

## ORIGINAL RESEARCH

# Breast cancer mortality disparities: Providers' perspective

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## ABSTRACT

This research is part two of a study to gain understanding of reasons for the large breast cancer mortality disparity between African-American and White women who live in Memphis, Tennessee. Among the country's 25 largest cities, the breast cancer mortality disparity is highest in Memphis, Tennessee, where African-American women are twice as likely to die from breast cancer as White women. In part one of this study, we sought to gain the perspective of African-American breast cancer survivors. Now we explore the perspective from the providers of care who interface with breast cancer patients, health systems, and health insurers. This is a descriptive research study that used qualitative methodology to interview seven medical, surgical and radiation oncologists who serve African-American breast cancer patients in Memphis. Data were collected using semi-structured in-depth interviews. Themes included: (1) socioeconomic factors; (2) lack of knowledge about treatment, progression and side effects, and diagnosis; (3) information/communication about the diagnosis; (4) support system: need for another person to process information given; (5) limited access and resources: no insurance and no available services for treatment in African-American neighborhoods; and (6) fear of the unknown: fear of cancer, fear of losing breast, and fear about the disease's impact on personal relationships. These results suggest that resources that aid geographical access to services need to change in order for disparities to decrease. A new model for health care delivery for African-American women at high risk of or diagnosed with breast cancer needs to be developed to address these findings.

**Key Words:** African-American, Breast cancer survivors, Socioeconomic factors, Support systems, Limited access, Health systems

## 1. INTRODUCTION

Health disparities by race and ethnicity is a well documented phenomenon. Among key national health indicators such as life expectancy, cardiovascular disease mortality, prevalence of adult diabetes, and infant mortality, African-Americans fare significantly worse than Whites; even after controlling for applicable covariates.<sup>[1]</sup> In the case for breast cancer, there is no exception. Despite the fact that from 2008-2012 breast cancer incidence in White women was

higher overall (128.1 per 100,000 White women versus 124.3 per 100,000 African-American women), African-American women were more likely to succumb to the disease (21.9 deaths per 100,000 White women versus 31.0 deaths per 100,000 African-American women).<sup>[2]</sup> Since 2012, the incidence rates for African-American women has risen to that of White women, 135 per 100,000 persons.<sup>[3]</sup> The corresponding mortality rates were 42 percent higher for African-American women compared to White women, and the mor-

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tality gap is expected to rise even higher.<sup>[4]</sup>

African-American women are more likely to be diagnosed with breast cancer at a younger age, when the prognosis tends to be poor. The median age of diagnosis for White females is 62, but 58 for African-Americans with the median age of death 62 for African-Americans and 68 for Whites.<sup>[3]</sup> African-American women maintain the lowest 5-year survival rate among all racial and ethnic groups (rate for White women is 88.6 percent, African-American women is 78.9 percent).<sup>[5,6]</sup>

While disparities in other cancers, ischemic heart disease, and stroke have declined in recent years, differences in breast cancer mortality rates between African-American and White women has broadened over the past 30 years.<sup>[7]</sup> The literature attributes a number of factors to racial differences observed in breast cancer outcomes including “tumor behavior and morphology, pharmacogenetic responses to therapy, socioeconomic status, access to early screening and treatment, and differences in patient-level behavioral factors<sup>[7]</sup>”. These studies also assert that African-American women still have worse outcomes, even after controlling for tumor type and genetic predispositions. Other studies note that the disparities may be associated with lack of access to: medical coverage/care, improved cancer treatments and clinical trials, breast health awareness information, regular health care providers, transportation and/or child care, providers who culturally identify with patients, perceived trustful healthcare providers, and prompt diagnosis and consistent follow-up care.<sup>[8]</sup>

Screening mammography rates among African-American and White women have been comparable for over a decade.<sup>[7]</sup> Consistent funding that provides free, state-level mammography screenings as well as free screenings provided through local, non-profit organizations has helped increase the availability of early detection screening for low-income, uninsured, and medically underserved populations. Additionally, the Affordable Care Act as early as 2012 required coverage of mammograms without deductibles or co-pays.<sup>[9]</sup> Publicizing and providing information about these various free mammography screening programs could nonetheless lead to follow-up issues with women in this population. For example, uninsured women may be apprehensive about getting a mammogram even though it is free because they may be concerned about availability and affordability of treatment if they are diagnosed with breast cancer. Similarly, comorbidities (diabetes, hypertension, etc.) are significantly more prevalent in African-American than White women, which could result in delayed treatment for breast cancer, fewer treatment options, reduced effect of treatment, or inability of the patient to effectively follow-up and coordi-

nate multiple health conditions.<sup>[10]</sup>

DeSantis, et al.<sup>[11]</sup> analyses indicate that another factor associated with disparities in mortality outcomes is that African-Americans are diagnosed with the highest percentage of Triple Negative Breast Cancer, (one of the most aggressive types with poor prognosis) and no targeted treatment is currently available for this cancer subtype. Their research also confirms that the percentage of lymph node metastasis is higher for African-Americans than Whites.

In a 2011 study, Whitman et al.<sup>[12]</sup> determined that Memphis, Tennessee has the highest breast cancer mortality disparity in the country, when compared to the 25 largest metropolitan cities. According to the study, an African-American woman in Memphis is 2.09 times more likely to die from breast cancer than a White woman.<sup>[12]</sup>

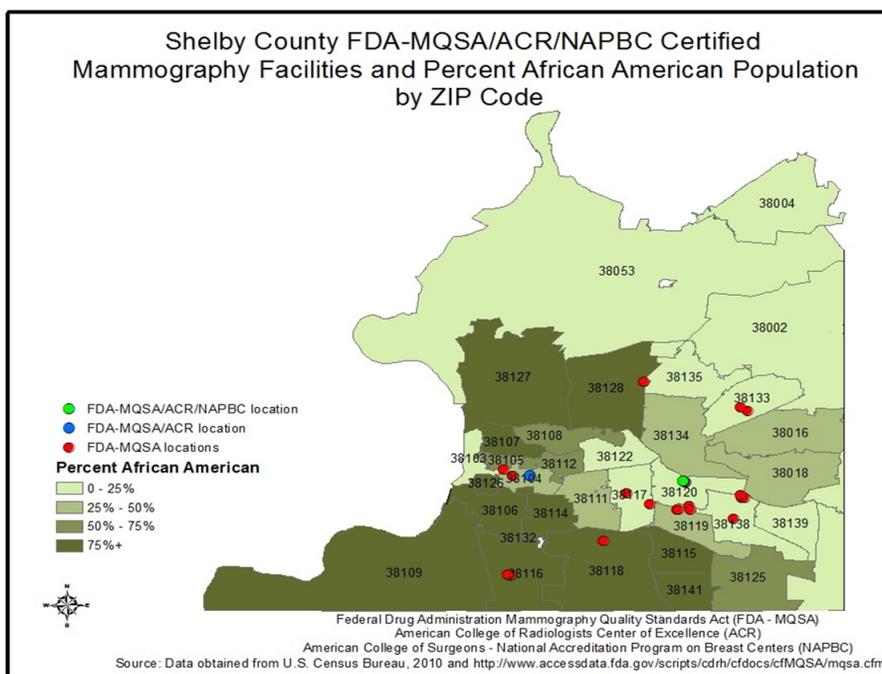
A follow up study, by Hunt, Whitman & Hurlbert<sup>[13]</sup> revealed that this disparity for African-American women has been trending across the nation since the 1990's. Despite initiatives that target early detection and affordable high quality screening in minority and low socioeconomic status (SES) women, the improvements in the rate of breast cancer deaths have been mostly limited to White women. When comparing breast cancer mortality rates in Memphis from 1990 to 2009, the rate for African-American women has only declined slightly from 46.3 to 44.3 (a rate ratio [RR] for 2009 compared to 1990 of 0.96) while the rate for White women declined from 36.4 to 21.0 (a RR for 2009 compared to 1990 of 0.58). The overwhelming statistical differences call for further explanation and distinctive solutions.

The elimination of breast cancer outcome disparities in Memphis and in comparable regions will require multiple interventions from various entities. Memphis is the 23rd largest city in the United States. Among its 655,770 inhabitants, over 63 percent report their race as African-American.<sup>[14]</sup> Several demographic and socioeconomic factors within the city of Memphis contribute to the populations' poor health status. Twenty percent of persons under age 65 do not have health insurance.<sup>[14]</sup> Compared to the national unemployment rate of 4.7, the unemployment rate in Memphis is 5.4.<sup>[15]</sup> Poverty rates in Memphis are higher than the national average (29.8 percent vs. 15.5 percent).<sup>[16]</sup> Among African-Americans, the incidence of poverty is persistently high, 34.4 percent compared to 13.5 percent among Whites.<sup>[16]</sup> Memphis is also the national leader in income inequality and economic distress among cities with populations exceeding 400,000; over 68 percent of the population lives in economic distress based on indicators of educational attainment, housing vacancy rates, unemployment rates, poverty levels, median income ratio, change in employment and changes in business

establishments.<sup>[17]</sup> Communities also suffer under systematically imposed segregation of neighborhoods by income and consequently by race.<sup>[18]</sup>

To gain a grasp on the nature of the challenge faced by Memphis' African-American women in obtaining quality breast cancer care and its relationship to geographical access, we used GIS techniques to map in Figure 1 the geographical location of FDA Mammography Quality Standards Act (MQSA) certified mammography centers in Memphis/Shelby County and also the racial distribution of the population. The MQSA sets minimum quality standards for personnel, equipment, and record-keeping. As amended in 1998, the act

requires that facilities have systems for communicating mammography results, as well as for transferring the original mammograms at the patient's request.<sup>[19]</sup> A higher quality mammography facility is obtained when a facility receives American College of Radiologist's (ACR) Center of Excellence certification, and an even higher quality certification is American College of Surgeons' National Accreditation Program on Breast Centers (NAPBC). There are 24 facilities in Memphis/Shelby County with MQSA certification (noted in red) or higher certifications (noted in blue and green). These facilities are mapped in Figure 1 according to their zip code location.



**Figure 1.** Map of FQSA certified mammography facilities

Figure 1 also color codes the percent African-American population by zip code. The darker the shade of green used, the larger the percent African-American population living in the zip code. MQSA certified facilities are less likely to be available in zip codes where 50 percent or more of the residents is African-American. This depicts a disparity in access to quality mammography care and the potential challenge faced by low income African-American residents who live in the inner city and lack motor vehicle transportation. A similar geographic disparity exists in access to oncology providers.

This study is the second in a series to determine, “What makes the Memphis breast cancer experience so different that the largest disparity in breast cancer deaths occurs in Memphis?” Previously, we developed a descriptive, qualita-

tive study to explore the experiences of 10 African-American women living in Memphis who survived breast cancer. Our results were noteworthy. The women revealed difficulties preserving financial responsibilities and cited inadequate communication with providers pertaining to post treatment limitations, pain, and support. The study participants also acknowledged cultural differences between themselves and White women with breast cancer; and assumed their experience to be much different. In addition, we learned that the African-American women were not vigilant regarding pre-symptomatic screening and follow-up due to cultural influences or a distrust of healthcare providers.<sup>[20]</sup>

This second part of the series will further explore reasons the breast cancer experience might be different among African-

American women in Memphis by assessing the oncologist's perspective. The providers who serve many African-American women in this population may be at a vantage point to recognize the blanket needs of the community. This is because providers serve as the breast cancer patient's agent, as well as a resource used within health systems by health insurers. These roles influence oncologists' treatment decisions and perceptions of racial differences in breast cancer care outcomes.

Previous studies that included various levels of providers in diverse oncology settings confirmed the provider's perspective as effective in recognizing barriers to quality care as well as devising solutions to improve quality. A study conducted in Canada was successful in having healthcare providers identify barriers to cervical cancer screening for First Nations (aboriginal Canadian) women.<sup>[21]</sup> Another study established a pilot oncology team training program at a breast oncology ambulatory care clinic in Boston, Massachusetts.<sup>[22]</sup> The team successfully designed interventions that addressed issues of safety and quality within the site. Another study investigated staffing adequacy in a comprehensive cancer center from the prospective of 20 registered nurses, nursing assistants, and associate directors.<sup>[23]</sup>

Our investigation will delve into the perspectives of providers who service African-American women with breast cancer living in Memphis. From oncologists' system viewpoint and their patient/provider interaction, we seek additional understanding about the factors that are the primary root causes of the breast health disparity in Memphis. Perceptions garnered from oncologists who serve African-American women in vulnerable populations may prove critical in pinpointing unique features within Memphis and similar communities. We hope that solutions for improved breast health outcomes emerge.

## 2. METHOD

This research is a qualitative study of oncologists who serve African-American breast cancer patients in Memphis, Tennessee. The logic behind oncologist interviews was to gain more information about what oncologists perceived regarding: equity in access and treatment, providers' engagement of patients in the treatment process, racial differences in compliance and treatment, and strategies for improving quality of care. The research question aimed to discover what providers perceived as the reason for the difference in breast cancer outcomes in African-American and White women in Memphis. Using a semi-structured interview guide, face-to-face interviews with 7 surgical, medical and radiation oncologists were held between September, 2013 and October, 2015. The thematic analysis and a deductive a priori template of codes

were used to analyze the data. Themes were developed from the semi-structured interview guide, which were designed to elicit oncologists' perceptions of what was behind the disparities facing African-American breast cancer patients in Memphis and if these perceptions differed from the patients' perspective. Qualitative research was ideal because it is designed to provide a deep understanding of the oncologists' perceptions of their experiences and formulate relevant and useful findings, and to evaluate and make recommendations for improvements to screening, treatment and follow-up care of African-American women with breast cancer.

### 2.1 Providers

Nine oncologist who saw African-American breast cancer patients were invited to participate in the study. Invitations were extended via the oncologist office receptionist. Seven agreed to participate. The main criteria for inclusion were oncologist who provided breast cancer treatment to African-American women in Memphis Tennessee. The inclusion criteria also sought those from diverse ethnic groups, genders and primary institutions that provided breast cancer care in Memphis, TN. The sample included four females and three males. Five providers were White and two were African-American. The participating providers' had between 10-23 years of experience treating African-American breast cancer patients. Their ages ranged from 35-69 years of age (see Table 1).

### 2.2 Data collection and analysis

Institutional review board approval was granted for this study from the affiliated university. Data collection consisted of a fourteen question semi-structured guide. Individual interviews were conducted in the provider's office and set up by the office receptionists including dates and times. Interviews lasted 60 to 105 minutes. Verbal consents were obtained to audiotape the interviews. The interviews were then transcribed verbatim for analysis. Guiding questions were used to obtain information on how providers screened, diagnosed and treated African-American women with breast cancer. Data saturation was achieved when the interviewer was attaining the same kind of responses from each interviewee and no new information emerged during the final interview.

Transcriptions were analyzed question by question using open coding with each interview. Qualitative data analysis techniques were used to analyze the data. Data management was done through development of suitable classification or coding schemes. A thematic analysis and deductive a priori template of codes were used to make sense of the data.<sup>[24-26]</sup> Themes were established using thematic analysis and a deductive a priori template of codes. The template for the

coding was based on the interview questions. Internal quality and trustworthiness were attained by having two researchers (both authors on the paper) independently code the data and form consensus through analysis (see Table 2).

**2.3 Procedures**

To present the providers’ true views, words and phrases were transcribed verbatim. However, if grammar used by a

provider might confuse readers, the word sic is bracketed and italicized immediately after the error in the provider’s quote. Ellipsis points are used to omit words from a quote to improve understanding of statements made by providers. To increase understanding of raw interview data, words are occasionally added and placed in brackets. Also, punctuation was added to facilitate reading.

**Table 1.** Characteristics of the provider sample

	Gender	Race/Ethnicity	Age	Position
<b>Provider # 1</b>	Male	White	69	Medical Oncology/Surgeon
<b>Provider # 2</b>	Male	White	62	Medical Oncology/Hematology
<b>Provider # 3</b>	Female	African-American	41	Medical Oncologist
<b>Provider # 4</b>	Female	African-American	35	Radiation Oncologist/Thoracic Surgery
<b>Provider # 5</b>	Female	White	68	Surgeon
<b>Provider # 6</b>	Female	White	57	Surgical Oncology
<b>Provider # 7</b>	Male	White	61	Surgical Oncologist

**Table 2.** CHEER study of provider’s perspective on African-American women and breast cancer: Semi-structured interview guide

- 1) Please describe your role, history, or experience with treating breast cancer in African-American women.
- 2) Do you think that breast cancer care access, management, navigation and other support services are adequate for African-American patients in Memphis? Explain.
- 3) How do you inform a patient about a breast cancer diagnosis? Does this information vary according to the race or ethnicity of the patient?
- 4) Do you recommend that patients have a family member present during the above interaction? Do African-American women have adequate social support systems to help them cope with choices associated with abnormal screening results?
- 5) How are patients involved in treatment decision? Are African-American patients less knowledgeable about breast cancer treatments or less likely to ask questions or express concerns?
- 6) What treatment choices do African-American patients typically gravitate to? What questions/concerns do patients typically express to you about treatment regimens?
- 7) Are African-American women less compliant to treatment? Explain.
- 8) What is your role in supporting breast cancer patients and survivors?
- 9) Do you think that the quality of breast care treatments that African-American patients receive differs from the care that is received by White patients? Explain.
- 10) Do underinsured and uninsured women receive timely and complete breast cancer treatment and palliative care?
- 11) Is it a burden in terms of finances to treat underinsured/uninsured women? Explain.
- 12) Most African-American women present at later stages of breast cancer. Why do you think this is the case?
- 13) Based on your experiences, what do you think makes a difference in whether a woman receives timely and good quality breast cancer treatment?
- 14) What are two ways breast cancer treatment can improve for African-American women?

**3. RESULTS**

The overarching research question of the study was, “What do providers perceive as the reason (s) there is a difference in breast cancer outcomes for African-American women in Memphis, Tennessee?” Six themes emerged from the providers’ interviews. Themes include patient (a) socioeconomic factors, (b) lack of knowledge, (c) information/communication about the diagnosis, (d) support system, (e) limited access and resources, and (f) fear of the unknown.

**3.1 Socioeconomic factors**

The oncologists in this study stated socioeconomic factors had an impact on the services patients received. Six of the seven oncologists stated support services were not adequate for African-American patients living in Memphis. Transportation was identified as a major hindrance to treatment. The bus system only goes so far. Some providers explained that patients use taxi services to get to appointments, but that option is very costly. One oncologist stated, patients

who live in Frayser, Whitehaven, and Southwest Memphis neighborhoods, do not have transportation opportunities such as those available in primarily White neighborhoods, such as Germantown or Collierville. Thus, transportation problems are greater for African-Americans getting to areas where services are available. The provider stated,

“They don’t offer services where the majority of [African-American] patients live.”

Another provider put it this way,

“Patients can’t get to us so are they less likely to [get] quality care... It’s a sixty dollar cab ride. You know, take a bus, two hours on a bus you’re in the middle of getting chemotherapy, two changes. It’s cold and rainy in the winter. It’s hard.”

Five of the seven oncologists stated fragmented services are part of the socioeconomic factors that affected African-American patients who tend to be in a more disadvantaged group. One oncologist described,

“Places like Christ Community [Health Services] don’t perform mammograms. They refer them to other places.”

Transportation and fragmented services were socioeconomic factors that seemed to affect African-American women diagnosed with breast cancer in Memphis. These challenges could contribute to the high incidence of breast cancer patients not seeking or following up on care after the diagnosis.

### 3.2 Lack of knowledge

Five of the providers stated they did not believe lack of knowledge about breast cancer was specific to the African-American patient, but related to level of education. Insufficient education made the person less likely to be engaged in the decision making process regarding treatment. One provider remarked,

“I would say it is the level of education that the individual had... So those for example [that] have college education or for example have a healthcare background like nurses or lab techs will ask the same number of questions as anybody else or more.”

Some providers made these statements about level of knowledge,

“... [African-American] patients are less knowledgeable about the entire process and don’t know what questions to ask.”

“... [African-American] patients have challenges putting together information from [the] internet.”

“... [African-American females] don’t have the knowledge and computer literacy of younger White females.”

Several of the providers stated that patients typically want the treatment that will bring them the best possible outcome. Five of the providers stated that African-American women are less likely to ask questions of the physician and tend to follow whatever recommendation is made by the oncologist. One provider stated he tries to get African-Americans involved in the decision making but a common statement heard,

“You are the doctor, so whatever you say goes.”

### 3.3 Information/Communication about the diagnosis

Providers were asked how they inform African-American women of their diagnoses of breast cancer. Four providers used a standard approach to informing regardless of race and ethnicity. One provider does not diagnose. Another provider states he informs the patient if the x-ray indicates a biopsy needs to be performed. The comment below represents a third view,

“When you have a woman who has been diagnosed with breast cancer, you try to do your best to judge the context of this individual ... I don’t think it varies by race and ethnicity but ... they don’t need to learn all the information [that] instant.”

Another provider stated it this way,

“In terms of talking about the approach to therapy; I take into account all of the aspects of the patients life [sic] including comorbidities and social factors.”

### 3.4 Support system

Five providers stated they strongly recommend patients bring family or a friend for support when they are to be informed about the cancer diagnosis. Providers stated it is always good to have a second set of ears to hear the information to support what the patient hears or understands. One provider stated when treating a patient who already knows about her cancer, that patient already has someone coming with her. Another provider remarked, despite the availability of a support network to some African-American patients,

“You know sometimes African-American women are not willing to share that type of information in order to have adequate social support.”

The provider further reiterated that it is important to have support from the beginning when given the cancer diagnosis. Receiving support from the beginning can aid the patient in following through with next steps of treatment. Another provider stated,

“... always want patients to have someone with [the patient]. But if alone, tell them anyways. Don't send them home because they may not come back.”

### 3.5 Limited access and resources

A variety of services may be needed to assure African-American breast cancer patients get the quality care they need, according to providers. Knowledge about availability of services was mentioned as a problem by most providers, as well as identified as a problem for patients to receive timely care. One provider stated,

“We have services, but as an oncologist [I] may not know all services that are available. So patients won't know. We need to make our citizens aware of what is available.”

Another provider put it this way,

“Memphis is a medical care desert. They don't provide services where the majority of... [African-American] patients live. ... this town [is polarized]... it's black/white and it's rich/poor. There are no cancer treatment services where the patients need them.”

Huge areas of concern for providers were African-American women who are uninsured or underinsured. Five providers believe it is a problem for uninsured or underinsured patients to receive timely care and services. Several providers made comments like,

“... another barrier is a complex system. Many women cannot find a provider to help them or afford whatever cost that is associated.” “The burden is when a woman is uninsured; she is likely to [not] receive care that she needed earlier. She is treating [now] stage 4 rather than stage 1 treatable cancer.”

“If you don't have insurance... [when you call the doctor's office] the first question is, what is your insurance... next... you're told you have to pay \$150 to see the doctor.”

While some providers felt their clinic or hospital was accessible to African-American breast cancer patients who were uninsured or underinsured, providers make comments like,

“The way we are organized with reimbursement and our affiliation with... We are actually neutral to any insurance or lack of insurance.”

“Before if someone didn't have insurance, they might need to be hospitalized in order to get chemo. Now uninsured can walk in and get treatment... the government gives money, i.e., 340B gives discounted drugs and services...”

“Timely can be a problem. Need to get them enrolled in TennCare or Tennessee Breast and Cervical Cancer Care. It could take 2-3 weeks.”

Providers had mixed opinions about the quality of care an African-American breast cancer patient could receive if they were uninsured or underinsured. One provider believed,

“Many women don't know they can get care while uninsured... and delay getting care until [they] qualify for Medicare.”

### 3.6 Fear of the unknown

Providers discussed some fears that are present when treating African-American breast cancer patients. They also talked about information inaccuracies. Four of the providers in this study felt African-American women deal with a lot of fear which prevented them from following up on screening, diagnosis, or treatment when something could be wrong. As explained by several providers, African-American women,

“They are in fear, they know something [could] be wrong and they [could] be in fear or denial.”

“... small proportion of patients it's cultural.”

“Some fear that a biopsy will make the cancer spread (let air get to it).”

“In the African-American community, mastectomy is associated with loss of a significant other or husband.”

Also, several providers stated African-American women know less about breast cancer and they are less resourceful in seeking information about cancer. Additionally, family can give inaccurate information to patients. Some providers put it this way,

“The issue come[s] [in] when 'Aunt Mary' who tells horror stories.”

“[African-American women] always have the choice, but the most unfortunate choice is when they decide to do nothing.”

“Some [African-American] women don’t seek therapy due to religious reasons, but want to pray [and let God cure them].”

#### 4. DISCUSSION/CONCLUSIONS

While the literature points to a number of factors that might lead to racial disparities in breast health outcomes, our challenge in this paper was to identify the amalgamation of factors such that when women face these risks simultaneously, Memphis emerges as the location with the greatest breast health disparities in the nation. We sought answers from oncologists who could provide us a perspective based on their interactions with patients and with Memphis’ health care system. They shared that poverty, lack of insurance, and transportation were barriers to care. A paucity of knowledge about the disease, its treatment and progression process and side effects, as well as fear about how this disease would affect personal relationships were identified as critical factors associated with poor breast health outcomes.

In contrast to the literature, unique concerns identified by oncologists in Memphis are computer literacy, availability of support systems during office consultation sessions, providers’ lack of knowledge about community services for breast cancer patients, and norms in African-American culture.

It was interesting that oncologists’ perspectives of disparities in breast cancer outcomes for African-American women significantly differed from that of breast cancer survivors. Breast cancer survivors focused mainly on interpersonal relationships between themselves and family members, friends, and medical providers as impacting their outcomes. Oncologists focused on system influences, such as lack of health insurance, information and access to available resources, structural/transportation barriers to care. While breast cancer survivors perceived that providers did not provide them with sufficient information about what they wanted to know concerning their treatment,<sup>[4]</sup> providers did not think patients could understand needed information and lacked the technological, i.e., internet skills, to acquire and process needed information. This difference in perceptions of ability to process information on the part of patients and providers suggests a serious communication barrier that needs to be addressed. Either one or both of the following occurs: 1) patients have difficulty communicating with providers in a way that leads providers to respond to their requests for information, and/or 2) providers have perceptions of their African-American pa-

tients’ abilities that may not accurately reflect the patient’s skills.

These results also suggest resources that would aid geographical access to services will have to change in order for disparities to change. New models for health care delivery may be needed in order to address this finding. Memphis is a highly segregated community, both racially and economically. Oncologists noted that high quality breast care facilities and medical providers are not located in neighborhoods that are primarily African-American.

What would a new model of health care delivery look like in a city with the type of geographical challenge in access to breast cancer care? A model of community-based collaborations, similar to those developed through collaborations between businesses and health care facilities via United Way, may provide an option.<sup>[27]</sup> Communities must embrace the idea that the relatively high premature deaths among African-American women poses a substantial cost on the community and cull private community resources to enhance care options. When transportation infrastructure presents a barrier for low-income residents to obtain services primarily available in distant areas of the city, access to breast cancer care can be increased by bringing the services to potential patients via mobile facilities and/or investing in additional capacity in the existing free and reduced-fee clinics and community health clinics that are located in areas where low-income African-American patients live. A new model of community-based breast cancer care for Memphis might also incorporate donated services from physicians, hospitals and pharmacies. Sustainability of such community-based efforts would require additional support from state and federal agencies.

Providers noted that African-American patients face greater challenges in using the internet to obtain information, are not as knowledgeable about the process, unsure of what questions to ask, and have perceptions of insurance barriers that don’t exist. Empowering patients to meet the challenges of the digital divide appear needed. Providers’ concerns also suggest that some type of information intermediary might be helpful. One strategy for addressing these challenges is to use patient navigators.<sup>[28]</sup> Health systems that incorporate patient navigators are considered effective in helping the patient connect with disconnected components of the continuum of cancer care, from prevention, detection, diagnosis, treatment, and supportive, to end-of-life care. Navigation is considered particularly important when patients face: 1) financial and access barriers, 2) communication and information barriers, 3) medical system barriers, and 4) fear, distrust, and emotional barriers.<sup>[28]</sup>

But at what point should navigation begin and what kind of

background should navigators have? The challenge in Memphis in the current navigator system is that the navigators are hospital based and the point of entry into the navigator system is after diagnosis. If we rethink the possible delivery system, one might envision a community resource that is available in at-risk neighborhoods where persons who have questions about breast cancer can seek information, can be assisted in the use of computer technology to learn about breast cancer, and can get help in developing questions to ask providers after they enter the formal delivery care system. Such a community resource could provide information in a manner that is culturally sensitive.

Providers also noted that patients may not be accompanied by a family member who potentially could provide support at the time the patient receives information about the diagnosis, yet it is important to inform the patient anyway so that the risk of the patient not returning is minimized. It is unclear whether, at such a time, the patient is in a mental state where she can learn. In these cases if providers have a shared support resource, such as a social work team member, this system resource could potentially provide requisite support for patients who are alone when they receive their diagnosis.

It was also important to note that providers thought it was necessary to focus on socioeconomic and health characteristics of patients when informing them about their diagnosis, and were careful to note how important it was to not make a difference in the race of the patient when information was provided. While providers noted that family members may provide inaccurate information about cancer diagnosis, the providers did not make the connection that African-American cultural traditions underlie this “misinformation”. Providers may find cultural competency training useful in helping them to develop patient compliance encouraging communication strategies when patients are spurred by cultural traditions that run counter to best practices and maximizing health outcomes for patients.

Empowering patients to be proactive and diligent in maintaining their own health can be important and extremely difficult. Therefore, survivor support groups may play a vital role. They can provide information about referral resources, inform members of changes in health insurance provisions, correct information about cultural traditions and myths, encourage survivorship through association, plus serve as a source of patient advocacy. Support groups provide opportunities for survivors to share what they know and ways to overcome obstacles. Funding for this type of community resource is needed and would serve as a complementary resource for the formal breast cancer care system.

Addressing insurance concerns for low-income women in

Tennessee is a challenge because Tennessee does not participate in the Affordable Care Act Medicaid Expansion program. The Tennessee Breast and Cervical Cancer Program and local Komen Foundation provide support for screening services for the uninsured, but it is unclear how well informed women are about the availability of these services, whether these programs have adequate financial resources to finance the care for all who need services, and whether the delay in qualifying for these services leads some women, particularly those who are fearful of the breast cancer diagnosis, to refrain from seeking care. Providers noted that women faced a barrier when uninsured and then sought physician treatment. This insurance challenge, similar to the transportation challenge, suggests that a different delivery model may be needed. Until Medicaid [TennCare in Tennessee] reform occurs, this insurance challenge may need to be addressed by a community-based and financed care system that provides financial resources to open the door to the physician’s office. A community financed bridge to physician care may close the breast cancer service gap for African-American women and mitigate untimely delays in obtaining necessary care. Given that breast cancer mortality outcomes can be reduced by offering this bridge, long-term sustainability of such community-based efforts would require additional support from state and federal agencies.

Several study limitations provide opportunities for future research on breast cancer disparities in Memphis and similar communities. One limitation is that no male African-American oncologists were interviewed. In Memphis there are four African-American oncologists, two women and two men. Both African-American women were interviewed, one male African-American oncologist refused the interview, and one male African-American oncologist did not return our phone calls requesting an interview. Thus, any unique perceptions of African-American men oncologists were missed by this study. We were however able to obtain perspectives of providers representing multiple practice sites. Providers serving patients of the two largest hospital systems and the largest cancer clinic were interviewed. We also interviewed a provider who served patients of the hospital whose patients are primarily indigent and a provider whose patients are residents of the tri-state region (Tennessee-Mississippi-Arkansas).

Another limitation of our study is that we did not ask providers about their perception of the role of genetics in influencing disparities in breast cancer mortality. Future research should focus on this biologic influence on disparities.

Our qualitative data was rich in its ability to help us glean insights about the Memphis breast cancer experiences that

are associated with the high risk of breast cancer mortality among African-American women in Memphis. Through analysis of these data, we were able to propose several system intervention strategies that may improve breast health outcomes in Memphis and similar communities. A valuable area of future research that could provide more insights

on mitigating breast health disparities is a longitudinal perspective on the breast cancer experience, from diagnosis to treatment to long-term survival.

## CONFLICTS OF INTEREST DISCLOSURE

The authors declare that there is no conflict of interest statement.

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