Breast Cancer Disparities in African American Women in Central Indiana
Epidemiology, Current Barriers, & Prevention
Applications for Little Red Door Cancer Agency

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Introduction

Breast cancer is one of the most common cancers in the world, affecting roughly 232,340 U.S. women every year [18]. Although U.S. White women are more likely to be diagnosed with breast cancer during their lifetime, African American women are more likely to die from this disease, at an excess of over 1,700 women per year [8]. This trend is what is defined as a racial health disparity, further defined by the Institute of Medicine as, “…differences in the treatment provided to members of different racial or ethnic groups that are not justified by the underlying health conditions or treatment preferences of the patient” (p.130) [8]. Although breast cancer research and treatment has advanced over the past several decades, the disparity between White and African American breast cancer outcomes has increased, and has specific implications for the African American population in Indianapolis, Indiana.

The population residing in Marion County presents many of the risk factors associated with those affected by this disparity. 26.37% of Marion County residents are African American, with 20.53% (of total population) living in poverty, and 18.22% of the population under age 65 being uninsured [42]. The Little Red Door Cancer Agency is a non-profit agency that has provided free cancer services, screenings, and education for low-income and underserved populations in Indianapolis and Central Indiana since 1945 [23]. This report provides a review of the existing literature around this disparity in breast cancer mortality, specific data for central Indiana residents, and future applications for Little Red Door Cancer Agency as they continue to address this growing issue.

Breast Cancer Mortality and African American Women

With 1,658,370 new cases each year, and 589,430 deaths, cancer is the second leading cause of death for Americans [1]. Breast cancer is one of the most prevalent forms of cancer with an estimated 232,340 new cases each year [4], which makes up for approximately 14.6% of all new cancer cases [28]; as well as one of the most treatable, with a 5-year relative survival rate of 89.7% for all races [28]. However, the relative 5-year survival rate for African Americans is only 79%, compared to 92% in Whites [4,8,30]. The age-adjusted incidence rate for breast cancer among U.S. White women is 127.4 (per 100,000), and is 121.4 for African Americans [18], with the exception of women under 45 years of age [30]. Therefore, although overall lifetime risk of breast cancer is lower for African Americans compared to Whites, mortality rates were higher among African Americans at 30.8 (per 100,000) and only 22.1 for Whites [18]. A study done by the National Cancer Institute in 1994 found African Americans to have a 30% higher breast cancer mortality rate than Whites [30], which has risen to over 40% within the last decade [28]. The growing racial disparity in breast cancer mortality has caught the attention of the public health and medical community nationwide, and has been noted as an area in need of intervention efforts within recent breast cancer research.

Several factors have been presented as potential causes behind this growing disparity, including low socioeconomic status, limited access to quality healthcare services, limited access to health insurance, poor quality of
interactions with healthcare providers, differences in screening and treatment adherence, differences in tumor biology that lead to more aggressive and less treatment-receptive cancer types, and a greater likelihood of comorbid health conditions [1,4,8,18,30,31]. Although research indicates that some level of biological predisposition may exist, the National Cancer Institute claims that only 25% of this disparity can be attributed to African ancestry and other biological factors, leaving approximately 75% to be attributed to socioeconomic or clinical reasons [30]. More evidence currently exists linking breast cancer mortality to poverty level, insurance status, screening risk prediction, and poor provider-patient interactions among African Americans, reinforcing the potential for this disparity to be somewhat reduced through proper intervention and prevention methods.

**African Ancestry and Predisposition to High Risk Breast Cancer**

In the United States, African American women are at an increased risk for being diagnosed with high risk breast cancers, such as cancers that are negative for the estrogen receptor (ER), progesterone receptor (PR), the human epidermal growth factor receptor (HER2), or negative for all three, otherwise known as triple negative breast cancer (TNBC) (p.579) [10,14,30,38]. These types of tumor biology put patients at a higher risk because they are more aggressive (more likely to metastasize at a quicker pace), and are less or non-receptive to common forms of cancer treatment, such as endocrine therapies like tamoxifen [10,30,37]. A study done in 2007 found that pre-menopausal African American women were twice as likely to be diagnosed with TNBC tumors, and sustained an elevated risk even when stratifying for all stages of cancer diagnosis [30]. Prevalence of TNBC and ER-negative breast cancer is also proven to be higher among low-income and underinsured populations [1], which are often largely comprised of African Americans and other racial minorities [43]. It has been hypothesized that advancements in treatment technology, specifically in terms of endocrine therapies, may be a major contributor to the current disparity [1,18,30].

Other genetic or biological risk factors related to African ancestry are not as prominent in the literature. A study done among breast cancer patients in Florida demonstrated a BRCA1 (Breast Cancer Gene 1) gene founder mutation that was unique to African American patients, which was significant as BRCA1 is a breast cancer susceptibility gene, and is associated with developing high-risk tumors at a younger age [30]. Other studies have found some similarities in cancer biology among African American patients and patients of African descent in other areas of the world, but the existing international research is so limited, that no substantial conclusions can be made based on this data alone [3,4,10,30].

**The “Amenability Index” & Other Frameworks**

As mentioned previously, the National Cancer Institute suggests that 75% of disparity in breast cancer mortality between White and African American women can be attributed to socioeconomic and clinical factors [30]. These claims support findings indicating that the gap between these two racial groups did not
become evident until treatment therapies began to rapidly advance during the mid-1980’s, at which time breast cancer mortality rates in White patients began to decline significantly, but not across other U.S. racial/ethnic groups [1,18,30,31]. Hunt and colleagues [18] describe this idea that advances in technology actually increase health disparities as the “amenability index”. In similar terms, the “amenability index” concept suggests that as treatment (or treatability) advances for a certain condition, the more likely a disparity is to exist, and with greater severity [1,18].

Due to the fact that treatment of breast cancer is (1) a significant factor in overall cancer mortality risk, and (2) is largely determined by socioeconomic factors, many of the other determinants of breast cancer disparities examined in the existing literature can be attributed to, or explained by, the “amenability index” theory. Hunt and colleagues claim that there are four main barriers experienced by African American breast cancer patients that contribute to the “amenability index”: (1) limited access to screening services, (2) quality of available screening services, (3) limited access to treatment services, and (4) quality of available treatments (p.5) [18]. Although research supports this hypothesis, the National Cancer Institute (NCI) proposes a framework for addressing health disparities that is more inclusive, and may offer a more supportive foundation for Hunt, et al.’s theory. The IOM claims that there are three categories of barriers that contribute to racial health disparities: (1) structural barriers, (2) physician/clinical barriers, and (3) patient barriers [37]. A flowchart of this framework is included in Appendix A (p.22). The following sections will review factors contributing to the “amenability index” within the IOM framework for racial health disparities.

**Structural Barriers**

**Health Insurance Status**

21% of African Americans are uninsured compared to only 13% of Whites in the United States [1]. Multiple studies have cited that the underinsured and uninsured have higher rates of breast cancer, higher rates of being diagnosed later in the disease process, and less utilization of surgical treatment, radiation, and chemotherapy [1,30,43]. Individuals utilizing Medicaid benefits are also found to have reduced rates of breast cancer screenings, as well as reduced utilization of all treatment options [1,31,43]. In addition, compared to African American patients with employer, Medicare, or private insurance, survival outcomes and receipt of cancer treatment were both higher than patients without insurance, or receiving Medicaid benefits [48]. In terms of early detection and screenings, Medicaid patients that were receiving benefits during the year prior to their diagnosis were found to have less advanced tumor biology, and less likely to be in later stages of disease, than those that had intermittent enrollment, or enrollment at the time of diagnosis [32].

This is particularly pertinent when addressing health disparities in Indianapolis, as 18.2% of Marion County residents under 65 years old report having no health coverage, and 21.6% report receiving Medicaid benefits [42]. These coverage demographics extend across a majority of Marion County zip code areas that
Breast Cancer Disparities in Indiana

A study examining racial disparities in breast cancer in Texas found that, in addition to African American women having limited access to health care facilities, the facilities that were most available to them did not have updated mammography screening technology, and were reported to not use best-practice standards [43]. Another study evaluating mammography trends among racial minorities found that “facilities that served minority women, when compared to non-minority, were less likely to be academic (27% vs 71%) or private (29% vs 43%), and less likely to have digital mammography capabilities (18% vs 71%)” (p.6) [1]. In addition, breast cancer patients utilizing Medicaid are reported to struggle to find hospitals and providers that will accept their insurance, or treat them due to little financial incentive [1,31].

Geographic Region

Research on African American breast cancer patients revealed that the proximity of the patient’s residence to the nearest mammography facility to be (1) highly associated with racial disparities in screening behaviors, (2) treatment behaviors, and (3) breast cancer mortality [43]. In a survey of African American breast cancer patients in Chicago, participants expressed interest in educating the provider community about how their geographical location determines what resources are available to them, even as it pertains to healthy food access [6]. Several studies identified transportation as an issue for African American and low SES cancer patients to receiving adequate preventative care and treatment [1,10,11,48]. However, a majority of these findings were in reference to rural communities as opposed to urban communities, and did not include findings related to public transportation or inner city transportation systems and their effects on increasing healthcare access and utilization. Other studies have also supported geographical location as a primary barrier to many patients accessing screenings and treatments, ultimately having a direct impact on cancer outcomes [1,8]. Findings around geographical location further supported the “amenability index” theory by providing evidence that urban communities with cluster mammography facilities reported the highest levels of racial disparities in breast cancer mortality among African Americans, as opposed to all other races [43]. This is particularly pertinent when addressing the patient population in Indianapolis, as it is one of the largest urban cities in the nation, with many available mammography options.

Clinical & Physician-Centered Barriers

Patient/Provider Relations

In addition to evidence of provider hesitation to care for patients on Medicaid contributing to racial disparities in breast cancer [1], additional research suggests that there may be significant provider-patient communication issues for African American breast cancer patients. Racially discordant health care interactions, or interactions in which the patient and the provider do not belong to the same race, have been proven to
result in (1) fewer topics discussed during visits, (2) fewer questions asked by the patient and/or on behalf of the patient, (3) less patient decision-making, and (4) less convergence after a physician visit [31]. Convergence refers to both the patient and provider agreeing upon, and understanding what was discussed, during their visit; which is experienced less by African American patients than White patients when a provider is White [31].

Penner and colleagues (2012) found that about 75% of medical visits are racially discordant for African American patients (compared to 20% for Whites), ultimately leading to healthcare visits that are: less positive and productive, shorter in length, include fewer attempts at relationship-building, and are verbally dominated by the physician [31]. These factors have a significant impact on patient trust, and are sometimes perceived as inherent racism or racial bias by the patient – which can ultimately affect their adherence to recommended treatments and treatment-related behaviors [31,37,46]. African American breast cancer patients in Chicago reported that they feel the provider community should be educated on racial disparities within patient-provider relations as it relates to quality of the health care visit, and over half (56%) of respondents were willing to participate in designing curriculum for providers, as well as advocacy training curriculum for other patients [12].

**Risk Measurement Tools**

The overall effectiveness of cancer treatment and intervention efforts is truly dependent on the ability to accurately predict risk of cancer and apply preventative methods [4]. Another contributor to disparities in breast cancer screenings is previous inaccurate risk measurement tools for African Americans in regards to breast cancer. It is safe to say that breast cancer risk is different in African Americans than in Whites, whether it is due to socioeconomic or biological factors. However, although African Americans have a higher incidence than any other race of being diagnosed with breast cancer before age 45, standard age to begin mammogram screenings for all races is 50 years old, per the U.S. Preventative Task Force [4].

Besides socioeconomic factors, other health-related factors have been associated with an increased breast cancer risk in African American women: (1) obesity, (2) being nulliparous, (3) use of oral contraceptives, and (4) having a family history of breast cancer [4, 13,14,27, 31,33,46]. These factors disproportionately affect racial minorities, and do pose a different level of cancer risk for those with more than one condition [14,27,33,46].

One of the most commonly used breast cancer screening tools, the Breast Cancer Risk Assessment Tool (Gail model), was recently recalibrated to properly assess risk in African Americans through the Black Women’s Health Study (BWHS) (p.1038) [4]. One example of the inaccuracy of the original tool is found in clinical trial eligibility results, in which only 3.0% of women were identified by the Gail model as having the necessary 5-year risk of at least 1.66%, compared to the 14.6% (within the same population) that were found to be eligible using the BWHS model [4]. This puts African American patients at a significant disadvantage, seeing as inclusion in clinical trials is often considered the best available form of treatment [31]. Although the newly calibrated tool had a
Tendency to overestimate the highest risk cancer types by approximately 10%, it was able to predict 486 of the total 506 breast cancers that occurred within the sample [4]. Although this tool is not yet widely available, utilization of this tool by providers that treat African American breast cancer patients may be helpful in reducing disparities in prevention behaviors.

Treatment Patterns

There are significant racial disparities in how treatment plans for African American breast cancer patients are formed and communicated by the provider, as well as differences in what type and amount of treatment is prescribed [1,6,11,12,31]. Supported by research on ineffective communication strategies during patient visits, both diagnostic patients and survivors report having trouble understanding information received from their provider regarding treatment, side effects, and follow-up recommendations [8]. There is also evidence of limited information sharing by providers. For example, side effects of treatment are discussed in only 62% of African American patient visits, as opposed to 97% of white patient visits, with at least one side effect being discussed with 44% of African American patients, compared to 77% of White patients [31]. Providers also spend twice as much time discussing treatment and side effects with White patients than with African American patients [31]. Lack of information, as well as lack of patient trust, may contribute to evidence that African American breast cancer patients are less like to participate in recommended surgical therapy, radiation, and chemotherapy; and are reported to have lower quality of services in all three areas [8,10,11,31,37,48].

One example of how African American breast cancer patients receive poorer quality treatment is evident in research addressing dosage specifically under dosing. Dosage guidelines for chemotherapy are not strictly regulated, therefore providers are allowed to prescribe dosage amounts lower than the 85% effectiveness standard that has been proven to prevent and reduce the recurrence of breast cancer [31]. Prescribing doses less than the 85% effectiveness benchmark is considered under dosing, which one study proved to affect only 28% of White breast cancer patients, and 39% of African American patients [31]. In addition to reduced dosage amounts, African Americans were also more likely to be prescribed a nontraditional chemotherapy treatment, and are less likely to be recommended for clinical trials, which are often the best form of treatment [4,31,36]. Under dosing was also reported to be more prominent in obese breast cancer patients when compared to patients of normal weight, which may disproportionately affect African American patients due to increased likelihood of obesity and other comorbid conditions related to obesity [5,8,33].

Patient-Centered Barriers

Socioeconomic Status

Socioeconomic status was cited by several sources as the most prominent patient-centered barrier contributing to the racial disparity in African American breast cancer [1,8,10,11,37]. Research shows that patients with low socioeconomic status (SES) are more likely to be uninsured or underinsured and have limited...
access to quality healthcare services, which ultimately leads to more advanced disease presentation, limited access to definitive treatments, and worse survival rates [1,2,4]. Several factors associated with SES include race, sex, income level, poverty status, education level, and employment status, many of which have been associated with later cancer stage at diagnosis, reduced adherence to recommended treatments, and higher incidence of fatal outcomes [1,8,10,11,43,48]. “Data from the California Cancer Registry have also demonstrated a correlation between advanced tumor biology in socioeconomically poorer regions” (p.6) [1]. Being female and African American greatly increases the likelihood of a patient being of lower SES, especially in Indianapolis. However, additional SES components increase the risk of poor cancer outcomes for this group, further contributing to racial disparities.

Breast cancer patients with lower educational attainment have been proven to have more difficulty communicating with and understanding their health care providers [22], and less likely to undergo recommended treatments [8,9,11,44]. One study found oestrogen receptor status to be directly related with poverty and educational attainment, with higher rates of ER-negative cancer among women with less education and greater poverty [1]. These findings have serious implications for Indianapolis, as almost half (43.81%) of all Marion County residents over age 25 have only a high school diploma or less than a high school education, which accounts for 14.85% [42].

Being low-income, or living in poverty, has been associated with being uninsured or underinsured [1, 9], later detection and diagnosis of cancer, limited access to healthcare services, limited access to treatment options, and increased mortality rates [1,8,13,18,43]. “Multiple studies in breast cancer have demonstrated lower overall socioeconomic status, income, race and place of residence to significantly predict for higher stage at diagnosis and worse survival outcomes [1].” Life stress resulting from coping with low-income status is also shown to have mental health effects, often leading to delays in care seeking [21]. Several participants in a study on stress reduction among (primarily low-income) African American breast cancer patients claimed that “breast cancer was the least of their worries” (p.321) [21]. These findings are pertinent to treating racial disparities in Indianapolis, as over half (57.78%) of Marion County adults age 18-65, are living in poverty as of 2014 [42]. In addition, of all Central Indiana counties, Marion County has the highest reported levels of low SES, particularly within the city limits of Indianapolis [42].

**Cultural Attitudes & Religious Beliefs**

Cultural competence must be considered when providing care or designing interventions for specific populations, particularly racial or ethnic minorities [1,8,21]. “There are differences in the understanding of breast cancer among different racial-ethnic and socioeconomic groups, and individuals from disadvantaged backgrounds may be more likely to have misperceptions about their risk of breast cancer” (p.254) [8]. Another study identified “understanding and attending to sociocultural aspects of patient care” (p.131) as one of four primary domains that should be addressed in curriculum addressing racial
disparities in breast cancer [6]. Several studies on African American breast cancer have claimed that cultural attitudes or beliefs may be a barrier to some patients seeking or receiving care [1,8,31]. Some studies have mentioned fatalism as a potential cause of individuals choosing not to undergo recommended treatments [1,8,41]. One study reviewing survivorship claimed that “when symptoms occur, patient attitudes, such as fatalism and denial, can lead to delays in presenting for medical evaluation (p.254)” [8].

Spirituality was mentioned in several studies as being an influential factor in the breast cancer experience for African American women, some even citing it as their main coping mechanism [41]. In fact, religious participation has been linked to improved quality of life, health status, and even reduced mortality risk in African Americans [47]. Researchers have defined African American spirituality as the following:

“Faith in an omnipotent, transcendent force; experienced internally and/or externally as caring interconnectedness with others, God, or a higher power; manifested as empowering transformation of and liberating consolation for life’s adversities; and thereby inspiring fortified belief in and reliance on the benevolent source of unlimited potential (p.65) [29].”

Based on the existing research, it is evident that African American women consider their relationship with God to be very personal, and consider it to be an active presence in the coping and decision-making process throughout their journey with cancer. Patients from several studies reported that God assisted in: healing their cancer, preventing the cancer from spreading, finding the right physician, choosing the right treatment options, and sending a support system [41]. Patients also reported that their cancer outcomes were predetermined as “God’s will”, and that a higher power is completely in control of their journey [41]. One patient claimed that her breast cancer diagnosis was “…in God’s plan. I never question it…I just accepted it and kept movin’ on” (p.220) [22].

However, spirituality can also intervene significantly with the ability of providers and public health practitioners to reach out and impact African American cancer patients. Patients often trust God to help them find the right healthcare provider when diagnosed with cancer, and often prefer the care of a physician who is openly religious and will participate in religious discussions and prayer with them [34]. Based on existing research in the prevalence of racial discordance among African American cancer patients and White physicians [31], the lack of spirituality from providers may contribute to the lack of convergence and patient trust in these interactions.

In addition, common community-based interventions, such as support groups or group therapy, are often considered to be culturally insensitive by African American patients unless spirituality and prayer are involved [41]. This may prevent patients from participating in readily available and low-cost community resources, and reinforces the need for culturally competent intervention strategies. Also, the belief that their risk is predetermined by a higher power can affect individuals’ perceived risk, and feelings about early detection and prevention [41,43].

Social Support

Lack of social support is cited in several studies as a personal barrier during African
American women’s breast cancer journey. Some have mentioned lack of domestic support as a common theme [1], and other studies have reported that African American patients are less likely to have someone in their life that can provide emotional support and assistance [31]. It is reported that this is one of the reasons that African American women rely so heavily on faith, as they are uncomfortable talking about their diagnosis and condition with others [41]. They are also afraid that using faith and prayer as a coping mechanism may offend others who are not religious [41]. In fact, one study found that 70% of African American breast cancer patients reported difficulty talking about their diagnosis with others [2]. However, lack of social support and emotional outlets can have significant mental health effects, and sometimes produce more negative health outcomes [21].

Within the scope of the healthcare setting, social support is important in terms of bringing companions to doctor visits. Bringing a companion to a visit nearly doubles the amount of questions that are asked of the physician, and is associated with a better understanding of the information being shared by the physician [31]. In addition, prayer and discussions of faith are desired by African American patients during their cancer journey [41], and some may feel less supported or less satisfied with their care if these are absent.

Late Stage Diagnosis in African American Breast Cancer

Obesity & Weight Management Interventions

Obesity is a risk factor for developing breast cancer, breast cancer recurrence, and survival [8,33]. Over half of all breast cancer patients are obese at the time of diagnosis, and 50%-96% of patients gain weight during treatment.
“Cancer patients with a body mass index (BMI) > 35 had worse disease-free survival than those of normal weight, independent of age, race, treatment, and sex” (p.117) [5]. However, although obesity is identified as a risk factor for developing breast cancer, most research indicates that this is less related to central obesity, and is truly related to the common comorbidities, such as diabetes and heart disease [5,33], which are more prevalent among African Americans than White Americans [8]. In addition, the relationship between obesity and breast cancer becomes more unclear in terms of pre-menopausal patients; more substantial evidence exists linking obesity and increased risk for cancer recurrence and poor survival rates for post-menopausal patients [5,33]. In fact, some studies even suggest that higher body weight or BMI may be associated with a reduced risk of breast cancer development in pre-menopausal women [5,33]. However, a breast cancer study conducted in Nigeria found that waist-to-hip ratio (as opposed to BMI) was strongly associated with increased breast cancer risk, regardless of age [5]. Positive association between waist-to-hip ratio and breast cancer risk in African Americans were also found in a study done in North Carolina in 2000 [14]. However, despite findings regarding waist-to-hip ratio, much of the research on the link between obesity and breast cancer focuses on post-menopausal patients, and breast cancer survivorship.

Suggested interventions and prevention efforts are mostly centered around nutrition and exercise programs for post-menopausal survivors in order to avoid comorbidities such as heart disease and hypertension, or recurrence of cancer [5,8,33]. Weight management efforts immediately after diagnosis or during treatment are discouraged in the literature, due to the already significant physical and mental strain associated with undergoing treatment [33]. However, programs including exercise, weight training, and dietary interventions have been studied within African American breast cancer survivors, and had favorable results [8]. Among obese cancer survivors, who are twice as likely to be obese if they are African American (compared to White), improved diet and physical activity are positively associated with weight loss [8]. Evidence from yoga interventions for breast cancer patients report body weight changes in patients that participate in regular practice [15]. Research regarding exercise programs for breast cancer prevention are mostly focused on mental health, stress reduction, quality of life, and physical strength, as opposed to weight management [5,15,33].

**Mental Health & Quality of Life**

Research on African American breast cancer patients suggest that they have low rates of social and emotional support at time of diagnosis and throughout treatment [1,8,21,41], which has been proven to predict higher mortality risk over a 10-year period [21]. Consequently, African American cancer patients have poorer mental health and quality of life scores than Whites [25]. African American patients diagnosed with breast cancer suffer from anxiety around existing biases regarding cancer within their racial communities, as well as fear of cancer returning (among survivors), leading to diminished quality of life [35,41].

“Complementary medicine”, or psychosocial interventions and programs used
along with clinical treatment, have been used to reduce stress, promote a healthy lifestyle, improve quality of life, and foster social support [21]. These interventions often include: exercise, weight training, nutrition education, yoga, and mindfulness-based stress reduction [8]. Exercise is proven to improve emotional well-being and reduce anxiety among breast cancer survivors [27]. Specific exercise interventions, such as yoga therapy for cancer patients, have been proven to reduce: depression, distress, anxiety, emotional dysfunction, social dysfunction, and chemotherapy-induced fatigue [8,15].

Several intervention methods can be used to apply these tools with cancer patients and survivors. The RENEW trial, which included telephone counseling and print materials on exercise, diet, and healthy habits, and was aimed at cancer survivors age 65-91, was successful in: increasing exercise, reducing weight, improving diet, and increasing quality of life [8]. Similarly, breast cancer patients and survivors that participated in 4-12 week, structured Iyengar or Hatha yoga interventions experienced: decreases in psychological or symptom distress, mood improvements, decreased anxiety, improved emotional well-being, improved fatigue severity, improvement in wound healing, and reductions in the frequency and intensity of chemotherapy-induced vomiting [15].

However, as mentioned previously, culturally competent interventions are necessary in order to truly impact the African American community [6,8,12]. One of the most commonly cited culturally adapted interventions for African American breast cancer survivors is the CARE study: a 10-week intervention which adopted a cognitive-behavioral stress management (CBSM) framework [21]. Lechner describes the CBSM framework as “effective in enhancing adaptation to illness among varied groups of individuals living with life-threatening and chronic diseases, including breast cancer” (p.316) [21]. Participants consisted of only African American women, and weekly sessions were led by a graduate-level, female African American intervention specialist, which was reported to be a source of comfort to participants [21]. Weekly sessions consisted of teaching techniques in anxiety and stress reduction, coping skills, interpersonal skills, and tools to build social networks [21]. Results of this culturally tailored intervention were positive, with 95% retention rate, and improvements in “psychosocial adaptation to cancer survivorship, including quality of life, perceived stress, depressive symptoms, and intrusive thoughts related to breast cancer” (p.319) [21]. Lechner, et al. recognized that African American women may be less likely to seek help and support from group resources if they do not include prayer or spirituality, as supported by the literature [41], but claimed that the ability to “come together as a sisterhood of Black women” was an effective strategy in overcoming this barrier (p.321) [21].

**Spirituality & Faith-Based Methods**

As mentioned previously, “African American women have long used spirituality to bring hope in dealing with hardships and this is true of those who are striving to cope with physical, psychological, and emotional burdens that can accompany a breast cancer diagnosis” (p.255) [21]. In a meta-analysis of the influence of spirituality on the breast cancer experience...
of African American women, it was reported that support groups were viewed as “culturally insensitive” without involving prayer and spirituality, and that both patients and survivors were hesitant to attend these interventions in fear of offending people with their faith [41]. Since the 1920’s, churches have been a popular setting for conducting public health research and interventions for African Americans [47]. As such, it is highly recommended that spirituality and faith be incorporated into prevention and survivorship interventions aimed at this population.

*Community-Based Education on Racial Disparities: Case Study from Chicago, IL*

It has been proposed in multiple studies that perhaps racial disparities could be mitigated through educating communities on this topic, as many African Americans may not be aware of the severity or impact of racial disparities in cancer [6,12]. In addition, the community setting has been identified as the ideal setting for health disparities education due to the following four domains:

“(1) Identifying and addressing a community’s health problems…(2) Understanding and attending to sociocultural aspects of patient care…(3) Coordinating local community health resources in the care of patients…(4) Assimilating into the community and participating in its organizations” (p.131) [6].

The city of Chicago, Illinois has one of the largest urban African American populations in the country, and consequently, exhibits significant racial disparities in breast cancer mortality [12]. Fritz, et al. (2015) outlines the efforts of an academic partnership, Chicago South Side Cancer Disparities Initiative (CSCDI), in creating a community-based intervention addressing racial disparities in breast cancer by engaging community members in the development of the curriculum [12]. Fritz and colleagues used curriculum guidelines released by the Society of General Internal Medicine on teaching about racial health disparities in order to guide curriculum development, and used a series of three qualitative assessments amongst eighty-six affected community members to identify important themes relevant to Chicago communities [12]. Among participants, 61% reported interest in taking a community course on cancer disparities, and 94% agreed that community members should be involved in curriculum development in order ensure that a local perspective on African American breast cancer was accurately expressed [12]. In addition, three general themes were produced from these qualitative survey results: “(1) community empowerment through disparities education – ‘a prescription for change,’ (2) student skill development in community engagement and advocacy training, and (3) community expression of shared experiences in cancer health disparities” (p.6) [12]. Overall, the value of obtaining local health data, as well as sharing local survivorship stories in order to help community members and providers truly understand local health struggles, were prominent findings retrieved from participants [12].

*Provider Education to Improve Racially Discordant Patient Interactions*

As discussed by Penner, et al. and others, there are significant communication
deficiencies that exist within racially discordant patient-provider relationships for African American patients and White providers [1,4,31]. The Institute of Medicine recommends training for providers in racial health disparities, in order to better understand and appreciate social contextual factors within these communities, and how they contribute to racial health disparities [6]. It is recommended that this curriculum “acknowledge that individuals are embedded within broader systems that shape their behavior and influence their access to health-promoting resources…focus[ing] on multilevel determinants, including familial, cultural, community, social, economic, environmental, and policy factors” (p.130) [6].

In addition, encouraging minority youth to enter the medical field was mentioned by multiple studies [6,12]. As racially discordant patient-provider relationships are so prominent in the U.S., inclusion of more minority youth into medical fields of study may promote better equality within these healthcare interactions, as communication and convergence issues are not evident within same-race patient-provider relationships [12]. It was proposed by community members participating in the Fritz, et al. study in Chicago that education on racial health disparities should be extended to medical and public health students as well as community members [12]. One participant stated, “Students should seek out community members who have actually experienced the disparities they are learning about…members of the community can provide unique personal stories” (p.7) [12]. This need for local health data, and personal input from affected community members, could offer valuable perspective for students preparing to serve and care for specific communities.

**Applications for Little Red Door Cancer Agency & Breast Cancer Disparities in Central Indiana**

**Current Successful Efforts**

Since 1945, *Little Red Door Cancer Agency* (LRD) has served the Central Indiana area with free cancer services, cancer prevention education, and a safe space for cancer patients, survivors, and their loved ones to connect and interact in a positive and supportive environment [23]. In 2015, LRD reached 30,941 Indiana residents through education, direct services, client navigation, and transportation services [24]. LRD currently provides free cancer services to clients who meet financial aid requirements; there are different eligibility requirements, depending on what services are requested, but general eligibility requires the client to be below 250% of the federal poverty level [24]. However, within the scope of breast cancer prevention, the expansion of the Healthy Indiana Plan (HIP 2.0) in February 2015 allows coverage for multiple screening and diagnostic services for individuals within 0%-138% of the federal poverty level [19], which accounts for approximately 80% of the LRD client base receiving mammography services [24].

In addition to providing direct services, some of the ways in which LRD support breast cancer patients that are supported by the evidence presented in this review include:

**Complimentary Therapies: Through the Door to Wellness program**, cancer patients, survivors,
and their families can participate in free yoga and massage therapy in order to help reduce mental stress and physical strain associated with cancer diagnosis and treatment. In 2015, LRD served 1,774 individuals with these services [24].

**Transportation Services:** Transportation can serve as a substantial barrier for cancer patients in receiving adequate cancer treatment and services. In 2015, LRD provided 13,035 free trips to and from cancer services for recipients in need [24].

**Prevention Education:** Education for the community regarding cancer prevention and differences in cancer mortality is cited as a critical factor in improving community awareness and understanding of racial health disparities. In 2015, LRD attended 271 community events within Central Indiana to provider cancer education [24].

**Walking & Cooking Club:** Multiple studies provide evidence of the effectiveness of exercise and nutrition intervention in increasing survivorship in breast cancer patients. LRD provides nutrition education and promotes regular exercise to their clients on a monthly basis through Walking Club and Cooking Club through their Door to Wellness program.

“**Face of Hope**” Storyteller Program: Through LRD’s “Face of Hope” campaign, cancer patients are able to publicly share their experiences with cancer with the community at the annual “Face of Hope” event. These are ways to provide hope, empowerment, and enlightenment to others struggling with cancer within the community.

**Potential Opportunities**

One of LRD’s goals for 2016 is to develop a targeted wraparound program to address African American breast cancer patients, in order to contribute to reducing the disparity within Indianapolis, and Central Indiana [24]. Based on the evidence provided in this review, the following suggestions may be taken into consideration during the development of these programs:

*Establishing an activity or club exclusively for African American females.* It was cited by several sources that African American breast cancer patients found being around other females of the same race to be a source of comfort [8,21,41], and contributed to high program retention rates, leading to positive program impact [21]. Also, providing an African American female to be the organizer or leader of this activity may also be a source of added comfort to participants.

*Incorporating faith and spirituality into program framework.* The role of spirituality and faith is very prominent in the cancer journey of African American females [8,21,41], to the extent that interventions that do not include spirituality are considered to be “culturally insensitive” by the intended audience [41]. Perhaps collaboration with local churches or faith-based organizations could assist in the development and delivery of spiritual components of these programs.

*Providing education specifically addressing racial disparities in breast cancer mortality in Indiana.* Interventions in other urban African American communities provide evidence that
education on racial disparities is encouraged in order to increase community awareness and action around this growing issue[8,12]. In addition, including LRD clients and other communities in the development of this curriculum through qualitative surveys and interviews may be beneficial in ensuring accuracy and validity of program in addressing local health issues.

*Expanding storyteller program to include series on racial disparities.* In other urban African American communities, community members expressed interest in sharing their experiences with racial disparities in patient-provider interactions, cancer treatment, and biases regarding cancer within their own social network[12]. Providing LRD clients with experiences of this nature to share their stories may empower these individuals, and educate and enlighten individuals going through similar experiences.

*Encouraging the provider and student community to learn more about racial disparities.* Although LRD does not work directly with the provider and student community, encouraging organizations that do educate these groups to provide information and materials on ways to increase effective provider-patient communications, reduce unintentional and inherent racism and racial bias, and improve equality in treatment plans for African American breast cancer patients may help in addressing these issues.
References


Appendix A:

The National Cancer Institute’s Conceptual Framework:
Potential Barriers to the Receipt of Optimal Cancer Treatment
(Shavers & Brown, 2002, p.336)