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Capstone Project

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Abstract

Persistent disparities in the burden of breast cancer and Women of Color have been well-documented for many decades. Despite decades of commitment, within the World of Health, to finding a cure, and raising funds, advancements in medicine, treatments, further educational tools, resources, and awareness through the month of October dedicated to Breast Cancer Awareness month and adopting the color Pink, there is still a continuous survival gap between Women of Color and every other ethnic group. What is disturbing is these same well-known cancer health disparities that have been discovered and documented, that plague Women of Color, are still a problem discussed today.

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Chapter One - Introductions

Capstone Focus and Rationale

Women of Color are disproportionately represented when diagnosed with breast cancer and survivorship. I am specifically interested in the intersection of education and resources and learning how these affect the marginalized or underserved groups within urban communities. As both an African American and Latina woman, who survived Stage 2, invasive ductal carcinoma breast cancer, this capstone focuses on what education and resources are available to black and brown women throughout the urban communities. As a concerned woman and breast cancer survivor, who happens to be of African American and Hispanic descent, and who learned of and took advantage of the resources available, need to learn why the mortality rate, among black and brown women, remains disproportionate versus white women.

The education and available resources on surviving, thriving, and living longer with breast cancer are needed and of great significance within the marginalized communities, of the disenfranchised African American woman. Having access to this information gives insight into diagnosis, the types, and stages of breast cancer, and gives hope. The various kinds of treatments, radiation, medications, and clinical trials are offered when diagnosed with breast cancer. The availability of education and resources provides support group information. Primary care physicians, healthcare institutions, and neighborhood clinics, within these communities, should provide this information along with women's health fairs. The mortality rates for Women of Color and breast cancer are concerning. The education and resources are out there and available just not accessible to ethnic minorities and other underserved populations.

Research Question

With all the advancements in medicine, treatment, and clinical trials alongside the huge platform of medical research, awareness, and advocacy, for breast cancer, which I had access to and utilized, why do African American women have the lowest survival for all subtypes of breast cancer?

Definitions

Disparity is the condition of being unequal, a noticeable difference, and usually refers to an unfair difference.

Marginalization is the act of placing a person or thing in a position of lesser importance, influence, or power.

Disadvantage is the absence or deprivation of advantage or equality; the state or an instance of being in an unfavorable circumstance or condition. **Underserved community** refers to groups with limited or no access to resources or otherwise disenfranchised, which means deprived of some right, privilege, or immunity.

An ethnic minority is a group that has different national or cultural traditions from the main population.

Scope of Problem

Women of Color are disproportionately represented when diagnosed with breast cancer and survivorship. The African American woman has the lowest five-year relative breast cancer survival rate compared to all other racial/ethnic groups for every stage of diagnosis and every breast cancer subtype. This same disparity has been reported year after year for a decade. Breast cancer is the second leading cause of death after lung cancer in women in the United States overall, but it is the leading cause of death in Black and Hispanic women. Ironically, the breast

cancer incidence rates have been lowered among African American women compared with White American women but with a higher breast cancer death rate.

A routine mammogram is one of the most effective ways to early detection of breast cancer. Yet, residents of low-income and poverty-stricken areas do not have access to healthcare facilities, that can perform a mammogram. Either their local hospital does not have working equipment to perform the mammogram, or the next appointment is not available until one month or later. These are the disparities and significant concerns on the impact of African American women on doing what is right and survivorship.

According to Stringer-Reasor, Elkhanany, Khoury, Simon, and Newman, MDs, 2021, “The Patient Navigation program was first initiated in 1990 at Harlem Hospital in New York, New York. At the beginning of its induction, the focus was on the critical window of opportunity to save lives by eliminating barriers to timely cancer care and finding resolution by diagnosis and treatment. The goal of the program was to diminish the high breast cancer death rate in a population of poor black women”. Today, patient navigation focuses on patients more likely to encounter major barriers and delays to timely quality care.

African American women continue to be underrepresented in clinical trials, even though Black women are seven times more likely to succumb to the disease than White women. The barriers to trial enrollment are extensive in racial/minority patients. There is a trust issue with minority groups and the healthcare system. All to know of the history of this country’s exploitation of enslaved Blacks for medical experiments, withholding treatment, and the noted racial injustices.

To improve representation and survivorship this is pertinent, life-changing information, and detriment to African American women. Women who are informed about breast cancer risks

and the benefits of mammography are more likely to follow screening guidelines. Effective educational initiatives can therefore help promote breast cancer screening engagement. Simple routine mammography, being aware of the patient's navigation program, and clinical trials are educational tools and available resources African American women need access to. The importance of education and resources is significant in health crises. Women of color lack knowledge and available resources within their communities due to misrepresentation and the lack of urgency in the medical world.

Chapter Two – Historical Informed Analysis

History of Problem

The origin of women of color being disproportionately represented, when diagnosed with breast cancer, stems from the racial and ethnic disparities that plague American history and culture. When it comes to the burden of breast cancer between women of color and white women numerous, persistent disparities have been documented over many decades.

Access to resources and education on women's breast care and surviving and thriving breast cancer is limited, not emphasized enough, or just not available. Due to the lack of emphasis, on the benefits of education and resources, from the world of healthcare within the communities of the marginalized on the severity of breast cancer and African American women, women of color are diagnosed at later stages, a more aggressive breast cancer, and the mortality rate is higher.

Although overall breast cancer death rates have declined over the past 25 years, recent improvements in breast cancer mortality have not benefited all women equally. The incidence rate for breast cancer is higher for white women compared to black women, but the mortality rate

continues to be higher for black women than white women. This is a great disadvantage and misrepresentation of African American women, and where the problem reveals the intersection.

The sociological aspect that affects breast cancer care among women of color is determined by the conditions in which they live. Living in poverty, in a disadvantaged community, access to primary care, access to transportation, social isolation, and discrimination.

The psychological issue encountered, by African American women, during a breast cancer diagnosis and survivorship is the denial, and mistrust in the healthcare system. Along with the stress, comes the thought of the health scare interfering with her going to work and providing for herself and her family.

Racism and discrimination significantly affect how women of color are misrepresented. Historically, the world of medicine has boldly established policies and performed medical injustices against African Americans for centuries. Racial discrimination and racial breast cancer disparities are well documented. There are plausible ways of tying women of color's risks and protective factors together with discrimination from a theoretical point of view. The lack of good healthcare and reaching those good healthcare facilities outside of their communities are barriers for them to obtain proper treatment.

In the business of medicine, and having access to proper healthcare, the legal system with its penal laws, this country, has allowed funding for policies and inhumane jurisdictions to form against African Americans and impoverished communities. The battle for access to proper, humane, and affordable healthcare for all is ongoing with the politics of healthcare and the racial and discriminatory disparity, women of color must deal with the financial hardship of battling breast cancer. Having a breast cancer diagnosis becomes a financial burden. There are copayments for the frequent doctor visits to specialists, treatments, travel costs, medicine needed,

and so forth. This hardship places yet another strain along with all the other challenges faced to survive in life.

Causes

There have been monumental strides made against breast cancer in the United States in recent decades. A long history of racism in the United States of America has resulted in discriminatory policies, systemic injustices, and structural barriers that cause and perpetuate cancer health disparities. Due to these injustices that cause disparities against women of color, surviving and thriving after their diagnoses, is not as high compared to the mortality rate. With all the medical breakthroughs, education, clinical trials, awareness, and advocacy, and women living longer and fuller lives, with breast cancer, women of color are still not benefiting equally.

The cause of the disparities is most definitely disempowering, segregative, and discrimination. It takes away the voice of the most vulnerable, and her God-given right to have access to reliable healthcare. A breast cancer diagnosis is a physical ailment, life-threatening, and a journey to get through. To have to fight against the disparity and discrimination of obtaining good healthcare to survive is also draining to mental health. The resources and educational tools are substantial and in great need of women of color living in impoverished communities.

Consequences

Women of color are truly suffering the consequences of racial discrimination and racial breast cancer disparity. The social and systemic injustices played out through policies, and healthcare workers' biases and prejudices are tangible and have negative impacts on the lives of women of color. The extent of the consequences is a matter of living, surviving, and thriving with breast cancer or death. Due to the extremities of racial discrimination and underrepresentation, there is a huge negative impact on the social, psychological, and financial

stability of women of color. The stresses of coping with a breast cancer diagnosis, tied with being discriminated against, leave her with a sense of insecurity, mistrust of the healthcare system, and question her immortality.

Role of Organizations, Policies, Practices, Funding

The American Association for Cancer Research, AACR, is the leading scientific organization dedicated to the conquest of all cancers and the core values of diversity, equity, and inclusion. The American Association for Cancer Research, AACR, works to eliminate cancer health disparities through scientific and policy initiatives and to eradicate racism and racial inequality in cancer research. The American Association for Cancer Research is deeply committed to realizing the bold vision of health equity for all populations.

The efforts put forth by the American Association for Cancer Research to change the culture of suppression against the marginalized are through its programs and services, and recommendations. The AACR recommends policymakers, and the medical research community can reduce cancer disparities by building a more diverse workforce. Increasing federal funding for medical research and public health initiatives that are tasked with reducing cancer health disparities. Improve collection of disaggregated data for racial, ethnic, sexual, and gender minority groups. Increase diversity in clinical trial participation. Enhance cancer prevention and screening efforts to reduce the burden of cancer among all medically underserved populations. Expand access to equitable and affordable quality health care. Build a more STEMM trainee pipeline and cancer research and health care workforce.

The Diverse and Equitable Participation in Clinical Trials (DEPICT) Act (H.R. 6584) would provide the Food and Drug Administration, FDA, with new authorities to improve the representation of racial and ethnic minorities in clinical trials, so new therapies are studied in

populations that reflect real-world use. The Diversifying Investigations Via Equitable Research Studies for Everyone (DIVERSE) Trials Act (H.R. 5030/S. 2706) would provide additional support for decentralizing clinical trials and decrease burdens associated with trial participation. This would be accomplished in part by supporting the use of telehealth and remote monitoring and allowing reimbursement for travel expenses.

The overall mission of the American Association for Cancer Research is to prevent and cure all cancers through research, education, communication, collaboration, science policy, advocacy, and funding for cancer research.

Chapter Three – Data Trend Analysis and Interpretations

Statistical Data

The American Cancer Society researchers are dedicated to continuing to research, report, and explain the statistics of Women and breast cancer through numerous written Journals for Clinicians. The reports provide detailed analyses of breast cancer occurrence and current information on known risk factors, early detection, and treatment.

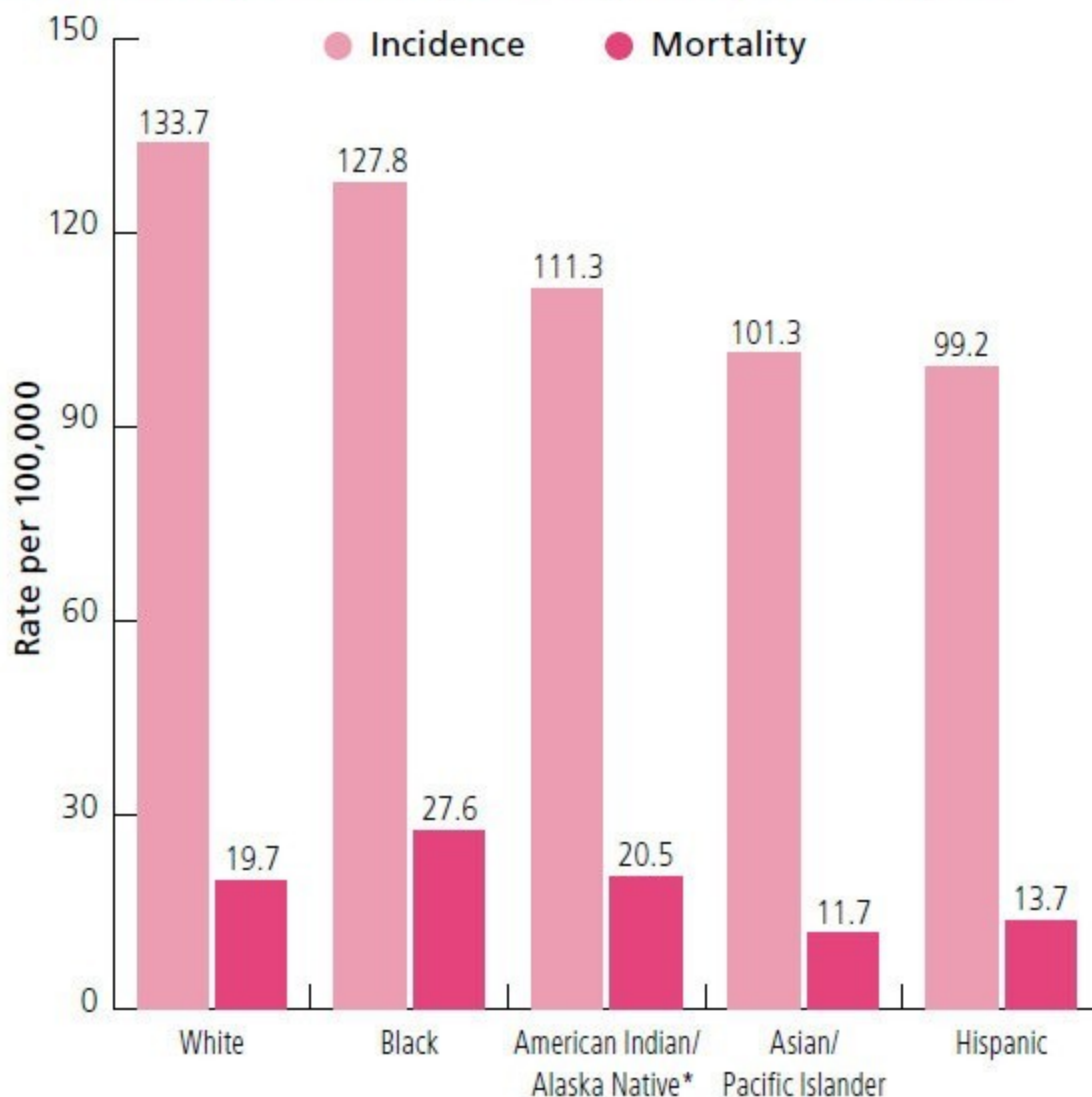
According to the article, *Breast Cancer Death Rates Are Highest for Black Women—Again*, by Sandy McDowell, “It has been reported that the death rate for breast cancer in the United States among women dropped 43% between 1989 when it peaked and 2020. Within the last decade, death rates declined similarly for women of all racial/ethnic groups across The United States except for American Indians/Alaska Natives (AIANs), which had stable rates. However, African American women are still more likely to die from breast cancer than White women across the United States, even though Black women have lower breast cancer incidence rates”.

“We have been reporting this same disparity year after year for a decade. The differences in death rates are not explained by Black women having more aggressive cancers. It is time for health care systems to take a hard look at how they are caring differently for Black women”.

*****Rebecca Siegel, MPH, Senior Scientific Director of American Cancer Society Cancer Surveillance and co-author of the study, CA: A Cancer Journal for Clinicians and in Breast Cancer Facts & Figures 2022-2024.***

According to these reports, in 2022, new breast cancer diagnoses will slowly increase. Most breast cancer cases are diagnosed at a localized stage. These early-stage breast cancer diagnoses have not spread outside of the breasts and are most often found during breast cancer screening and will typically have a high survival rate because treatment is more effective at this stage. And yet, according to this study, ***CA: A Cancer Journal for Clinicians and in Breast Cancer Facts & Figures 2022-2024***, “Black women still have a 4% lower incidence rate of breast cancer than White women but a 40% higher breast cancer death rate”.

Figure 3. Female Breast Cancer Incidence (2015-2019) and Death (2016-2020) Rates by Race/Ethnicity, US



Note: Rates are per 100,000 and age adjusted to the 2000 US standard population. Race is exclusive of Hispanic origin. *To reduce racial misclassification, incidence data are confined to PRCDA counties, while mortality data are for the entire US with adjustment factors for racial misclassification applied. (See Sources of Statistics, page 34).

Sources: Incidence – NAACCR, 2022. Mortality – National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention, 2022.

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Statistical Tables

In this statistical data graphic, *Figure 3. Female Breast Cancer Incidence (2015-2019) and Death (2016-2020) Rates by Race/Ethnicity, US*, the light pink bars represent the breast cancer incidence rate and show it is higher in White women and lowest in Hispanic women. The dark pink bars, represent the breast cancer death rate and are highest in Black women, followed by American Indian/Alaska Native women, and lowest in Asian/Pacific Islander women. As it is seen Black and American Indian/Alaska Native women both have a higher death rate than White women although they both have a lower incidence rate for breast cancer than White women.

Implications

The public database shows how women of color are disproportionately represented when diagnosed with breast cancer. The fact that the breast cancer incident rate for Women of color is lower than that of White women but the mortality rate for Women of color is much higher proves the intersectionality. When it comes to the burden of breast cancer between women of color and white women numerous, persistent disparities have been documented over many decades. And yet the struggle, the research, and the fight to develop decent policies and funding must continue. Not only to expose and eradicate the disparities but also to hold healthcare professionals, organizations, and local and state officials criminally accountable.

Chapter Four - Recommendations

Role of the Organizations

The American Association for Cancer Research, AACR, is the leading scientific organization dedicated and focused on preventing and curing all cancers. Diversity, equity, and inclusion have been at the foundational core of AACR's work. The *Cancer Disparities Progress Report* to Congress and the American Public is a cornerstone of the American Association for

Cancer Research's educational and advocacy efforts to achieve health equity. The report highlights areas of recent progress in reducing cancer health disparities, emphasizing the vital need for continued transformative research, and for increased collaborations to ensure that advances against cancer benefit all patients.

The American Cancer Society, ACS, researchers are dedicated to continuing to research, report, and explain the statistics of Women and breast cancer. The American Cancer Society recognizes breast cancer, all cancer health disparities are a complex and multifaceted problem.

The fact that Women of Color have a less incidence rate of being diagnosed with breast cancer than any other racial or ethnic group but have the highest mortality rate is alarming. And shows there is much more effort needed to be done. Both the American Cancer Society and the American Association for Cancer Research have found and written numerous reports, and statistical data exposing the many causes of health disparities. With all the research and data, there is enough information to put policies in place, close the gaps in awareness, advocate for change, and expose and hold individuals and organizations accountable for their role in causing injustice, disparity, or pain to the marginalized. There should be costly penalties, licenses revoked, and maybe even criminal charges for any individual, group, or organization that violates one human right to adequate healthcare.

Challenges

The American Association for Cancer Research has made a call to action. The AACR calls out systemic inequities and social injustices that impact every aspect of cancer research and patient care, including limited participation in clinical trials and differences in cancer incidence and outcomes among underserved populations. AACR believes while new research and

initiatives are closing these gaps, progress has been slow, and the cost of cancer health disparities remains monumental.

The American Association for Cancer Research calls on policymakers and stakeholders committed to eliminating cancer health disparities. Some of the outcries are to provide robust, sustained, and predictable funding for federal agencies and programs tasked with reducing cancer health disparities. Ensure cancer-related, disaggregated data are collected and analyzed for sexual, gender, racial, and ethnic minority populations. Improve representation in clinical trials by reducing barriers to patient enrollment. Prioritize cancer control initiatives, awareness, and improved access to cancer screening. Expand Medicaid and access to quality, affordable healthcare coverage.

One of the many challenges the AACR faces is not being provided with adequate funding for innovative research and believes Congress can be of enormous assistance in eradicating cancer health disparities. Another possible challenge in dismantling this health crisis is finding those of other ethnic backgrounds in the health world who will confront and even report those performing an unjust. How we confront these challenges are continued faceoffs with policymakers, stakeholders, and the Government. Find ways to sit in those boardrooms, and harass our local representatives, Senators, and Congress. It will take more than just research, statistics, and data to move the hand and hearts of those whom this crisis does not impact.

The two most urgent resources needed to resolve this health disparity are money and time. The money is needed to continue to make progress, break down barriers, bring awareness, and move hearts to empathize and want change. Time is needed because of its value to and limits of people. To make a dent in the health disparity impacting Women of Color, other minority

groups, and those living in impoverished communities, money and time will forever be imperative.

Desired Outcomes

When Women of Color are represented equally and fairly, there is a significant decrease in their mortality rate, and when the World of Health earns the trust of Women of Color, are the only desired outcomes deemed successful. Health care is not a privilege. Everyone has the God-given, human right to live an abundantly healthy life, and that means having adequate, quality health care. Alongside the American Association for Cancer Research and American Cancer Society, there are many organizations, groups, unions, public figures, and most importantly those directly impacted who continue the fight to bring an end to this epidemic. The breakthrough is coming.

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