationship for many women. In many cases, residents visit PCPs either at federally qualified health care clinics or at a private clinic. For the women in this study, PCPs were the first point of contact for their experience with breast issues and it was where they went back after surgery to seek answers for patient support services to deal with the side-effects of treatment. As such, there is a growing need for primary care to be a part of the conversations aimed at increasing the time to treatment for breast cancer patients. It is therefore essential that PCPs be well informed by oncologists of their patients' diagnoses, treatment, and side-effects needs.

The communication with the PCPs left women feeling frustrated, confused and underpowered to make informed decisions that impact their lives. In several situations the women were misdiagnosed or diagnosis was delayed. The structure of many PCP practices

contributes to the barriers to productive patient-centered care. PCP barriers reflect a combination of competing demands and inadequate training. The allowable time devoted to an issue is 5 minutes in many situations (Fiscella & Epstein, 2008). Rushed visits provide little time for informed decision-making. Fiscella and Epstein (2008) further suggest that disparities also result in part from a lack of resources to implement interventions which have been proven to decrease time to treatment within practices that serve medically marginalized communities, such as patient navigation.

Despite the key role that PCPs play in diagnosis of suspicious lumps and the patient's ease with contacting them for assistance with follow-up health care needs, a cancer patient's time to treatment may suffer from limited training provided to PCPs and limited communication with oncologists. Understanding these communication patterns and provider needs is important, especially for women who are medically marginalized. As shown in this dissertation, these women are at greater risk of presenting with later stage and more aggressive tumors with fewer treatment options. Therefore, timing diagnosis and treatment initiation is important. A mismatch between what a PCP needs to serve a community and the resources provided to them, leads to an increased disparity in time to diagnosis and treatment.

PCPs (including social work) have the unique position in patient-centered care because they are able to communicate both the needs of the patient from a medically marginalized community and those of oncologists with evidence-based treatment practices. The continuity of care that PCPs provide may be particularly important to future interventions to decrease time to treatment. Therefore, they need to be trained and equipped to have conversations with their patient population. PCP's (including physician, nursing, and social work) are uniquely positioned to be able to translate best practices in ways that community residents can visualize. These

conversations would include such language as, “like you have been able to address circumstances like (blank) with such fervor, you can face this challenge as well”. Or “I know it was important to you to know what would happen to your boys if you had the previous procedure. Do you have questions that I can address about following through with care for your breast abnormality”? Because the woman has more trust in her PCP than she does in other health care providers, I think it will be important for the PCP to support the patient in her decision to speak with a cancer care team that the PCP trusts. Enhancing training and post referral communication between these two groups will serve to enhance patient-centered care.

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APPENDIX 1: REGISTRATION AND PRESCREENING TELEPHONE SCRIPT

Project Title: A Phenomenological Approach to Understanding How Women Make Breast Cancer Treatment Decisions Within the Context of Communities

Principal Investigator: Lailea Noel

Research Team Contact: Lailea Noel – 314.326.6316

Note: The PC (using a list of SMHW participants who meet the eligibility guidelines) will contact the woman to invite her to participate in the study. Identified women who agree with the PC to participate in the study will: (1) The PC will receive her permission to forward her contact information to the PI and the PI will follow-up with a phone call within 48 hours; and (2) The PC will give the woman the PI's contact information and the woman will make contact with the PI.

A secondary source of referrals is community-based breast cancer patient navigators, churches, homeless shelters, community centers, and other community locations who serve women. The contact person at the will women who meet the study eligibility guidelines to inform them of the study and pass on the PI contact information. Interested women will make contact with the PI.

Pre-Screening Script

Hello! Good morning/afternoon/evening, Ms. _____. Thank you for your interest in my research study on breast cancer and treatment decision-making. <I'm glad you called> or <skip to next section if PI calls the woman>.

My name is Lailea Noel and I'm a doctoral student at Washington University School of Social Work. Is this a good time to talk? I will need about 30 minutes to explain the project, the consent document and the next steps.

NO: I understand. I'd be happy to call back. Is there a day and time that may work better for your schedule?

What is a good number to reach you at?

Is there an alternative number?

Great I will call you on _____ <day> at _____ <time> using
phone number _____.

YES: Proceed with script.

My research centers on hearing about the experiences of women who have received an abnormal mammogram or clinical breast exam that was suspicious for breast cancer as well as women who have had a biopsy or diagnostic test that was confirmed to be breast cancer.

Have you received an abnormal mammogram or clinical breast exam within the past year?

NO: I am sorry to have bothered you. Thank you very much for your time.

YES: Proceed with script.

Have you received a biopsy or diagnostic test that was confirmed to be breast cancer within the past year?

NO: I am sorry to have bothered you. Thank you very much for your time.

YES: Proceed with script.

I have received permission from Washington University to invite you to participate in a research study regarding treatment decision-making. May I tell you a little bit more about the study?

NO: I am sorry to have bothered you. Thank you very much for your time.

YES: Proceed with script.

The purpose of this research study is to better understand what it means to you to go through the process of making treatment decisions as it relates to follow up care for a suspicious lump or breast biopsy. I am looking to interview African American women who have not started treatment for breast cancer, but have received an abnormal mammogram or clinical breast exam result or have received a biopsy or diagnostic exam, which is most likely cancer or confirmed to be cancer. If you have yet to make a decision to start treatment or have decided not to follow up on any further care at this time, this is a opportunity for your voice to be heard. This information will be helpful in understanding the challenges a woman faces when making treatment decisions. You are being invited to participate in this study because we believe that you can help us in our mission to better understand the needs of women in similar circumstances. Before I go any further, would you be so kind as to respond to the following questions?

Are you 18 years of age or older? [If yes, patient is eligible.]

Would you consider yourself to be African American/Black/ or of biracial heritage which includes African American/Black? [If yes, patient is eligible]

Do you live in St Louis City or St Louis County? [If yes, patient is eligible]

Have you started treatment for a breast cancer diagnosis [if no, patient is eligible]

BASED ON THE RESPONSES TO THE QUESTIONS ABOVE ...

IF THE PATIENT IS IN-ELIGIBLE: Thank you for your willingness to participate in this study. At this time, we cannot include patients <select one or more>: who are (under age 18)/ who are (of other racial heritages other than African American/Black)/ who do not (live in St Louis City or County)/who have started treatment for breast cancer.

IF ELIGIBLE, BASED ON THE ABOVE RESPONSES: Proceed with 'Study Full Written Consent' script (See Appendix 4).

At this time I'd like to go over the study consent document. This document outlines what is expected from you as a participant in this study, what is expected from me as the interviewer, and the steps taken to protect your privacy throughout the study. I'm going read through it over

the phone, but I will bring 2 hard copies with me when we meet for the study interview. One copy will be for your signature and a second copy for your records.

Upon conclusion of the ‘Study Full Written Consent’ script, proceed with the following:

Given the consent information I just provided to you, would you be willing to participate in this study?

NO: Thank you very much for your time today.

YES: Proceed with script.

Thank you! At this time I have a brief survey that is intended to help us understand more about the women we will be interviewing. It will only take a few minutes to answer the following questions. May I begin asking the questions at this time?

NO: I understand. I’d be happy to call back. Is there a day and time that may work better for your schedule?

Great I will call you on _____ <day> at _____ <time> using phone number _____.

YES: Proceed with the Socio-Demographic Information Script (See Appendix 2).

Great! Let’s begin the questions

Upon completion of the demographic information, proceed with the following:

Now that we have completed the survey, I’d like to schedule you for the second phase of this study. As I explained earlier when reviewing the consent information, you are asked to participate in an in-home interview or a location in the community that is convenient for you. The interview will take about 1 1/2-2 hours and is conducted by me, as the main investigator for this study. The purpose of the interviews is to hear your story and to gain a better understanding of what it means to you to have received {choose based on preceding conversation} <an

APPENDIX 2: SOCIO-DEMOGRAPHIC INFORMATION

Demographic Information

Age _____

Residential ZIP code _____

How many times have you moved within the last 10 years (Just give me your best guess)?

_____ Times -8 DK -9 RF

How many of these moves were within the same neighborhood? (How many were within 3 miles of your current home?)

_____ Times -8 DK -9 RF -6 NA

For how long have you lived in your present location? _____ (months) -8 DK -9 RF

Type of residence

1. _____ House
2. _____ Apartment
3. _____ Residential Facility
4. _____ Senior Living Facility
5. _____ Homeless
6. _____ Other: _____

-8. _____ DK
-9. _____ RF

Number of people in household (including participant) _____

Number of dependents under the age of 18 in household _____

Race/Ethnicity

1. _____ African American / Black, not of Hispanic origin
 2. _____ American Indian or Alaskan Native
 3. _____ East Indian
 4. _____ African
 5. _____ Latino / Latina/ Hispanic
 6. _____ White, not of Hispanic origin
 7. _____ Biracial / Multiracial
- PLEASE INDICATE: _____
- 8. _____ DK
 - 9. _____ RF

Marital status

1. _____ married
 2. _____ widowed
 3. _____ divorced or annulled
 4. _____ separated
 5. _____ single (HAVE NEVER MARRIED)
 6. _____ living with someone as if married
- 8. _____ DK
 - 9. _____ RF

Highest level of education

1. _____ less than 9 years of school
 2. _____ some high school (9-11 years)
 3. _____ high school graduate
 4. _____ some college or technical school
 5. _____ college graduate
 6. _____ post graduate education
 7. _____ graduate degree
- 8. _____ DK
 - 9. _____ RF

Employment

1. _____ a student

- 2. _____ retired
- 3. _____ unemployed not retired
- 4. _____ employed
- 5. _____ a homemaker not employed outside the home
- 6. _____ on disability
- 7. _____ Other PLEASE SPECIFY _____
- 8. _____ DK
- 9. _____ RF

Total family income last year

- 1. *less than \$3,000*
- 2. *\$3,000 to \$9,999*
- 3. *\$10,000 to \$19,999*
- 4. *\$20,000 to \$29,999*
- 5. *\$30,000 to \$39,999*
- 6. *\$40,000 to \$49,999*
- 7. *\$50,000 to \$59,999*
- 8. *over \$60,000*
- 8. _____ DK
- 9. _____ RF

Primary payer at time of diagnosis

- 1. _____ Not insured
- 2. _____ Private insurance (Managed care, HMO, PPO)
- 3. _____ Medicaid
- 4. _____ Medicare
- 5. _____ Other PLEASE SPECIFY _____
- 8. _____ DK
- 9. _____ RF

Other Healthcare conditions

- 1. _____ Heart disease

- 2. _____ Diabetes
- 3. _____ Mental Illness
- 4. _____ High blood pressure
- 5. _____ Asthma
- 6. _____ COPD, other chronic lung conditions
- 7. _____ Other Cancer Sites

PLEASE SPECIFY _____

-8. _____ DK

-9. _____ RF

Had an Abnormal Mammogram/CBE Yes No

More than 3 months ago Yes No

More than 6-months ago Yes No

More than a year ago Yes No

Had a biopsy Yes No

Met with Medical Oncologist Yes No

Met with Surgeon Yes No

Recommended treatment

Surgery Yes No

Chemotherapy Yes No

Radiation therapy Yes No

Followed up with treatment

Surgery	Yes	No
Chemotherapy	Yes	No
Radiation therapy	Yes	No

APPENDIX 3: OPEN-ENDED IN-DEPTH INTERVIEW GUIDE

GOALS

This study hopes to capture the essence of how women facing a breast cancer diagnosis make healthcare decisions, specifically decisions regarding follow up. For the purpose of this study, follow up care refers to a diagnostic exam, a biopsy, surgery, chemotherapy, and/or radiation therapy.

INTRODUCTION – Health Decision Making

When you think of health decision-making, what comes to mind?

Probe: What's involved with making treatment decisions for you?

What's involved with making treatment decisions for your family?

What might be some of the reasons that would prevent someone from following up on care?

Probe: Is this true for you or someone you know?

Tell me about a time in which you have gone along with the treatment suggested for any illness?

Could you describe the events that led up to this decision? What influenced your decisions?

Tell me about a time in which you have discontinued treatment altogether for any illness? Could you describe the events that led up to this decision? What influenced your decision?

Health Decision Making – Follow Up Care Abnormal Findings for Breast Cancer

QUESTION 1:

What have you experienced in terms of health decision-making as it relates to follow up care for an abnormal mammogram or clinical breast exam or a biopsy?

Probe: Tell me about when you found out that a recent mammogram or clinical breast exam was suspicious for breast cancer or found to be abnormal.

Further Probe: What did you understand about what you were told?

What was confusing about what you were told?

How did you feel after being told you had an abnormal result or a suspicious finding?

What happened?

Where were you?

Who did you speak with?

What was the experience of diagnosis like for you?

Probe: What were some of the important moments for you in the weeks/months following your mammogram or clinical breast exam?

Probe: What if anything changed about your life when you received the news?

Probe: If you think about that time period (the weeks/months following your mammogram or clinical breast exam) what made the health decision making more difficult? What made the decision making process less difficult?

Probe: Did you speak with a health care professional about follow up care for your abnormal result?

(if yes) What was that experience like for you?

Further Probe: What did you understand about what he/she told you?

What did you not understand about what he/she told you?

How did you feel about what he/she told you?

(if no) What prevented you from seeing a healthcare professional for follow up care?

QUESTION 2:

What contexts or situations have typically influenced or affected your experiences of the health decision-making process as it relates to follow up care for an abnormal mammogram or clinical breast exam or a biopsy?

Probe: What people or programs have typically influenced or affected your experiences of the health decision-making process as it relates to follow up care for an abnormal mammogram or clinical breast exam or a biopsy?

Further Probe: Have you discussed your results and health care decisions with anyone? Family? Friends? Church Pastor?

Probe: If you want assistance making treatment decisions, where do you go or look for assistance?

Probe: Have you had abnormal mammogram or clinical breast exam results before? What was that experience like for you?

Health Decision Making – Decisions Made/Care Received

Now I'd like to hear more about your follow up decisions and your treatment decisions.

Did you follow up with a (biopsy/diagnostic test)? What was that experience like for you?

Probe: What did you understand about what you were told?

What was confusing about what you were told?

How did you feel after being told you had an abnormal result or a suspicious finding?

What happened?

Where were you?

Who did you speak with?

What was the experience of diagnosis like for you?

What were some of the important moments for you in the weeks/months following your biopsy or diagnostic test?

Probe: What if anything changed about your life when you received the news?

What are your next steps?

Probe: Will you follow up with any further care?

(Yes or No responses) What influenced your decision?

CONCLUSION OF THE INTERVIEW

Is there anything that I have not asked you about that you think would help me understand your experiences with health decision making?

Would you like to add any last comments?

APPENDIX 4: INFORMED CONSENT DOCUMENT

Project Title: A Phenomenological Approach to Understanding How Women Make Breast Cancer Treatment Decisions Within the Context of Communities

Principal Investigator: Lailea Noel

Research Team Contact: Lailea Noel 314.326.6316

This consent form describes the research study and helps you decide if you want to participate. It provides important information about what you will be asked to do during the study, about the risks and benefits of the study, and about your rights and responsibilities as a research participant. By signing this form you are agreeing to participate in this study.

- You should read and understand the information in this document including the procedures, risks and potential benefits.
- If you have questions about anything in this form, you should ask the research team for more information before you agree to participate.
- You may also wish to talk to your family or friends about your participation in this study.
- Do not agree to participate in this study unless the research team has answered your questions and you decide that you want to be part of this study.

WHAT IS THE PURPOSE OF THIS STUDY?

This is a research study. We invite you to participate in this research study because you have received an abnormal mammogram or an abnormal clinical breast exam, or because you have received a biopsy or diagnostic test that was confirmed as breast cancer.

The purpose of this research study is to better understand what it means to you to have breast cancer and what it means to you to make treatment decisions.

WHAT WILL HAPPEN DURING THIS STUDY?

What are you being asked to do?

- Complete a brief demographic survey over the phone.
- Complete an in-home interview. The purpose of the interview is to learn what it means to you to make treatment decisions.

Will you save my comments to use in future research studies?

As part of this study, we are seeking opinions on your experience with being diagnosed with breast cancer and making treatment decisions, which will become the property of Washington University. This information will be helpful in understanding the challenges and difficulties women encounter when making treatment decisions but it is unlikely that what we learn from these studies will have a direct benefit to you. It is possible that your comments might be used to develop or change existing practices or describe experiences of other women in similar situations. There are no plans to provide financial compensation to you should this occur. If you agree, this means we will securely store your responses and may use them for studies going on right now as well as studies that are conducted in the future.

Audio/Video Recording or Photographs

One aspect of this study involves making audio recordings of you. These are being made so that investigators can analyze patient comments. Only members of the research team will have access to the audio recordings. These recordings will be stored in a secure manner for an indefinite period of time.

I give you permission to make audio recordings of me during this study.

_____ **Yes** _____ **No**
Initials **Initials**

HOW MANY PEOPLE WILL PARTICIPATE?

Approximately 15 African American women will take part in this study.

HOW LONG WILL I BE IN THIS STUDY?

If you agree to take part in this study, your involvement will require 2 hours or less of your time the first meeting; with an optional 2 hour or less second meeting.

WHAT ARE THE RISKS OF THIS STUDY?

As a result of being in this study, you may feel dissatisfied due to circumstances impacting your health. You may experience potential discomfort with discussing personal matters involving health or socioeconomic factors related to health. Additionally, you will potentially be volunteering information related to your health status, with loss of confidentiality related to discussing this information in front of others. Finally, there may be other unknown risks, or risks that we did not anticipate, associated with being in this study. If at any time you feel uncomfortable, you may skip any questions and/or withdraw from the study at anytime.

One risk of participating in this study is that confidential information about you may be accidentally disclosed. We will use our best efforts to keep the information about you secure. Please see the section in this consent form titled “*How will you keep my information confidential?*” for more information.

WHAT ARE THE BENEFITS OF THIS STUDY?

It is our hope that future patients will benefit from this study, in part due to your participation, to help improve and increase the care patients receive after receiving a breast cancer diagnosis; however, there will be no direct benefits to you from being in this study. This study will not influence your current relationship with your healthcare providers. As a research scientist, the study investigator has no relationship with any healthcare providers associated with your care. This is an independent research study conducted by a doctoral graduate student at Washington University School of Social Work aimed at capturing your story for research purposes only.

WILL IT COST ME ANYTHING TO BE IN THIS STUDY?

You will not have any costs for being in this research study.

WILL I BE PAID FOR PARTICIPATING?

You will be paid for being in this research study. You will need to provide your social security number (SSN) in order for us to pay you. You may choose to participate without being paid if you do not wish to provide your social security number (SSN) for this purpose. If your social security number is obtained for payment purposes only, it will not be retained for research purposes.

You will receive \$30 cash per interview session (for a total of 1 or 2 sessions depending on the study data) for your study participation.

WHO IS FUNDING THIS STUDY?

The American Cancer Society is funding this research study. This means that Washington University is receiving payments from the American Cancer Society to support the activities that are required to conduct the study. No one on the research team will receive a direct payment or increase in salary from the American Cancer Society for conducting this study.

HOW WILL YOU KEEP MY INFORMATION CONFIDENTIAL?

We will keep your participation in this research study confidential to the extent permitted by law. However, it is possible that other people such as those indicated below may become aware of your participation in this study and may inspect and copy records pertaining to this research. Some of these records could contain information that personally identifies you.

- Government representatives, (including the Office for Human Research Protections) to complete federal or state responsibilities
- The American Cancer Society
- University representatives, to complete University responsibilities
- Washington University's Institutional Review Board (a committee that oversees the conduct of research involving human participants) and Human Research Protection Office. The Institutional Review Board has reviewed and approved this study.

The Siteman Cancer Center at Washington University School of Medicine and Barnes-Jewish Hospital is supported by funding from the National Cancer Institute (NCI). To meet NCI

requirements, identifiable information about you relating to your participation in this study (including your social security number) will be stored in a secure database at the Siteman Cancer Center. This database and also your health care records may be reviewed by Siteman Cancer Center personnel. All information will be securely and confidentially maintained.

To help protect your confidentiality, we will keep your information securely stored in a lock file cabinet and a password protected electronic file; identifying information from any of the participants in the research study will be kept separately from any of the interview narratives and recorders on which they record their responses. Records linking individuals will be assigned a unique identifier and the information used to link records will be only accessible to investigators trained project staff, who has secured IRB compliance with Washington University's Human Research Protection Office (HRPO). The results of this study will be presented in community forums, newsletters, and journals, but your name will not be used in these reports.

If we write a report or article about this study or share the study data set with others, we will do so in such a way that you cannot be directly identified.

We will disclose to the proper authorities information shared with us or activities we observe concerning abuse, neglect or harm to others or yourself.

IS BEING IN THIS STUDY VOLUNTARY?

Taking part in this research study is completely voluntary. You may choose not to take part at all. If you decide to be in this study, you may stop participating at any time. Any data that was collected as part of your participation in the study will remain as part of the study records and cannot be removed.

If you decide not to be in this study, or if you stop participating at any time, you won't be penalized or lose any benefits for which you otherwise qualify.

What if I decide to withdraw from the study?

You may withdraw by telling the study team you are no longer interested in participating in the

study.

Will I receive new information about the study while participating?

If we obtain any new information during this study that might affect your willingness to continue participating in the study, we'll promptly provide you with that information.

Can someone else end my participation in this study?

Under certain circumstances, the investigator might decide to end your participation in this research study earlier than planned. This might happen for no reason or the study might be ended without the participant's consent, e.g., because in our judgment it would not be safe for you or the investigator to continue.

WHAT IF I HAVE QUESTIONS?

We encourage you to ask questions. If you have any questions about the research study itself, please contact: Lailea Noel at 314.326.6316. If you feel that you have been harmed in any way by your participation in this study, please contact Sarah Gehlert, PhD. at 314.747.1937.

If you have questions about treatment decision-making or health care decisions and you are a part of the Show Me Healthy Women Program, you may contact Maisha Flannel, Program Nurse Coordinator, at 314.657.1413 or contact your healthcare provider for assistance.

If you are not a part of the Show Me Healthy Women Program, I encourage you to follow up with a member of the healthcare team where you received your screening and/or diagnostic test.

If you have questions, concerns, or complaints about your rights as a research participant please contact the Human Research Protection Office at 660 South Euclid Avenue, Campus Box 8089, St Louis, MO 63110, 1-(800)-438-0445, or email hrpo@wusm.wustl.edu. General information about being a research participant can be found on the Human Research Protection Office web site, <http://hrpo.wustl.edu>. To offer input about your experiences as a research participant or to speak to someone other than the research staff, call the Human Research Protection Office at the number above.

This consent form is not a contract. It is a written explanation of what will happen during the study if you decide to participate. You are not waiving any legal rights by agreeing to participate in this study.

Your signature indicates that this research study has been explained to you, that your questions have been answered, and that you agree to take part in this study. You will receive a signed copy of this form.

Do not sign this form if today's date is after April 2016.

(Signature of Participant)

(Date)

(Participant's name – printed)

Statement of Person Who Obtained Consent

The information in this document has been discussed with the participant or, where appropriate, with the participant's legally authorized representative. The participant has indicated that he or she understands the risks, benefits, and procedures involved with participation in this research study.

(Signature of Person who Obtained Consent)

(Date)

(Name of Person who Obtained Consent - printed)

APPENDIX 5: OUTLINE OF THE MODIFIED VAN KAAM PHENOMENOLOGICAL MODEL OF ANALYSIS

(Adapted from Moustakas, 1994, p.180-181)

Epoche

(1) Epoche: setting aside prejudgments and thematic expectations and approaching the data with an unbiased perspective.

Phenomenological Reduction

(2) Horizontalization:

Horizons are the conditions that give the phenomenon its distinct character and allow us to understand an experience in the form of sections of narrative (Gavin, 2016, p.80; Moustakas, 1994). The process involves reviewing each transcript as its own case. Each transcript is reviewed multiple times, while highlighting significant portions of narrative relevant to the phenomenon. This step involves both the identification of significant narratives that arise from the verbatim words of the participants (emic codes), as well as, the inclusion of significant narratives that relate to theory (etic codes) (Creswell, 2013). Narratives that do not represent the phenomenon are eliminated.

(3) Reduction and Elimination:

At this step relevant narrative is reduced to significant statements (invariant constituents). Moustakas (1994) describes this step as the identification of invariant constituents, or the unique qualities of the lived experience. They are the relevant horizons of the phenomenon, the conditions that give the phenomenon its distinct character. At this step of the process statements that do not relate to the experience are eliminated.

(4) Clustering Invariant Constituents

This step involves organizing significant statements (invariant constituents) into groups of statements with similar thematic meaning (clusters). In phenomenology these clusters are referred to as “meaning units,” or statements related to the phenomenon which have significant meaning to the participants. Meaning units in phenomenology serve a similar purpose to common themes in other qualitative methods. Since the usage of common themes is more familiar in the social research field, I will report the results as common themes.

(5) Individual Textural Descriptions:

Develop textural descriptions of “what happen” for each narrative individually; describing “what” was experienced as described by each woman from her point of view.

(6) Develop a composite textural description:

An integration of all of the individual textural descriptions into a composite textural description

Imaginative Variation

(7) Describing the essential structures of the Phenomenon (‘how’ it was experienced’)

Moustakas (1994) describes this stage as engaging in creative thinking. The investigator explores the hypothetical world of the lived experience through the lens of universal structures. Through this process the investigator sheds light on aspects of the phenomenon that make it unique. This stage uncovers the universal structures that lead to how participants experienced delay in the initiation of treatment. In other words, under what circumstances does the lived experience

persist? The process involves returning to the horizontal data to uncover common universal structures that help explain how women arrived at a delay in treatment initiation.

(8) Develop Structural Themes

Construct a list of structural qualities of the experience. Cluster the structural qualities into themes.

(9) Individual Structural Descriptions

Integrate the structural qualities and themes into each individual narrative to create individual structural descriptions.

(10) Composite Structural Description

Integrate all of the individual structural descriptions into a composite description of the experience.

Crafting the Essence of the Phenomenon

Synthesize the Composite Textural and Composite Structural Descriptions

A visual representation of the process is illustrated in Figure 4.3 and 4.4 and 4.5.