MY SISTER'S KEEPER:

A CRITICAL ETHNOGRAPHY ON SOCIAL SUPPORT AMONGST BLACK WOMEN CANCER PATIENTS AND SURVIVORS

Dissertation in Practice

Submitted to

The School of Education and Health Sciences of the

UNIVERSITY OF DAYTON

In Partial Fulfillment of the Requirements for

The Degree of

Doctor of Education

By

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UNIVERSITY OF DAYTON

Dayton, Ohio

May 2023

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EXECUTIVE SUMMARY

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This study utilizes an intersectional ecological systems theory to explore social support network formation amongst Black women cancer patients and survivors though the use of critical ethnography. Critical ethnography is employed to explore the lived experiences of Black women cancer patients and survivors as it impacts the unique needs they require in a culturally responsive support program. Black emancipatory action research is utilized as a framework to propose an intervention aimed at improving the mental well-being and increasing the social support experienced by this demographic.

Dedicated to all Black women who have fought alone in silence.

ACKNOWLEDGMENTS

My special thanks to the brave and beautiful Black women who allowed me to interview them for this study, who believed in my work, and helped me when I could not help myself.

I would also like to express my eternal appreciation to my mother who stayed by my side every single night of my own cancer journey and every day since.

Finally, I would like to thank my husband, my friends, and my classmates for carrying me through this project. I truly could not have done this without your unwavering support, belief, and continuous displays of love. It will never be forgotten.

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LIST OF ABBREVIATIONS AND NOTATIONS

AAVE	African American Vernacular English
BEAR	Black Emancipatory Action Research
CNA	Comprehensive Needs Assessment

CHAPTER ONE: PROBLEM OF PRACTICE

Topic

This study sought to understand social support network formation among Black women cancer patients and survivors across all diagnoses within Cancer SSN, a pseudonym for a small non-profit dedicated to providing resources for marginalized individuals impacted with cancer. This is done with the goal of proposing an intervention aimed at increasing the support and well-being of Black women cancer patients and survivors through the formation of social support spaces specifically tailored to their unique needs through the exploration of their experiences.

The Problem of Practice

The organization selected for this study, Cancer SSN, offers a wide variety of free activities and resources aimed at providing social support, building community, education, and awareness throughout the cancer journey. Though Cancer SSN has experienced success, the limited size of the organization, coupled with its relative inexperience in this space, has created a deficit of information surrounding the exact needs of their participants. Similarly focused organizations such as the American Cancer Society or Gilda’s Club, commonly offer a universalist approach to cancer support groups however this “commonality” implies a universalism of experience which in the face of a legacy of medical racism reaching back into slavery is far from the truth (DiAngelo, 2011). Accordingly, the problem of practice this study sought to address is the limited understanding organizers at Cancer SSN have about the unique needs of Black women cancer patients and survivors as created by their unique experiences.

Justification of the Problem

Nationally there is a striking lack of organizations which cater to the unique needs of Black American cancer patients and survivors. Presently, "African Americans have the highest death rate and shortest survival of any racial and ethnic group in the US for most cancers" (American Cancer Society, 2021). From an intersectional perspective, Black women are tasked with the double burden of fighting for survival while also navigating a field with a long legacy of delegitimizing their pain (Washington, 2008). Medical stereotypes surrounding the perceived “strength” of Black women highlight the perception that Black women do not experience pain or suffering as intensely as their white counterparts (Pryma, 2017).

Compounding issues that Black women experience also include economic challenges, poor patient-provider communication, fear, and distrust of the healthcare system (Whitehead & Hearn, 2015). Though it has been reported that Black women do experience support through personal relationships with spirituality and faith (Phillips & Cohen, 2011), Black women are more likely to report a lack of social support and greater cancer-related stigma, two things which also contribute to the disparity in health outcomes (Whitehead & Hearn, 2015).

Given the lower rate of survivorship within the Black community, and the negative health outcomes that a lack of social support may promote, the creation of organizations or the implementation of interventions specifically targeted towards increasing the social support and well-being of cancer survivors is vital (Gudina et al., 2021). The goals of increasing the support and well-being of Black women cancer patients and survivors and expanding the social support networks available to Black women cancer patients and survivors are timely and relevant given the disparity in survivorship, the burden of stereotype, and limited social support.

The Racial Equity Readiness Assessment highlights the importance of race-explicit strategy stating that organizations should frame improvement by directly and explicitly addressing disparities that affect specific communities to promote positive and equitable outcomes ("Ready for Equity", 2018). By exploring the creation of sanctuary social support spaces for Black women, and how these spaces may contribute to mental well-being, this study is poised to present valid information with the intent of influencing future organizational programming.

Deficiencies in the Organizational Knowledge Record

Previous research has addressed various aspects of this study such as Kimberle Crenshaw's (1991) work on intersectionality and Deborah King's (1988) work on multiple jeopardy. Edward Lindop's (2001) study on experiences of women with breast cancer, Jane Pryma's (2017) study on moral boundary-work, Crawley et al. (2008) study on the perception of medical discrimination and cancer screening behaviors, Mouton et al. (2010) study on the impact of perceived discrimination on health screening in Black women and Taylor et al. (2007) study on racial discrimination and incidence of developing breast cancer in US Black women all explore the disastrous impact racial discrimination has on positive health outcomes.

Gudina et al. (2021) study on the importance of social and emotional support in adult cancer survivors, John Cacioppo's (2014) work on social relationships and health, Koopman et al. (2001) study on distress, coping and social support among rural women with breast cancer, Waxler-Morrison et al. (1991) study on the effects of social relationships on survival and Jacob Weiss' (2013) work on implementing social support communities each speak to the positive impact social support has on health outcomes. However, there is an intersectional void when addressing the multiple jeopardous statuses of being Black, a woman, and critically ill in relation to social support network formation.

Audience

This study is relevant to community organizers, mental health practitioners, physicians, and caregivers who are involved with the treatment and care of Black women cancer patients and survivors. This study is also relevant to Black women who, though reading this, may experience the visibility and solidarity so often missing within the medical experience. By exploring the relevancy of forming spaces of sanctuary through the creation of social support networks, parallels to many other marginalized communities may become applicable.

Theoretical Framework

Intersectionality is a theoretical perspective which seeks to explain how various statuses, such as race, gender, and class, all intersect to create a unique lived experience (Crenshaw, 1991). Built from the revolutionary work of notable Black feminists such as Patricia Hill Collins (1986) and Audre Lord (1984), intersectionality provides an analysis of the structural, political, and representational marginalization experiences of Black women. For Black women, the duality of these statuses can often create a double or multiple jeopardy from which social mobility, equality, and even trustworthiness is difficult to attain (King, 1988). This study utilizes an intersectional framework to analyze how the unique lived experiences of Black women seeking medical care underscore the need for the formation of social support networks while navigating the medical industrial complex.

Social support networks do not function in a vacuum. Therefore, this study utilizes an ecological systems perspective, in conjunction with an intersectional framework, to analyze the interdependence between program participants. Ecological systems theory views a person's environment as comprising several concentric parts all interrelating and constructing the whole (McLaren & Hawe, 2005). In this model, interdependence between the self, community, society, and culture all affect how an individual navigates daily life (McLaren & Hawe, 2005).

The promotion of a social support network necessarily involves interdependent social contexts which may include neighborhoods, community partners, medical systems, family relationships or other broader organizations (Weiss & Lorenzi, 2009). Utilizing an ecological systems perspective, in conjunction with an intersectional framework, not only explains how ascribed statuses impact personal social location but how those statuses cocreate community within a social support system.

The formation of these sanctuary spaces of social support is a radical act of self-love and care within an often-hostile society. Creating space which uplifts and centers the unique struggles Black women endure while seeking medical care is a profound resistance to the effaced dehumanization Black women suffer within a system of marginalized oppression. As bell hooks explored in *All About Love*, the practice of love is a revolutionary path out of oppression (2000).

The Critical Theory of Love celebrates the endurance of the human spirit by continuing the work of reshaping the notion of love into an actionable stance of revolution, a notion reinforced through Black emancipatory action research (Akom, 2011; Brooks, 2017). Transforming the notion of love from a dubious emotional state to a radical space of resistance offers insight to how the formation of sanctuary social support spaces can not only be places of healing and well-being but also the catalyst of organizational change in the future. This study employs the critical theory of love in conjunction with ecological systems theory to propose an organizational change plan that emphasizes radical compassion.

Methods

This study utilized a Black emancipatory action research model and a critical ethnographic approach to data collection. Critical ethnography is an approach tasked with the burden of uncovering areas of oppression through listening to the stories of marginalized communities (Hagues, 2021). Researchers utilizing this approach function as participatory members within community spaces, often sharing the same statuses as those researched (Hagues, 2021). Methodologically, this necessitates a consistent exploration of the self-other relationship to provide trustworthy and credible data (Foley, 2002). Accordingly, this study includes sections detailing researcher positionality and bracketing as well as political and ethical considerations.

Black emancipatory action research, like critical participatory action research, centers research as being done cyclically and collaboratively with marginalized communities with the goal of elevating the voice of the community to promote change (Akom, 2011; Fine et al, 2021). Black emancipatory action research further centers the intersectional experience of race as experienced by Black people across the diaspora as a radical site of information ultimately promoting the transformative power of healing through love (Akom, 2011). An underlying tenant of this methodological perspective is the principle of structural racialization, an understanding that race and racism supersedes individualism and instead resides in the structures we create, inhabit, and maintain (Akom, 2011). As such we are each formed, and in turn inform the systems we inhabit contributing to our conception of the world and each other (Akom, 2011).

Research question

What are the unique needs of Black women cancer patients and survivors within Cancer SSN?

Sub-Question

How can Cancer SSN expand the social support networks available to Black woman cancer patients and survivors?

How can Cancer SSN increase the support and well-being of Black women cancer patients and survivors?

Limitations

This study focused on social support network formation and the improvement of well-being for Black women cancer patients and survivors within one organization and ancillary contacts created through that organization. As such, this study is primarily regionally and demographically specific. Qualitative research is inherently subjective as the researcher is the instrument for data collection and analysis. Furthermore, an ethnography is limited by the information the participant chooses to share, and the analysis conducted by the researcher. To address researcher limitations, bracketing including memo writing and reflexive journaling, community collaboration, and member checking have all been incorporated throughout the research process (Tufford & Newman, 2010).

Literature Review

This literature review seeks to explore myriad issues surrounding the legacy and contemporary reality of medical discrimination, social support, and social support network formation. This is done with the goal of providing a firm background on the related issues surrounding the implementation of social support groups specifically targeted towards Black women cancer patients and survivors. In addition, this information is presented to provide context for the assertion that race, and racism is imbedded within the medical industrial complex and the inescapable fact that a universalist approach to organizational programing cannot account for the legacy of medical discrimination, horror, and brutality Black women have, and continue, to face.

This literature review is thematically divided into two sections, context, and intervention.

Historical Context: A Brief and Brutal History of Racism Within Medicine

Social support network formation amongst Black women is a necessity resulting from centuries of abuse within medicine. A comprehensive accounting of the legacy of medical experimentation, testing, and discovery made at the expense of Black pain and suffering is unfeasible in the confines of this study. To follow is a brief history of such an undertaking provided with the explicit understanding that it is impossible to fully comprehend the current climate of mistrust, discrimination, and disparity without some understanding of how it began.

The earliest instances of exploitation against Black Americans occurred in the antebellum south by physicians, in the service of white slave holders, who were contracted to provide "medical treatment" for their slaves (Washington, 2008). Plantation slaves were often plagued with sickness due to exposure to new diseases such as hookworm and yellow fever, malnourishment, physical exhaustion, and poor sanitation (Washington, 2008). Limited knowledge of human physiology, in addition to a cold disregard of Black suffering, led to "medical treatments" such as bleeding, induced vomiting, diarrhea, and pole whipping to be common cures employed in the service of "health" (Washington, 2008). A wide variety of "medicines" were often used including flour, calomel, arsenic, and mercury (Savitt, 1978). Surgery, when attempted, was almost always fatal (Savitt, 1978). Slave owners, not wanting to waste money on slaves who were no longer productive, would often forgo medical treatment all together, often to the fatal detriment of the enslaved (Washington, 2008).

The accusation of false illness was a common theme for enslaved Black Americans (Washington, 2008). Many times, slaves suffering from illness were accused of malingering as a means to escape work (Washington, 2008). Whippings and other punishments were constant, and slave owners relied on physicians to tell them if slaves were guilty of malingering or true illness. Motivated by a continued need for employment, physicians catered to slave owners by reinforcing the lying nature and intellectual inferiority of slaves commenting things such as “stimulation was a characteristic of his race” (Washington, 2008, p. 31).

The calculated brutality of health care for Black Americans during this time pales in comparison to the horrors of slave medical experimentation. Early physicians, still on the cusp of many medical breakthroughs, would often purchase, or rent out slaves, upon whom they could experiment on (Savitt, 1982). Slaves and freedmen alike found their way to “dissecting tables, operating amphitheaters, classroom or bedside demonstrations, and experimental facilities” all in the pursuit of a greater understanding of human anatomy (Savitt, 1982, p. 331). Some medical institutions, such as the Atlanta Medical College, the Medical College of South Carolina, and the Medical College of Virginia, even placed newspaper advertisements encouraging slave owning whites to send their sick slaves for treatment (Savitt, 1982).

Some notable experiments include an attempt to discover the best remedies for heat stroke conducted by Dr. Thomas Hamilton and discovering a surgical cure for vesicovaginal fistula conducted by Dr. James Marion Sims (Savitt, 1982). In each instance these brutally relentless procedures were conducted on slaves over many months for the fame, glory, and advancement of medicine (Savitt, 1982). Black women were often used for experimental surgical reproductive studies including ovariectomies as performed by Dr. Ephraim McDowell and the advancement of cesarean operations (Roberts, 1997).

Though many physicians did their best to ensure the survival of the persons under their charge, cadavers were extremely valuable at this time and many infirmed feared that they would be left to die in the pursuit of specimen collection and autopsy (Savitt, 1982). Attitudes towards autopsies during this period were overwhelmingly negative and fueled by superstition and prejudice; accordingly, physicians relied heavily on Black bodies for dissection as their tenuous legal status and insignificance in society provided them no protection (Savitt, 1982).

This horror did not end with the end of slavery. Many notable experiments involving the mistreatment of Black Americans for the purpose of medical advancement continued throughout the 20th century. Social Darwinism, a prelude to the eugenics movement, was still a new theoretical perspective at the time. Social Darwinists argued that “particularly prone to disease, vice and crime, Black Americans could not be helped by education or philanthropy” (Brandt, 1978, p. 21). This understanding of the inherent inferiority of Black Americans provided new justification for the brutal treatment inflicted on Black Americans in the name of medical advancement.

One of the most infamous examples of this form of medical mistreatment perpetrated on Black Americans in modern history, the Tuskegee Syphilis Study, commenced in 1932 and ran until 1972 (Brandt, 1978). Physicians involved with this study believed the racist and unfounded stereotype that fostered the idea that the rampant promiscuity, lust, immorality, and barbarism of Black males made them particularly prone to venereal disease (Brandt, 1978). The Tuskegee Syphilis Study tracked the evolution and progression of syphilis in hundreds of Black men through the 40 years of the study (Brandt, 1978). Though no one involved in the study was purposefully infected with syphilis, a myth which is quite prevalent, none of the men studied were ever provided with a cure even after the effects of penicillin in fighting the disease became known in the 1950s (Brandt, 1978).

While the Tuskegee Syphilis Study may be the most well-known of such modern-day medical experiments, it is by no means the only one of this nature or even the most barbaric. Black Americans such as Ebb Cade, who was injected with plutonium to track the progression of radioactive materials on human bodies, were subject to all manner of medical experimentation without the benefit of knowledge or consent (Washington, 2008). Radioactivity was of particular interest in the early years of the 20th century and was advertised for all manner of uses including bleaching Black skin white (Washington, 2008).

A brief, yet tragic accounting of these early experiments into the effect of radioactivity on the human body involved activities such as irradiating the gonads of 131 prisoners in an Oregon state facility between 1963 and 1971 (Katz et al., 1972). Sixty-six of the men experimented on were Black, and all were given radioactive thymidine (Katz et al., 1972). Another experiment involved giving experimentally high doses of TBI on 200 cancer patients, 150 of whom were Black, at the University of Cincinnati between the years of 1960-1972 (Stephens, 2002). Gruesome and tragic, occurrences such as these provide yet another instance of the disproportionate usage of Black bodies for medical progression (Washington, 2008)

For women, the brutal regulation of their bodies through reproduction has been a prevalent theme since slavery and has persisted throughout the 21st century. Slave breeding was a widespread practice as the prevailing belief was that strong slaves would produce good workers for the next generation of the plantation labor force (Roberts, 1997). After the import of slaves was outlawed in 1808, the continuation of the slave system was entirely dependent on slave reproduction (Roberts, 1997).

In the modern era, the regulation of Black reproductive freedom is no less insidious. Forced sterilization or a “Mississippi Appendectomy” were unfortunately common throughout the early parts of the 20th century (Washington, 2008). Bolstered by eugenic purposes, visionaries such as Margaret Sanger were proponents of the regulation of Black reproduction targeting the Black population through allyship with prominent Black figures such as W. E. B. Du Bois, Black churches, and community members (Washington, 2008).

The forced management of Black women’s bodies was by no means limited to reproductivity. One of the most instrumental women in the fight against cancer, Henrietta Lacks, a Black woman from Virginia, was the unwitting and uncompensated victim of cell harvesting once again under the guise of medical progression (Washington, 2008).

While undergoing treatment for cervical cancer, a tumor biopsied provided the cells which became the first ever immortalized human cell line, HeLa (Washington, 2008). Though she died in 1951, these cells transformed medicine in the modern age by facilitating experimentation on new vaccines such as the Salk polio vaccine and enabling the cultivation of stem-cells in the modern age (Washington, 2008).

As previously stated, this section is by no means a comprehensive account of the brutality suffered by Black Americans under the guise of medical advancement and discovery as such an undertaking could easily fill several volumes. Instead, the intent of this section was to provide historical context upon which the modern-day mistrust of medicine within Black communities is built. It is an unfortunate historical fact that discrimination within the medical environment was such a frequent practice, the legacy of which we are still combating today. The perception of discrimination throughout the medical environment is a common thread which, in part, has created the extreme disparities in health outcomes between Black and white Americans.

Contemporary Context: Modern-day Perceptions of Discrimination Within Medicine

Racism within the medical community is not a new phenomenon as has been demonstrated above. Medical advancements have resulted in increased life expectancy across all demographics, however, for the majority of the 15 leading causes of death Black Americans continuously have a higher likelihood of mortality than their white counterparts (Williams & Mohammed, 2008). Racism functions as a system of organization which places people in racialized categories for the purpose of distributing social goods, resources, and positive outcomes (Bonilla-Silva, 1996). The distribution of these outcomes are so deeply ingrained in our society that although individual attitudes may move towards more equitable behavior, structures within society remain stagnant and persistently yield discriminatory outcomes (Williams & Mohammed, 2008)

Within medicine, this trend remains particularly insidious and can manifest itself in many ways. The power of stereotypes for example is often a leading cause of the persistent stigma BIPOC women experience when attempting to receive disability or any socially funded aid (Pryma, 2017). Images of the undeserving “welfare queen” harken back to the accusations of malingering made so many years ago as a justification for the denial of or lack of assistance (Pryma, 2017). Stereotypes and ideologies surrounding pain within the medical environment support falsehoods such as “Blacks do not feel pain at the same intensity as whites, and that Black women are exceptionally strong and accustomed to suffering, regardless of class” (Pryma, 2017, p. 68).

These stereotypes, bolstered by cultural events such as the war on drugs and the inception of the welfare queen dialogue, create instances in which “hospital staff often read patients’ claims of pain through racial stereotypes of criminality” (Pryma, 2017, p.68). The claims made by hospital staff that patients may be prescription pain medicine abusers, underpin a greater issue of the consistent racialized discrimination Black Americans face from the medical environment (Pryma, 2017). Stereotypes are deeply rooted in popular culture and can create discriminatory outcomes even in the most nonracist people (Williams & Mohammed, 2008)

Discrimination, or the perception of discrimination, can have devastating effects when seeking medical treatment. Studies have shown that individuals who report experiencing, or perceiving discrimination may disproportionately not adhere to medical advice, consistently delay filling prescriptions, and delay receiving medical testing all of which can contribute to disproportionate health outcomes (Crawley et al., 2008) (Casagrande et al., 2007). Other negative health impacts caused by discrimination include being less likely to make use of preventative medical services such as cholesterol testing, diabetic monitoring, or vaccinations such as annual flu shots compared to those who perceive no discrimination taking place (Crawley et al., 2008).

In relation to cancer specifically, the perception of medical discrimination has been shown to create disparities in relation to the rate of preventative screening (Crawley et al., 2008) (Mouton et al., 2010). A study conducted in 2008 suggested that "some persons may delay or avoid getting screened for cancers and that this delay may be associated with racial or ethnic-based experiences they encounter within the medical setting" (Crawley et al., 2008, p. 1942). These findings are reflected in a 2010 study which found that racial discrimination is "associated with lower utilization of cervical cancer screening" (Mouton et al., 2010, p. 5) Another study conducted in 2006 found that the perception of racism while receiving medical care eroded trust in healthcare (Adegbembo et al, 2006).

Other related studies have shown a correlation between perceived discrimination and occurrence of breast cancer in Black women (Taylor et al, 2007). It is believed that one contributing factor to this correlation may be that "discrimination acts as a chronic stressor in the lives of many African Americans" thus negatively contributing to health outcomes (Taylor et al, 2007, p. 47). That the physiological effects of the perception of discrimination can contribute to the occurrence of breast cancer for Black women is a grim indicator of the strain on the body and mind that many Black women suffer daily.

As stated in the introduction of this study, "African Americans have the highest death rate and shortest survival of any racial and ethnic group in the US for most cancers" (American Cancer Society, 2021). Yet Black Americans are routinely subjected to racial stereotypes, negative statements pertaining to credibility, and other barriers such as cost when attempting to receive equitable medical care. Considering the long legacy of medical discrimination and mistrust, creating social support networks dedicated to providing social support, promoting mental well-being, and fostering community is essential for Black American women. Fighting the multiple jeopardous statuses of being Black, a woman and critically ill within a system which was quite literally built upon their pain and suffering is a tragic and unifying circumstance which deserves more consideration.

Intervention: Social Support Networks

Cancer patients, survivors, and their caregivers often depend on resources provided through community membership to meet emotional, financial, and other psychosocial needs (Weiss & Lorenzi, 2009). It is estimated that 22% to 50% of patients newly diagnosed with breast cancer meet the criteria for an official psychiatric diagnosis of depression (Classen et al., 2001). Individuals experiencing depression, anxiety, mood disturbance, or dysthymia not only suffer more but also are more likely to seek extensive medical services (Simpson et al., 2001). One method to combat these negative health outcomes is through membership in a social support group (Gudina et al., 2021). Group membership for cancer patients has been shown to reduce psychological symptoms, improve coping ability, increase knowledge about the disease, and reduce pain (Koopman et al., 2001). Other benefits for group membership include an improvement in the quality of life, improved immune response and a decrease in the fear of relapse (Koopman et al., 2001).

Social support consists of both structural and functional aspects (Gudina et al., 2021) Structural support incorporates the composition of a social network or various sources of support such as family, church, or support organizations (Gudina et al., 2021). Functional support includes the provision of specific resources such as wigs or hats for individuals who have recently lost their hair or types of support such as emotional -well-being support (Gudina et al., 2021).

Having social support has been documented as promoting positive health outcomes such an increase in preventative health screen utilization, a decrease in superfluous doctor visits, and an improved quality of life for adult cancer survivors (Gudina et al., 2021; Simpson et al., 2001; Waxler-Morrison et al., 1991). A study conducted in 1991 assessed the relationship between social support and survival outcomes of women with breast cancer four years past diagnosis. It was found that being unmarried, having support from at least three or more friends, having total support including relatives and neighbors of at least 11 people and belonging to a medium network size were all positively associated with improving rates of survival (Waxler-Morrison et al., 1991).

Despite the well documented benefits of social support networks, utilization of these resources remain low. One such study on social support utilization conducted in 2001 found that the most reported barriers to using support services include already having adequate support, lack of awareness and lack of provider referral (Eakin & Strycker, 2001).

Given the beneficial health outcomes that social support utilization may offer, creating an intervention directly focused on providing social support for minority patients may be one method to overcome the gross health disparities resulting from discrimination. The structural aspect of social support may require creating or including space within organizations dedicated to facilitating support with other community partners. Curated social support programing may encourage preventative health behaviors and build trust, two negative health outcomes associated with discrimination experienced in healthcare.

Social Support Network Implementation

Communication in the modern era has drastically changed the method by which information is shared and consumed. Social media has created a space in which communities share information and experience to an audience far beyond their physical vicinity. Medically, social media has revolutionized the ways in which information is shared and consumed (Moorhead et al., 2013). As a result of the power that social media connectivity has fostered, people are able to share tailored information, experience increased accessibility to relevant information and create brave spaces of peer and emotional support (Moorhead et al., 2013).

Though social media has created a space in which information and testimony can be shared to a wide and varied global audience, implementing a social support network online can be difficult. Research on social media within elderly communities for example demonstrated that community building outside of personal relationships online can be limited (Spineli Silva et al., 2020). A study conducted in 2020 during the height of the Covid-19 pandemic highlighted that elderly social-media users are most likely to engage with people already known, typically close family members (Spineli Silva et al., 2020). Examples such as these emphasize the distinction between real world and online community building when targeting marginalized communities. Successfully implemented online social support networks may have greater impact when online support is supplemented by in person interaction (Weiss et al., 2013).

An organization with a similar mission to Cancer SSN of community building amongst cancer survivors, CanConnect, is an online community focused on cancer survivorship in Tennessee. CanConnect utilized a model grounded in an ecological systems theory which focused on the power of community relationships (Weiss et al., 2013). Incorporating a community centered design as opposed to a strictly patient centered model has increased the network of community participants, as well as the stories they are able to share (Weiss et al., 2013).

A consistent theme amongst cancer survivors is the need to re-establish in person relationships following the completion of treatment (Lindop & Cannon, 2001). Utilization of a blended method of both online and in person programming enables members to simultaneously connect to a wider network of people while also recapturing precious interaction lost while undergoing treatment.

A 2013 study addressing successful social support network design, implementation, and evaluation recommended six initiatives for the creation of successful cancer survivorship groups (Weiss et al., 2013). These recommendations are:

1. Address the interdependence between online support and real-world support

2. Address the individual's existing social networks (family, friends etc...)

3. Target community-wide outcomes and participation of local community groups

4. Adapt and/or develop evaluation measures of support specific to online environments

5. Consider all units of analysis (from interpersonal to community-wide measures of support)

6. Employ ecological systems theory and principles of community-based participatory research

This study has incorporated these suggestions in both the analysis of social support network formation and organizational recommendations for change.

Potential Barriers

Although social support implementation may prove highly beneficial, it is not without challenges. The following is a brief discussion of potential barriers to successful social support network implementation.

Access to Technology

Successful implementation of social support networks, ideally, should include an element of in person interaction to cement bonds and reacclimate survivors to in person interaction. However, in a post Covid-19 world this may not always be feasible. The spread of Covid-19 has caused significant changes to in person social interaction, and in its wake, digital technology transitioned into being the primary tool by which interaction occurs (Tran et al., 2020). While this shift is slowly dwindling as the outside becomes habitable again, for survivors of critical illness, the focus on interacting through digital technology may become a long-term reality.

With this shift in digital interaction, yet another element of structural inequality becomes more prevalent; that being the digital divide. Access as a component of the digital divide became a topic of research in the early 1990s when the use of personal technological devices began to rise (Scheerder et al., 2017). As internet access became more prevalent, the focus on the digital divide shifted to encompassed disparities in digital skills and technical competence (Scheerder et al., 2017). Although the availability gap has narrowed, surveys of internet access show that there still exists a disparity along the intersections of race, social economic status, immigration status, geography, gender, and age with individuals in minority statuses more likely to suffer from limited access, skill, or technical competence (Wilson et al., 2004).

These limitations often have serious implications for the successful implementation of a social support network specifically targeting Black women cancer survivors online. As disparity in internet access persists along the intersections of race and gender, creating a social support network online may inadvertently exclude the very population its existence is meant to target.

Recruitment

Expanding a network in the absence of other successful examples creates unique challenges. In a study of the case of a small coalition tasked with creating a social support group for breastfeeding mothers in Michigan, it was found that barriers to successful implementation arose along several axes (Hudson et al., 2015). These barriers included challenges in recruitment, securing meeting locations and creating an organizational structure itself (Hudson et al., 2015). These challenges become amplified when targeting marginalized communities.

Focusing on recruitment, creating space for the support and well-being of Black women cancer survivors is useless if no one is aware of, or inclined to utilize this service. With regard to the case study of the breastfeeding support group, one challenge they consistently faced was getting interested mothers to attend meetings (Hudson et al., 2015). Despite the fact that many individuals expressed interest, the translation from expressed interest to program participation was low (Hudson et al., 2015). Though the coalition marketed through flyers and in-person recruitment events, reaching their target audience was difficult.

As there is a lack of community organizations which serve Black American cancer survivors in general, and Black women in particular, generating community interest for a service which currently only exists in sporadic social media groups is daunting. One proposed solution to the recruitment barrier is through community partnership. To increase interest in participation, the coalition partnered with health providers, or other relevant community facing entities to drive recruitment (Hudson et al., 2015). This is a tactic which may need to be implemented to achieve the goal of expanding the social support networks available to Black woman cancer survivors.

Action Research Design

Conducting a critical ethnography lends itself to Black emancipatory action research through the collaborative collection of data focusing on impact, community, and methods to disrupt unjust trends. This study employs a Black emancipatory action research model utilizing an intersectional social-ecological systems framework to gather data via critical ethnography. The overall aim is to understand the needs of a social support network specific to Black women cancer patients and survivors.

Black Emancipatory Action Research (BEAR)

Black emancipatory action research is an orientation aimed at the creation and dissemination of liberation strategies from interlocking and intersecting forms of oppression experienced by Black people throughout the Diaspora (Akom, 2011). Similar to other forms of critical action research, BEAR also focuses on research with community members as equal partners throughout problem definition, information collection, and data analysis (Akom, 2011). What makes BEAR a unique approach is the centralization of race and racism in all aspects of the research process while simultaneously challenging the false individualism of race, class, gender, nationality, sexual orientation, special needs, and religion (Akom, 2011). Through recognizing the interconnected nature of these statuses, BEAR utilizes a Black feminist understanding of interlocking systems of oppression (Hill-Collins, 1986).

Black emancipatory action research employs an asset building approach to systems of oppression by centering transformative solutions and community building (Akom, 2011). Focusing on the experiential knowledge of Black people as sources of their own strength, BEAR recognizes that marginalized communities harbor "critical social knowledge" which should be used as a conduit for self-empowerment and a determination of what is valid or useful knowledge (Akom, 2011, p 121). The central tenants of Black emancipatory action research are the acknowledgement of "1. Structural racialization 2. Intersectionality and the social construction of knowledge 3. The development of critical consciousness, and 4. Love, healing, and a commitment to social justice", each of which are in deep spiritual alignment with the research aims of this study (Akom, 2011, p 122).

Informing Black emancipatory action research, structural racialization centers the understanding that racism supersedes individual experience and instead is located in the social construction of societal systems including education, employment, and healthcare (Akom, 2011). Viewing structural racialization through the interconnectedness of an ecological systems approach, BEAR utilizes the principle of structural racialization to look at the relationship between race, space, and place (Akom, 2011). Black emancipatory action research challenges the color-blind, universalist, approach of false neutrality by acknowledging how spaces hold racial conventions outside of themselves, which in turn create limiting experiences and if left uninterrupted may neutralize social meaning.

Action research is conducted through a cyclical model of reflection, data collection, and action in which each step is considered and evaluated to promote continual improvement (Creswell & Gutterman, 2019). Through experiencing, enquiring, or examining, data may be collected via qualitative or quantitative research methods as determined by the needs established by the research team (Creswell & Gutterman, 2019) Black emancipatory action research builds on this model through the intentional centering of community voices at all stages of the research process to promote community development through love and healing (Akom, 2011).

Black emancipatory action research was selected due to the historic injustices Black women have, and continue to face, when seeking medical care which have created an urgent need for individualized, community based, care and wellness solutions. Centering intersectional experience and prioritizing those who have historically been silenced shifts from a narrative of victimhood to an emancipatory stance of self-advocacy turning strife into strength. Black emancipatory action research was also selected due to its radical positionality towards love as a conduit for healing and transformative change. That I hold membership within this community by being both a Black woman and a cancer survivor only strengthens my participation, insight, and desire for emancipation.

Study Site

This study took place within Cancer SSN, a small non-profit organization dedicated to offering resources, social support and education for persons impacted by cancer. This Midwest location offers a wide variety of events in conjunction with other cancer supporting networks to meet stakeholder needs across their service area. Though membership is open to everyone impacted by cancer, women disproportionately attend events. Typical monthly activities include online support groups geared towards providing community for cancer survivors and caregivers, community events, fundraising, and giveaways.

Cancer SSN was founded in August of 2019 for the purpose of promoting education, charity, guidance, and support for individuals impacted by cancer. To that end their mission statement, “to empower, encourage, and inspire individuals impacted by cancer”, influences each aspect of the organization. Their leading purpose is to disrupt the inequities in health care through bringing cancer support, loving compassion, and faith-filled encouragement to underserved communities.

Disrupting the inequity in healthcare through providing support to underserved communities however underscores a larger social justice crisis founded upon discrimination within medicine. The community within Cancer SSN has a myriad of stories detailing the horrors of the intersectional struggle of receiving healthcare while being Black and a woman. Though this group is not specifically targeted towards women and have taken great strides to promote outreach towards men and masculine identifying people, women still comprise the vast majority of participants. As such, most interactions, and programs, including the “Crowing Star Wig Program”, “Purses with a Purpose”, and “Care Bear” are primarily targeted towards women which has influenced the direction of this study.

Setting

This study was conducted between two online support groups offered by Cancer SSN. Though not explicitly advertised as community groups for Black women, Black women are the primary attendants. One meeting is held weekly during the day and the other is held monthly during the evening. Though there is considerable overlap in attendance, the varied time and frequency allows for a wider variety of respondents who may have dissimilar needs.

Participants for this study are Black women who have self-identified as either currently fighting cancer or have self-identified as a cancer survivor and who regularly attend the two specified community groups offered by Cancer SSN. This study did not sample based on specific diagnoses or time in remission. This was an intentional choice taken as to center the experiences and identity of Black women cancer patients and survivors as a group as opposed to centering their diagnosis. A non-probability convenience sample was used due to my membership within these two support groups, and the collaborative nature of Black emancipatory action research.

Researcher Role and Positionality

To state it plainly, I am a Black, woman, cancer survivor who is an active member of the organization I am focusing on. I attend both group meetings as a participant, and through my in-group status, have developed relationships with the members I intend to interview. My own positionality has granted me access to this space in a holistic way providing me with a depth of detail and insider knowledge difficult to obtain other than through personal experience. Due to my own background, there are no gatekeepers preventing me from gathering this information. As an authentic participant, my ability to engage in Black emancipatory action research is unhindered.

As a member of this organization and not an employee, I hold little influence outside of the two groups I regularly attend. Similarly, I hold little official influence over the other participants who regularly attend this group. Though my power is limited, I hold this to be an asset as there is no power imbalance preventing authentic participation between myself and the other women within these spaces. Due to my own positionality, and the nature of Black emancipatory action research, I will be a participant in this study. Gaining access to these spaces necessitates participation as these spaces are full of vulnerability and bravery.

As an active participant in these spaces, I have used my own personal history with cancer and my social position as a Black woman as tools to build trust over time. I began regular attendance at Cancer SSN in June of 2021. Through these months of weekly and monthly meetings, I have given people the opportunity to know me and for me to get to know them in return. Through trust, and my in-group status, I have built a rapport, respect, appreciation, admiration, and affection.

Ethical Considerations and Political Considerations

C. Wright Mills, one of the fathers of contemporary sociological theory, once suggested that neither everyday life, nor the history of a society, could truly be understood individually without genuinely understanding both as they relate to each other (1959). The interrelatedness of personal understanding and historical trends as they co-create our daily lived experience is foundational to the interpretation of the social creation of reality. It is an emic understanding of the world which addresses historical inequities, relativity of experience, and subjective truth. These are themes which must be addressed in any sound critical social research.

Epistemologically and ontologically, the critical paradigm provides the greatest context for the creation of our social reality in that how we come to know things and how we interpret our reality must be understood in the context of our history. Underrepresented voices have long been neglected in academic literature, research studies and the daily workings of everyday life. Reflecting on the words of Mills, it is impossible to proceed with any sense of equity in research without acknowledging the discriminatory history which has created the social reality we are currently experiencing.

The assumption of a critical perspective is that due to power and the nature of domination, those not in a position of power suffer under that oppression. The belief in a social hierarchy implies a difference of experience which in turn creates a biased position in research. Some potential implications which may arise from these assumptions are that there are differences in experience for Black women cancer patients and survivors when receiving medical care and that those differences are built upon a legacy of discrimination.

This implication clearly influences the way I would go about addressing my research, selecting my participants, and crafting my research design. The critical perspective utilizes dialogic collection methods as opposed to objectivist observation which in turn modifies the sort of conclusions I am likely to draw. Additionally, relying on research methods such as interviews limits the number of participants in any given research study which in turn limits the variety of responses. Though I can try to design a study which accounts for bias, the conclusion I would draw could be considered biased by virtue of this ontological and epistemological perspective.

In addition, my own in-group status has also created an enormous amount of bias. Having suffered racism directly affecting my cancer treatment personally, I have firsthand experience at how insidious medical racism can truly be. It is with these experiences and concerns in mind that I selected emancipatory action research. Through collaboration I can center the voices of my participants as opposed to my own and through joint exploration conclusions can be drawn which reflect the experiences of each participant within this study. Furthermore, through journaling, member checking and bracketing I mitigated biased unacknowledged preconceptions not only increasing the rigor of this project but also protecting myself from the emotional drain of delving into personally challenging emotional subjects.

As this is a study surrounding several protected groups, specifically those being minorities and individuals suffering from critical illness, all care has been taken to retain the anonymity of the participants and the organization name has been changed. Furthermore, all data collected during this study was stored on a password protected desktop, laptop, or flash drive. Using emancipatory action research enables the collaboration of all those interviewed thus minimizing the potential for harm to the individual and maximizing joint benefits. It is important that this study center the voices of Black women as these are the voices so often left out.

Methodology

Critical theory research is built upon the belief of the disruption and transformation of the status quo (Ponterotto, 2005). Attributed to the Frankfurt school and influenced by renowned German philosophers Marx, Kant, Hegel, and Weber, a core belief in this tradition is the inherent injustice and subjugation which shapes our lived experiences (Ponterotto, 2005). Critical theory is connected by several philosophical stances which mediate the direction and use of research outcomes. Taken directly from Kincheloe and McLaren (1994):

> All thought is fundamentally mediated by power relations that are socially and historically constituted; [b] facts can never be isolated from the domain of values or removed from some form of ideological inscription; [c] language is central to the formation of subjectivity; [d] certain groups in society are privileged over others; [e] oppression has many faces and that focusing on one at the expense of others often elides the interconnections among them; and [f] mainstream research practices are generally implicated in the reproduction of systems of class, race, and gender oppression. (pp. 139–140)

Critical Ethnography

Data was collected through critical ethnography. Critical ethnography is a methodology built upon critical theory which seeks to understand culture through examining political, social, and economic issues which focus on oppression, marginalization, conflict, and power for the purpose of promoting change (Cook, 2005). Critical ethnography asks ‘what could be’ though the analysis of what contributes to what is (Hagues, 2021). In addition to its critique on the dynamics of oppression, critical ethnography was selected due to its epistemological and ontological assumptions pertaining to the reproduction of cultural realities in relation to culturally specific shared histories, an ideology foremost within Black emancipatory action research (Foley, 2002) (Akom, 2011). Critical ethnography is a useful tool in researching health promotion, such as social support, as it has been used to understand not only the experiences of the researched, but also social factors that contribute to their lived experience and their health (Cook, 2005).

Through the lens of cultural ethnography all cultural groups are understood to produce and reproduce an individual yet unified subjective reality which is both inherited and perpetuated (Foley, 2002). Though intensely personal, this shared reality is also external in that it encompasses distinct historical traditions and structured practices such as cultural conventions or public policy (Foley, 2002). The external bonds of culture replicate a living historical tradition which create collective memories surrounding values, beliefs, geo-political perspectives, and the importance of space/place (Foley, 2002.) Studying the replication of external historical traditions as they function to produce and reproduce contemporary cultural reality is the genesis of information surrounding what is required of a culturally specific and transformative social support network.

Black women in the United States share an intensely personal yet objective cultural tradition which is continuously replicated through the bonds of intergroup solidarity and external forces of marginalization. Addressing care and critical illness utilizing critical ethnography enables not only the analysis of the phenomena of illness but also a wider discussion of the replication of culture and the legacy of discrimination which produces objective ideologies and historical traditions surrounding receiving care. Our stories shape our realities, and it is important to honor the history of medical discrimination which has, in part, shaped our relationship to medical care and in turn shapes our needs when receiving social support for critical illness.

Data Collection and Analysis

Critical ethnography works in conjunction with Black emancipatory action research through the perspective of researcher as collaborative participant supporting and promoting the voice of community members who have been historically silenced (Akom, 2011). Traditionally, ethnography involves the analysis of both participant observations and interviews (Cook, 2005). Similarly, critical ethnography employs the same data collection methods. All audio and video recordings were kept secure on password protected devices including a desktop, laptop, or flash drive throughout the duration of the study and for four years post completion.

Observations

Similar to critical participatory action research, the ideological foundation of Black emancipatory action research is the idea of engaging in research collaboratively with the community (Akom, 2011; Fine et al., 2021). To maintain the ideological perspective of true collaboration while engaging in ethnography, participant observations were conducted and member checked so that a collaborative interpretation of gesture, place, space, and symbology is generated. Recorded participant observations were conducted twice per month, once at the weekly meeting and once at the monthly meeting over five months totaling in ten meetings observed.

Data was collected during participant observation through field notes, journaling, and researcher reflections all focused on capturing rituals, social interactions, and routines (Hardcastle et al., 2006). Through comparing observations in multiple meeting spaces, a greater depth of understanding pertaining to cultural perspectives about social interaction and social support can be observed (Hardcastle et al., 2006). Analysis of participant data included a description of the cultural context of the site including social interactions, routines, roles, and power relations (Hardcastle et al., 2006). A thematic analysis of recurring elements from this data was member checked to ensure authenticity and credibility (Hardcastle et al., 2006).

Interviews

Participants were located through a non-probability convenience sample taken from membership and participation in the two selected groups ran through Cancer SSN. Semi-structured interviews were approximately one hour in length and conducted over the course of five months between April 2022 and September 2022. Semi-structured interviews are useful in mutually constructing knowledge and can be beneficial in many methodological approaches including critical phenomenology and critical ethnography (McIntosh & Morse, 2015). Additionally, holding individual interviews increases the depth to which each participant can explore the topic providing a richness of context which may otherwise be lost in a group setting (Creswell & Gutterman, 2019). Interview questions were constructed based on information gathered through participant observations and presented in advance so that informed consent may be gained.

Interviews were recorded, transcribed, and coded over the course of this study. Through the multistage transcription process a combination of low inference codes, in vivo codes and pattern codes were developed to track similar ideas and experiences. This iterative process underwent three rounds, first beginning with an open process to understand what was said (Creswell & Gutterman, 2019). A second more focused round to capture vital details and connections (Creswell & Gutterman, 2019). This process concluded with a third round to analyze emergent themes and similar storylines (Creswell & Gutterman, 2019). Multiple stages were used to ensure that all themes were captured.

Throughout the coding process emergent themes were presented to participants for member checking to maintain authenticity of participant voice. Concluding suggestions were constructed in collaboration with participants and presented in narrative form supported by quotation.

Trustworthiness

Trustworthiness in qualitative research can be established in several ways including credibility and transferability (Creswell & Gutterman, 2019). Trustworthiness is reinforced through strategies including triangulation or the method of verifying evidence through multiple data sources such as individuals, types of data or data collection methods, and member checking or the process of asking participants to check the accuracy of the data collected (Creswell & Gutterman, 2019). As a critical participatory action research study, member checking and triangulation is a foundational aspect of the research design. The credibility of this study, as measured through the development of themes and codes using multiple data sources has the potential to be quite reliable (Creswell & Gutterman, 2019).

Transferability

The transferability of this study, as measured through the establishment of context, the detailed descriptions of data collecting procedures and detailed findings supported by quotes also has the potential to be reliable (Creswell & Gutterman, 2019). The site, purpose, participants, and research questions are all clearly defined establishing context. The data collection process has been explicitly detailed as well as measures for data analysis and ethical concerns. Findings as defined by emergent themes were reinforced through the joint construction of meaning and validated by quotation.

Bracketing

Bracketing is a technique commonly used in qualitative research to minimize unacknowledged preconceptions which may influence conclusions (Tufford & Newman, 2010). Beginning as a phenomenological practice, bracketing is a widely used methodological technique consisting of several stages 1. Abstract formulation, 2. Research praxis, and 3. Reintegration (Gearing, 2004). This is done as a means of suspending presuppositions, assumptions, or theories to facilitate seeing and accurately describing the research phenomenon (Tufford & Newman, 2010).

Bracketing techniques to develop research praxis include memo writing throughout the data collection and analysis process, interviews with outside unrelated sources to uncover and bring awareness to preconceptions and biases and reflexive journaling (Tufford & Newman, 2010). Throughout this study, I engaged in memo writing and reflexive journaling as a means of mitigating bias, engaging more deeply with the material, and to help process any negative emotions which emerge due to the personal nature of this research material. Reflexive journaling was done weekly after every meeting, bi-weekly during the coding process, and as needed due to emotional responses. Memo writing happened consistently during the transcribing and coding process as thoughts emerged. These self-memos were kept separate from official thematic codes to alleviate confusion and eliminate bias.

CHAPTER TWO: RESULTS OF RESEARCH

Research Findings

This chapter explores emergent themes surrounding social support networks amongst Black women cancer patients and survivors. Critical ethnography was used as a research technique to delve deeper into the life-stories of participants to better answer the leading research question, what are the unique needs of Black women cancer patients and survivors. By better understanding their relationship with healthcare as it relates to their personal histories, a more informed, culturally responsive intervention is attainable. Personal relationship to healthcare is intensely individual and directly shapes the needs one may have upon diagnosis. Results indicated that a shared community reflective of the cultural experience they live, an open conduit of information, and community with individuals who have shared a similar burden of critical illness are all key elements necessary in a culturally responsive social support network targeted towards this demographic.

The purpose of this study was to investigate the unique needs of Black women cancer patients and survivors in relation to their emotional well-being for the purpose of expanding the social support networks available through Cancer SSN. At the conclusion of data collection, several themes have emerged highlighting the multiplicity of experience, and the conspiracy of silence present within the Black cultural reality, both indicators of a larger conversation surrounding the variability of what constitutes acceptable social support.

Through a combination of semi-structured interviews and participant observations the nature and degree of social support received, cultural connotations of health care and perspectives on community have been explored. Each participant spoke about their individual history with healthcare both before and after diagnosis, knowledge about healthcare going into treatment and any stigma experienced as it relates to receiving treatment. Emergent themes were further investigated through narrative to present a rich and representative account as is consistent with the goals of an ethnographic study (Argyriadis, 2021).

Participants

Participants in this study were reached through a combination of email outreach, and word of mouth. Participants were also solicited through the group meetings held by Cancer SSN in which I attend as a participant observer and member. This study included Black women who have been diagnosed with cancer who are either currently undergoing treatment or who are in remission. Participants spanned a wide demographic in relation to occupation, marital status, age, career, and previous medical history prior to their cancer diagnosis. This was done with the intent of gaining a variety of lived experience and to not limit the information gained to one singular perspective.

An initial email requesting participation in this study was sent out to 12 program participants. Of that initial invitation four participants responded. An additional four participants were sent to me through the outreach of the other group members totaling in eight participants overall. Table 2.1 presents each participant by assigned pseudonym and their current treatment status as an indicator of the relative support they may require. All remaining demographics have been purposefully omitted to protect participants' anonymity.

Table 2.1

Participants

Pseudonyms	Status
Gail	Treatment
Sandy	Remission
Meredith	Remission
Angelica	Remission
Linda	Treatment
Martha	Remission
Carolyn	Remission
Diane	Remission

Data Collection

The eight interviews were scheduled over the course of two months from June till August 2022. Each interview was conducted through Zoom, a teleconferencing software also used for the support group meetings offered through Cancer SSN. Transcription was primarily done through Otter.Ai, an automated transcription online software. This platform created automated transcripts which were then checked against the audio within the platform to ensure accuracy. Participant observations were recorded over the course of this study from May till August 2022.

All data collected commenced after approval was granted from the institutional review board (IRB) at the University of Dayton (see Appendix A) and from Cancer SSN (see Appendix B), a pseudonym used to protect the anonymity and private health information of the participants. Each participant was sent the interview questions ahead of the interview due to the sensitivity of the topic (see Appendix C). The email to the participants included the invitation to participate, the interview questions and a brief explanation of the nature of this study. The email explicitly stated that their participation was completely voluntary, and they reserved the right to exit the interview at any time.

Results

To follow is an exploration of the observations, interviews, and artifacts I gathered from May till August of 2022. Consistent with the methodological expectations of ethnographic research, these data sources have provided me with a rich contextual experience from which to construct this critical ethnography (Argyriadis, 2021).

Participant Observation

“We are family” -Anonymous

Ethnographic research is characterized by intensive participant observation as a primary form of data collection (Morgan-Trimmer & Wood, 2016). Through sharing community, particular attention was paid to observing and describing the daily life, narratives, social interactions, and cultural meanings displayed by the members of Cancer SSN. Unlike typical ethnographies which are conducted through in person interaction however, digital ethnographies explore online social groups (Morgan-Trimmer & Wood, 2016). Pursuant to the construction of ethnography, I focused my observations on language, rituals and events, and individual and group patterns of behavior.

Due to the Covid-19 pandemic, the surge of Monkeypox, and the prevalence of RVS, digital life has taken the place of in person interaction for the foreseeable future for those fighting critical illness. However, this change has not stopped the vibrancy of community life within Cancer SSN. From my earliest experiences within this group, I was struck by how overwhelmingly positive the conversations were despite the heavy undertone of critical illness.

> Already I am being confronted with my own preconceived notions and biases. I cannot believe how happy everyone seems. How joyful. I have been in remission for 21 years and I still feel depressed about it lol. I am blown away by how…at peace, maybe, everyone seems (Research Journal, June 2021).

From the very beginning of my time with this group I was treated as an insider which I attribute to the combination of being both a Black woman myself and a cancer survivor. Sharing community twice over, despite my age gap, gave me the type of loving support from the other group members which I have been truly lucky to receive. From my very first group meeting I have been forthcoming with not only my own diagnosis and experience with cancer but also my work and what inspired me to join this group. Far from being discouraged, the members of this group fully embraced me, my research and have prayed for and encouraged my success.

This is not to say that conversations have never been heavy. A group focused on social support for individuals currently undergoing cancer treatment and survivors is bound to have difficult discussions. I have specifically observed group members join zoom meetings from their hospital beds, from doctors' offices, from physician visits for their spouses, their vehicles, outside and all manner in between. Joy is found even in the midst of tears, prayer is offered even for the worst of news, and hope is always present.

I have observed friendly banter and differing opinions. Often the members will share their own personal stories or testimonies to provide strength and reassurance to other members. Resources such as mental health articles, prayer requests, and gratitude challenges are often emailed to members not only of Cancer SSN but several other sister organizations doing similar work, many of whom share membership with Cancer SSN.

On one notable occasion, I observed information being shared about how to record an instance of medical neglect. One participant had been the victim of a mishandling of care and another participant was able to share specific knowledge about how to seek justice. I have observed participants sharing some truly heart-breaking tragedies and overwhelming triumphs. The theme of both being that Cancer SSN provides a brave space of vulnerability in which whatever you share will be cherished and respected with care.

Care underscored the rituals of community life within Cancer SSN. Each meeting, members greeted one another with the news of their day. This news could be large and impactful such as an update on treatment or status report on their children. This news could also be mild such as a funny anecdote or pressing news story. Commiserate with the boundaries of respect expected within Black community, names are always preceded by Ms., Mother or, in my case due to my age in relation to most other members, Ma'am.

This news was typically followed by a group share in which each member speaks on what they are grateful for this day and occasionally followed by a game. Each ritual is constructed for the purpose of solidifying community and expanding social support. Focusing on the positives of gratitude as opposed to the negatives of the disease itself creates an environment of positivity, hope and prayerfulness.

This is a community immersed in care, so much so that prayers and concern were given to members even if they were not in attendance. I have observed several instances of members inquiring about the health and well-being of members who were not present. This behavior was extremely common and always well received. If a member did not attend several subsequent meetings, call requests or even wellness checks were organized to ensure the health and well-being of that member. This in person interaction was one such instance of removing the boundaries of the digital divide.

Other such instances included community outreach events such as fundraising drives, anniversary parties or resources provided such as rides to the hospital. These events were organized both by program facilitators and community members alike although they were uncommon. I personally did not attend any such event, and to date have not met any of the program participants in person.

My observations were recorded through written "fieldnotes" and memos. Field notes are taken to formally record the observation while immersed in the observed community (Argyriadis, 2021). These notes were rarely written during meetings themselves as while I was in attendance, I prioritized being a true participant. These notes have been invaluable in orienting myself to the cultural dimensions of Cancer SSN while also aiding in my reflexivity and bracketing.

Interviews

Eight semi-structured interviews were conducted as a part of the data collection. These conversations gave me the opportunity to explore topics which I had observed throughout my time participating in Cancer SSN, the flexibility to explore new themes as they arose, and provided me the opportunity to clarify my understanding to ensure their voice, and not my own interpretation, was presented. I did not purposefully select participants for these interviews. I announced my intention to the group and allowed those who were interested in sharing their stories to do so. This announcement spread which created a snowball sample. All interviews were completely voluntary, and no payment was provided.

Each interview was transcribed initially using the auto transcription platform Otter.Ai which was then checked against the original audio to ensure accuracy. Once transcription was completed, the interviews were read to better understand what was said (Creswell & Gutterman, 2019). This approach allowed better identification of general concepts which were then incorporated into the second more targeted round of coding. This round of coding presented finer details which were used to identify common themes. A third round of coding was used to identify the main themes and similar storylines which are presented in narrative format (Creswell & Gutterman, 2019).

Reflexive thematic analysis presents themes derived from codes constructed to make meaning of the content collected (Ayre & McCaffery, 2022). Themes presented may include ideas both explicit or implicit, concepts, and interpretations of constructed meanings (Ayre & McCaffery, 2022). Maintaining reflexivity throughout this process is paramount to promoting non-biased results. Researcher reflexivity has been maintained through bracketing including journal writing and memo-writing throughout the coding process (Tufford & Newman, 2010). Four main themes and five sub-themes have been identified and presented in table 2.2.

Table 2.2

Themes from interviews

Main Themes

- Previous Medical Experience
- Current Medical Experience
- Social Support Communities
- Suggestions For Improvement

Sub-themes

- The Financial Burden of Care
- Discrimination
- Limited Communication
- The Conspiracy of Silence Surrounding Critical Illness
- The Importance of Shared Culture in Social Support

Previous Medical Experience

To better understand the ways in which culture inhabits the decisions we make regarding receiving care one must have a sound understanding of the ways in which care has been perceived and experienced throughout the life history of the participant. The first theme identified, previous medical experience, explores the relationships with formalized and informalized care from childhood till cancer diagnosis. Each participant's historical relationship with healthcare is of particular importance when conceptualizing what may be necessary in a social support network. Individuals who have a long history of positive experiences with health care may require vastly different resources than those with more tumultuous experiences.

Each participant was asked about their feelings and experiences with going to the doctor before they were diagnosed. Carolyn shared her experience that doctors' visits were infrequent however home remedies were often used in substitution.

> We use a lot of remedies, a lot of home remedies, a lot of them that my mother got from her mother. So, we didn't go to the doctor that often. Probably not as often as we should have. A part of it was just finances, and just not really having the resources to really get the care that we would have wanted going to the doctor, so we didn't go. We did go but it had to be a really serious, serious situation before. You know, she can't stop the bleeding, you know. Okay, then we'll go to the doctor.

Sandy shared a similar experience in that the financial burden of going to the doctor as a child was a prohibitive factor.

> I was raised in [redacted], which is, you know, we didn't know we was poor. But you know, I was in a low-income neighborhood. And so my mother had nine children. And so we didn't go to the doctor. Right? The only thing that we went to the doctor for was like, strict emergency.

Home remedies used often included items such cod liver oil, castor oil, Epsom salt, Robitussin, Vicks and various other generationally passed down home treatments. For the participants who did have experience with going to the doctor prior to their diagnosis, their experiences were varied. Meredith shared her experiences with healthcare under segregation.

> As a child, I had an African American doctor. So I did not suffer any discrimination or anything like that. And this doctor was on staff at [redacted] hospital I think, was the name of the hospital, because at that time, that is the only place an African American doctor could be on staff. You know, all of the other hospitals were not open to African Americans. So I felt very nurtured, very comfortable going to the doctor.

A common theme present throughout these narratives is that many did not have access to regular healthcare until adulthood. Joining the labor force, and being exposed to the expectations of annual visits, was the catalyst many experienced that prompted them to the physician.

> It was when I entered the workforce that I actually started going, I had benefits then so I could go to the doctor. I would go and part of that, too, is just having the physical, your annual physical and that kind of thing. It was not required. But it

> was expected that you could do that as part of my work. And so that's when I started going on a regular basis to the doctor.

The theme of labor in relation to healthcare was present throughout many of the narratives collected. Prior to diagnosis, many participants shared stories about their experiences in receiving medical care as facilitated by their jobs. Linda shared an experience of a workplace accident which caused her to visit her physician.

> I had an experience, where I was once working a job, and they had cords and everything around the office. They were remodeling, and I tripped on one of the cords and fell, headfirst. I went to my doctor who gave me some pain pills and sent me home. I mean, he didn't even do a thorough examination as far as X-rays or anything. Years later, I won't even say it was 20 years after that, when I did develop cancer. I had a full x-ray and they could still see the trauma in my head from that fall. He hadn't done anything but give me some painkillers or send me off. And, you know, I'm blessed that I survived that.

Sandy shared a similar story in which she experienced challenges with limited physician communication.

> I was working, you know, going to the doctor. It almost felt like, even though I had my employee’s insurance, they still treated me like I was on public assistance. I still got treated that way. They're gonna give you a prescription for something or say there's nothing wrong with you. The whole visit lasted five minutes. They didn't even give me a chance to say why I was really there. It was almost like we

> really don't want to be bothered with you. If we get 10 of you all in an hour. We can make a whole lot of money, you know. I did not feel comfortable at all.

Throughout these conversations, several stories were shared about unsatisfactory experiences when seeking medical attention. In particular, challenges with stilted communication with physicians was a theme which was interwoven throughout most of the stories collected. In a 2022 study conducted by Fahmer et al., exploring patient's challenges, competencies, and perceived support in dealing with information needs, the barrier of doctor-patient communication was found to be of chief concern. They say, "During medical consultations, structural barriers such as short conversation durations because of limited time capacities and frequently changing physicians or other practitioners hindered obtaining information and clarifying concerns" (Fahmer et al., 2022).

In subsequent sections limited communication with physicians is a theme which shall be revisited. Though not every participant shares this experience, this theme was common enough to warrant concern and remain of chief importance when considering strategy to create interventions targeted towards providing greater social support.

Current Medical Experience

“Racism might have just saved your life.” – Anonymous

This section explores the various experiences participants had with receiving care after their diagnosis. It is important to note that there was a wide spectrum of experiences reported from gentle, informative, and supported to being completely blind sighted to being outright ignored. Throughout it all however, several themes were present such as the financial burden of care, limited patient communication and the ever-insidious undertone of medical discrimination.

Cancer diagnosis is an intensely personal and very emotional experience. Meredith shared her experiences with being diagnosed, stating that her mother’s battle with cancer was always present in her mind.

> I found my own lump. I was doing a, and I don't know that you would even call it a self-breast exam, because I didn't know that terminology at the time. My mother died of breast cancer. In the back of my mind, I kind of always felt I was going to have it because it runs in my family. So when I found this lump, I knew how important it was for me to go to the doctor and get diagnosed. So I did and he was a very understanding, very gentle person. He had been a surgeon oncologist for a long time and was well known and well respected. He was the kind of person that told me every step of the way, what's going to happen, which relieved my fears and anxiety, not totally, but I felt better. I was still fearful, afraid of what he would say. I was still anxious and nervous. When he called to say, come back, I

> have a diagnosis I went back, and my husband went with me. He told me, yes, that it had come back. That I do have cancer, it was cancerous.

Gail shared her very harrowing story with being diagnosed recounting how discrimination impeded discovery of her condition for many years.

> I knew that man for 20 years not knowing 15 out of that 20 I had cancer. He didn't know either. When you're that proud you allow your pride to defeat your purpose. When we did the investigation, we found out they missed a lot of size. And that was based on color. Because the medical books are based on if you're African American, we do this. If you're a Black male this, Black woman this, White woman this, White man this, Asian, Hispanic, whatever this. The problem was that when they exhausted all the tests and still could not find out what was causing the symptoms, they stopped looking. And I wasn't aware of it. They stopped looking. Keep in mind, that's 15 years of a cancer spreading throughout my body that was totally unchecked.

Later on, when recounting her emergency room visit, she goes on to say

> When you arrive at the emergency room they do the usual protocol, ignore you. I'm in agony and was being totally ignored. A female doctor comes in, next thing I know just when I get back in the gurney, she throws open the curtain. They don't, they don't knock, they just throw the curtain open. She says "No one has told you they found a mass? That's five centimeters." My mind stopped right there. I heard five. That's all I heard. What do you mean? I said no. She disappeared. She never came back. She never came back.

Martha spoke about her experience with being diagnosed, recounting how little care her physician showed when providing her diagnosis.

> I read a book which said an inverted nipple is a sign of cancer. Well, I didn't have any insurance at the time, so I went to [redacted]. It's a clinic because I was registered with them anyway. I went there, they looked at it and said, Let's do a needle biopsy. They pulled some fluid from my nipple. Now, this was when the guy was nasty. The doctor came in and said, “Oh, I see. It's cancerous. What are you gonna do about this.” He told me, “Well, you have cancerous cells, what are you going to do about it?” I'm going to get off this table, put my clothes on and leave.

Others spoke about the stress of family and cultural relationships with receiving care. Angelica spoke about her mother’s reaction to the idea of receiving surgery.

> I told her that I might have to have them cut this [lump] to see what it is. And she lost it. “Don't let them cut you. Don't let nobody cut on you. When they start cutting on you they keep cutting and the next thing you know, you just be cut all up. Once they know you're gonna let them cut. You don't do it.” So, I go in my room. I'm sitting there thinking about cancer. I'm not trying to die, but I'm not trying to get cut up either. So what am I going to do?

When directly asked about their experience with discrimination when receiving healthcare, participants recounted a wide array of encounters from not having experienced discrimination at all, to having experienced discrimination often. One of the ways in which discrimination intersects with patient experience is through the struggles of self-advocacy.

> Sometimes I will end up going to facilities where, you know, the whole staff is white. If you ask for a particular test, “Oh, you don't need that test”. Well, why is this hurting me? You know, can you investigate that more? When you try to be proactive with your health you almost get shut down or degraded. I'm the doctor or I'm the nurse with the degree. You know, we know what's best for you, and you don't need that.

Discrimination has also manifested in much more insidious and direct ways.

> They thought I was having a heart attack and the attending totally ignored my symptoms. He told me he didn't want to know my history. I should have ran. I walked in with chest pressure, pain, electrical, shooting, from left to right on the inside front back, I'm sick. Time goes on and it started getting better. But then they came back hard. I felt like I had put my finger in the socket. I go to urgent care and the next thing I know they call the paramedics. Next thing I know they run all the lights and all the sirens they thought I was having the heart attack that he missed the first time.
>
> This man walked in I never met before. He told me all about my life experience with this cancer, because he knew all about carcinoid heart disease. He wanted all these tests done before discharging me that Sunday. The young lady still standing there knew that the previous doctor ignored my symptoms and didn't care about

> what happened in my past. She says, “This is gonna be hard for you to hear but I'm gonna tell you this, Racism might have just saved your life.”

Pertaining to treatment itself, many recounted their difficulties with understanding their treatment plan, primarily due to limited time spent exploring options with their oncologist. Several participants spoke about how valuable outside sources were, either through personal connections with other healthcare professionals or deeply invested primary care physicians, in understanding the true scope of their diagnosis.

Angelica spoke about how lost she felt in the early stages of her treatment.

> That was my first experience. And I felt so damn… I didn't know anything. And nobody was telling me anything. They would just say sign here, do this, do that. And I'm like, okay. But what is that? You know? They really don't know how to communicate with us. The white counterparts, they can talk to them, they know how to talk to them.

Linda echoed the sentiment of bewilderment throughout her treatment by sharing her experience with changing, yet uncommunicated, treatment plans.

> It seems like to me they just say, Okay, you're doing this, we're doing that, you know, not really much explanation as to why. I was getting a lumpectomy one day, and then the next day, they decided not to do the lumpectomy but to give me chemo, and then go through that whole process. It was almost exactly a year later

> from my diagnosis that I had the mastectomy. I didn't really understand what was going on or why.

However not everyone experienced hardship with limited communication. Diane shared a very positive outlook on physician communication.

> They were very patient. Especially my oncologist. Very patient and explained everything, you know, all the questions that my family, my kids, and my husband asked there in the room. He was first to explain everything.

The financial burden of receiving care, particularly for cancer patients, can be ruinous. The total healthcare cost associated with cancer treatment is significantly higher than other chronic conditions (Kazzi et al., 2022). Cancer survivors who are of working age, female, nonwhite and who have received treatment more recently are significantly more likely to report financial hardships as opposed to their peers (Yabroff et al., 2016). As such, several participants explored the financial aspect of receiving care through their diagnosis and treatment such as working while undergoing treatment, concerns about insurance or the out of pocket cost itself.

Carolyn shared her experience of the necessity of working through treatment.

> I worked the entire time. I didn't know how that was going to work out. But I said all I can do is try because I needed the money. I couldn't, you know, just not work. And it worked out okay. My manager, she was understanding of the whole thing.

Gail shared her experiences managing the rising burden of healthcare costs.

> Politicians who have stock in these companies are able to promote laws to funnel individuals into their systems that they own stock in to gain a profit at the expense of more minorities. Medicare is an 80/20 program. That's the reason why I paid for two health insurances. Medicare does not pay 100%. Four months, I received two chemo treatments because those four months have five Mondays. I receive 16 treatments a year. For the last nine years. Well, what if I didn't have the $1600 dollars I pay for that extra insurance? What if I didn't have the ability to pay for Humana Blue Cross Blue Shield or an additional resource?

Overall, the stories shared here are but a small sample of the rich and nuanced stories shared in regards to the trials, triumphs, and tribulations these women experienced while undergoing treatment. These stories are critical however in that they paint a vivid picture of the way in which race, class and gender intersect to craft a unique cultural reality surrounding receiving care. An intersectional approach to health views the way in which race and gender jointly and simultaneously influence health trajectories and define access to life chances (Warner & Brown, 2011). This is a lived reality for the members of Cancer SSN which must be accounted for when convincing a culturally responsive social support network.

Social Support Communities

"There is absolutely no way in the world that they can understand what an African American person deals with on a daily basis" – Anonymous

Social support is a fundamental aspect of navigating care while going through treatment. Similar to their experiences with healthcare, participants recounted a wide variety of experiences with receiving social support from having it in abundance from family members, church communities, and co-workers to navigating this illness virtually alone. Two themes were overwhelmingly present however through these conversations, the necessity of shared culture and the conspiracy of silence when disclosing critical illness.

Meredith shared her experience with receiving support from her family and friends.

> I have a group of friends that have been friends, some of us since we were in grade school. They all of course knew that I had been diagnosed with breast cancer. So the day after I came home, they were at my house, all sitting around the bed, because the doctor had said I should rest for a few days. I couldn't go back to work right away. They were all sitting on the bed telling jokes, talking about everything. So, I had them of course, I had my family. By then my mom had died. So it was me and my husband. He was very attentive but not doting. Which I really appreciated. He kind of waited for me to say, can you do this for me? And then of course he would, he would do that.

Linda shared her own experience with receiving different degrees of support throughout both of her diagnoses.

> The first time I didn't really have much support. As I remember. I was pretty much on my own. But this time I had my friends and my sister. My sister, she lives in Tennessee, she came to stay with me for almost two weeks. She told me to get to the surgery, you know, and she stayed with me.

Prior to joining a social support group, many participants reported receiving support from family, friends, coworkers or other well-meaning individuals. However, several participants shared stories about remaining silent in the early days of their diagnosis. A 2004 study exploring the relationship between disclosure patterns and unsupportive social interactions in the well-being of breast cancer patients found that unsupportive responses received from other people contributed to greater emotional problems and a decrease in social functioning (Figueiredo et al.).

Carolyn shared her experience with remaining silent in the early days of her diagnosis.

> When I was diagnosed, I didn't really share my experience with the world so to speak. I just told the people that I felt needed to know. You know, my boss, of course, needed to know, and a couple other people, a couple of neighbors, but not everybody knew. Some of the comments, mostly from family members, of course they all knew, just really let me know to avoid it. “Your hair is never going to grow back”, "You're never gonna gain your weight back”, "You're gonna be in a wheelchair”. I just didn't really talk about it.

Sandy shared a similar story about her motivations for remaining silent.

> When I got diagnosed the first time, I had to get it right for me first. So I didn't tell anybody. My son knew and my mom knew but I had to get it right in my soul. Because I knew that I had to accept the fate that I was in before I could tell anybody else. So they won't try to bring me down. Because they want to, you know, treat it as a death sentence. And that's not the way I wanted to treat it. So initially, I hid it. Both times until I was okay with it.

Martha shared this sentiment as to what could be contributing to the silence.

> Women don’t want to talk about it, and still don't want to talk about it although we got all these different organizations you hear on TV about breast cancer. Women don't want to talk about them being sick. They don’t want people looking at them all crazy, and pitying them and stuff. Let me tell you, if I'm sick, everybody in this world will know about it. I'm not holding nothing in about me having breast cancer. They fear that it makes them less than a woman if they get their breasts removed or people know they had breast cancer.

Angelica shared this bit of context as to how Black culture itself may also contribute to the conspiracy of silence surrounding critical illness.

> Growing up you did not discuss your business. As a Black family, you better not take none of that out of this house. And talk to nobody about nothing. Everything was a secret. You didn't know what Uncle Joe died of. Why did he die, it's none of your business? You did not know.

This trend of non-disclosure has had greater implications in seeking out social support. Meredith shared her experience with feeling shocked at how many fellow cancer survivors she discovered upon first joining her social support group.

> My feeling coming into that room that first day was, golly, I am not alone. I mean, I’m looking at all these other ladies here and ladies that I knew from church, and I just thought oh, I didn't know you had it. Yeah, I didn't know you had it. I just felt camaraderie right away.

Angelica shared a similar story about her shock of discovering so many members of her community were afflicted with this disease, and she never knew.

> One day, they announced that they were thinking about having a support group and asked was anybody interested. If you were interested, you go sign up. Well, I think I might do that. So I went out there, kinda apprehensive, and I signed up for it. They told us when the meeting was and everything, and I went. These were my sisters. Everybody that was sitting in there was Black and they had breast cancer. I was surprised how many people came. It was about 15 to 20 people with breast cancer, so I felt like wow. Yeah. They had cancer and I never knew that.

When asked about being approached with the offer to join social support groups while in the hospital by other national organizations such as the American Cancer Society each participant reported that yes, they had been approached but most were ultimately uninterested. Previous studies have suggested that one contributing factor to the lack of participation by African Americans in online cancer support groups is a general sense of suspicion of the medical establishment and a lack of trust (Fogel et al., 2008). Martha shared her reasoning in response to her disinterest in attending support groups offered by other organizations.

> Our bodies are different from Caucasian women, you know, and I wanted to be with someone else, somebody of my color to tell me about their experiences with it. I just didn't feel comfortable being around the Caucasian women versus African American women. So I didn't go to no support group.

Angelica shared a similar sentiment when asked why she never attended any groups offered by other national organizations.

> It is absolutely no way in the world that they can understand what an African American person deals with on a daily basis. I mean, they can try. But unless they were in your body, and they followed you around all day, everything is different. The house is set up different. It's just different. It's just different. And they can't wrap their head around that. They try, I guess, but it's just different.

When asked about her experiences with being offered social support while in the hospital Gale shared her struggles with receiving anything.

> While I was in the hospital those ladies came to my room, held my hand. We're representing the American Cancer Society, and we're gonna do this, we're gonna do that, and we're gonna do this. And I believe them. Until I found out that July when I got home and needed help with the rent, denied. Utilities denied, transportation denied. I even asked for a wig. I was denied a box of food because I lived in the wrong ZIP Code.

When asked about the benefits of joining a social support group filled with individuals who reflect their own cultural experiences, participants gave a wide variety of responses. Many individuals quoted the sense of freedom and support they felt by having the ability to share their troubles with, and gain wisdom from, a group of people who have shared their experiences.

> What I've found the most valuable is just the conversation with the different members of the group. Because generally, whatever you're going through, somebody else is either going through it, or they've been through it. And if they've been through it, they can give you some information on how they got through it. You know, we share resources, and that kind of thing. So that I really appreciate it in terms of just everything. And not even the cancer itself, but just life experiences.

Diane shared this about how inspiring being in community with other survivors is.

> Very encouraging and very informative to hear all the ladies tell you about their experience. I believe some of them are like, 22-year cancer survivors. So it was very encouraging and very informational. It is supportive.

Sandy shared this story about how her group members helped her solve her health insurance troubles.

> I'll give you a typical example. We all ended up in the hospital, like six of us ended up in hospital at the same time. Somehow, we all ended up in the cafeteria around the same time and I was talking. I was like, man, what I'm gonna do, I'm gonna lose my private insurance because I'm not going back to work. I don't know

> what I'm gonna do. I don't know how I'm gonna, you know, finish my treatment, right? So one of them says let me tell you what to do. You go downstairs and in the front of the hospital, you go through this door, and you ask for this person. They got this program that's called IBCP program where when you lose your private insurance you get a free medical card.
>
> What am I gonna lose? So, I go after I left them, I went down there. And I asked for the lady. And we sat down. I've never been able to get any kind of additional support, but it wasn't dependent on your income. The only factor is that you are in currently in treatment and you're losing your private insurance. And just those two elements right there were what qualified me for a medical the medical card. I've used it for seven years.

She went on to share her thoughts about what has inspired her to help others within her community.

> Well, ever since my first diagnosis, I have had people call and say, “Can I give this person your number? I'm working with this lady. She just got diagnosed and I was talking to her about how well you did with your diagnosis. Can you talk to them?” So ever since the first diagnosis, I've been talking to people and supporting them. I knew it was something I needed to do, because I've always been passionate about it. And then after the second diagnosis, I really knew it was something I needed to do, because the first time it's like, well, yeah, I understand, you know, when you get diagnosed, I understand if you had a mastectomy, right. But the second time, I can actually sit down and say, damn, I know how you feel.

> To go through chemo or radiation, and then, you know, you lose your job, you lose friends, you lose so much of your life. You have to define your new norm, because your old one doesn't fit anymore. You know?

Linda shared this about how being in community with her support group improved her knowledge going into her second diagnosis.

> I'm a little more knowledgeable now, because of joining a cancer support group and hearing the ladies talk about their experiences. I just learned a lot just from being in a group that I did not know. The first time around, I was not even given any information on reconstructive surgery. It wasn't even put on the table. I'm just assuming that it was because at the time I didn't have insurance but seemed to me they could have given me the option to look into it for myself you know. But it was not even mentioned. It was not even mentioned anywhere, and as a result, I did suffer some problems. From having my body changed so dramatically.

Carolyn offered this very powerful concluding thought about the value of belonging to a social support group.

> Let's talk about life. Because we talk about life in this group. And I think that's the main thing, is that with our group, we talk about life. I think that that's something that should be very upfront, in any group, with Black women in particular. Let's live, you know, this is about living, this isn't about how you died. It's about how you live, and what resources you're going to need to help you.

Ultimately, being in community with individuals who share a cultural reality as well as a cancer diagnosis has many positive benefits. The positive health outcomes associated with belonging to a social support group have been well documented. What has been revealed through the course of these interviews isn't that social support is necessary but rather social support within the confines of a shared cultural reality is paramount. Any organization which proposes a social support program must be culturally responsive as personal experiences with receiving care, cultural connotations of receiving care, navigating the medical industrial complex, the potential for medical discrimination and comfortability within social support groups themselves are culturally and relatively constructed as demonstrated above.

Suggestions for Improvement

The goal of this study was to answer the question as to how Cancer SSN can expand the social support networks available and increase the support and well-being of Black women cancer survivors. To follow are suggestions for improvement in their own words.

Table 2.3

Suggestions for Improvement

Pseudonyms	Suggestion for Improvement	Takeaway
Gail	They're [national organizations] not even willing to learn. I was willing to teach them about this war, but I cannot do that if no one calls you back or replies to your emails. I've got emails from months ago no one has replied too.	Communication & Education
Sandy	I would love to be able to, to get into a hospital. So along with the oncologist, and the nurse, and social worker Cancer SSN is right there, as their patient navigator. Not in the medical aspect, in the physical, emotional, and spiritual aspect of support. My ultimate goal, really, is to just be right there initially. So they don't have to go look for anyone. So as soon as they are diagnosed, we're right there. To talk to them.	Outreach
Meredith	I would like to institute a library. A library that would have books, pamphlets, newsletters, any kind of reading material that ladies can take home, especially early diagnosed ladies. That this is what breast cancer looks like, or, you know, a primer. I think the emotional support that we give to a newly diagnosed woman is to surround her with mentors.	Education
Angelica	We need honesty. We need to know that what you're selling me is real.	Honesty
Linda	I wish there was a way to be able to reach more people, you know. To let people know that they're there and that they're, you know, available for them.	Outreach

Martha	Go out more and let people know about the group. Share it with other churches, communities, things of that nature. We haven't been doing that, and we need to do that.	Outreach
Carolyn	We do a lot, well we used to do a lot of things before COVID. I would say more activity. Like the in-person interaction definitely.	Interaction
Diane	Probably getting information out more. We get new community members all the time. But getting the information out more about the group is low. People haven't heard of the ministry, you know. But if you found out about the ministry, then you can go to that ministry.	Outreach

Summary of Findings

This study strove to answer several key questions, including primarily, what are the unique needs of Black women cancer patients and survivors. Overwhelmingly, the answer to this deceptively simple question is shared community reflective of the cultural experience they live, an open conduit of information, and community with individuals who have shared a similar burden of critical illness. Throughout the interviews several themes emerged, including the conspiracy of silence, the financial burden of care, and the importance of shared culture in social support, each of which have larger implications for the direction of the intervention proposed.

In particular, the conspiracy of silence is of key importance. Throughout most of these stories, participants recounted repeatedly the shock they experienced at discovering members of their community were similarly afflicted. The cultural expectation of keeping one's business "in the house" is in direct conflict with the necessity of spreading awareness about the availability of programs such as those offered by Cancer SSN. Though findings show that being in community with those who share a similar cultural background are of key importance to the success of a culturally responsive support program, breaking the taboo of disclosure may prove difficult.

Though discrimination did come up often, sometimes more critically and brutally than others, discrimination was not the unifying experience. More than anything, the knowledge that support is best when offered by individuals who have shared your cultural experience was the greatest take away. This is a response shared by all participants regardless of their experience with discrimination in healthcare. This suggests that there is something unique about the experience of Black womanhood afflicted with critical illness that is independent of having experienced discrimination promoting this desire.

One potential analysis of these findings from an intersectional ecological systems theory approach may suggest that the interlocking statuses of being a critically ill Black woman uniquely creates a cultural reality only understood by having experienced it. This status informs both how society views and interacts with these women and how these women view and interact with society. Through this understanding, any information offered through a social support network must account for the social location of its recipient as utilizing any suggestions must be filtered through the lens of their expected outcomes.

The financial burden of care should be similarly understood through this framing. Many respondents spoke about the cost of healthcare and its impact on their family, jobs, and lives. However, the solution to these problems must be conceptualized through the lens of each person's social location as many suggestions may ultimately prove useless as in the case of Gayle who was offered resources only to not "qualify" for anything. The heartbreak of this, compounded with the stress of fighting critical illness is too difficult to bear. Sharing community with those of similar background helps to alleviate this concern by surrounding yourself with individuals who have already forged this path.

These stories have weight. A heaviness which permeates not only these pages but this organization and the shared history we all live within. In the subsequent chapter an intervention, incorporating the knowledge gained through this study is proposed.

CHAPTER THREE: DESCRIPTION OF ACTION/INTERVENTION/CHANGE PROCESS

Organizational Change

Organizational change has been theorized in many incarnations since its inception as a unique phenomenon deserving analysis. One understanding of the analysis of organizational change is to view organizational change theory as being comprised of one or more general perspectives. Van De Ven & Poole, after conducting a detailed literature review, posited that many organizational change theories can ultimately be deduced to belong to a combination of four ideal-type developmental theories (1995). Accordingly, organizational change is understood to be either change as a life cycle or a developmentalism perspective, change as evolution or a Darwinism perspective, change as dialectic or a Marxist conflict theory perspective, or change as teleology or a goal setting social constructivist perspective (Van De Ven & Poole, 1995).

Concentrating on organizational change as a life cycle as is consistent with ecological systems theory, there are many models of change which explore the nature of a maturing organization (Alase, 2017). Many of which differ in terms of how many stages of change exist and who within the organization acts as the catalyst for change (Alase, 2017). Focusing on the Greiner model first introduced in 1972, organizational change is understood to consist of five stages of evolution and revolution (Mosca et al., 2021). Including some elements of what Van De Ven & Poole would classify as dialectic, the Greiner model explains organizational change as cyclical consisting of growth and pushback (Mosca et al., 2021). Utilizing the Greiner model of organizational change as a series of evolutions promoting growth and revolutions consisting of pushback, it is imperative to incorporate equity oriented theories within organizational change models as it is impossible to sustain organizational growth while simultaneously marginalizing organizational constituents.

Equity oriented organizational change is fundamental to the continuous growth of any organization. Creating an intervention tailored to the specific lived experiences of Black women cancer patients and survivors utilizing an ecological systems framework facilitates change through conceptualizing organizational development as various stages within an organizational life cycle. Pushing each stage of growth is a constant progression between organizational evolution and organizational revolution utilizing intersectional experience within health care to inform change.

Within this model, organizational change should be focused towards creating opportunities for a diversity of knowledge and experience focused on adaptation, integrity, and emancipation. These ideals are created through utilizing the narratives of the participants and the information gained through the intervention process throughout each cycle of organizational growth and development, a cycle ultimately commiserate with the goals of Black emancipatory action research. Viewing organizational change as necessarily involving the direct lived experiences of its constituents is a radical departure from other reactive conceptions of change focused more on profit than compassion, and image over love.

This action plan, crafted in response to the narratives presented in the previous chapter, is proposed as an intervention for Cancer SSN, an organization tasked with disrupting health disparities within underserved communities. To follow is a brief contextual review for the necessity and value of such an intervention, an exploration of the goals and objectives this action plan hopes to accomplish, and the logic model.

Description of the Action/Intervention/Change Process

To follow is an in-depth look at the action plan, communication, and engagement strategies proposed to address the themes uncovered through this study. Incorporating the strategies proposed by CanConnect, in conjunction with the themes which emerged through interview, underscore the importance of community centered design (Weiss et al., 2013). The implementation of a social support network must account for interdependent social contexts including community partners, family relationships, or other interpersonal ties (Weiss & Lorenzi, 2009). In particular, this action plan incorporates both individuals and community partners as important stakeholders, key priorities in an ecological systems based intervention (Weiss et al., 2013).

Contextual Necessity

Three themes emerge from reviewing the relevant literature pertaining to this proposed action plan. One is the devastating impact discrimination has on receiving equitable healthcare thus creating the contextual necessity for the intervention. The second is the positive impact receiving social support has on facilitating favorable health outcomes which has cultivated the nature of the intervention. The third is the importance of assessment in facilitating culturally responsive intervention.

Any responsible program must explore the context for which intervention is required. A brief overview of the contextual necessity for providing an intervention specifically targeting Black women cancer patients and survivors, in addition to the positive impact receiving social support creates, is recanted here in response to the harrowing tales presented above.

Contextual Overview: Why is this action plan needed?

Instances of discrimination have a devastating impact on receiving equitable healthcare. The perception of experiencing discrimination has been linked to the development of cancer in Black women (Taylor et al., 2007), limiting the frequency of preventable cancer screenings in Black Americans (Crawley et al., 2008; Mouton et al., 2010), limited trust and lack of adherence to medical advice in Black Americans (Adegbembo et al., 2006), and decreasing the ability receive government resources for disability (Pryma, 2017).

Given the consistent health disparities Black Americans experience, the perception and experience of discrimination within medicine may be one large contributing factor perpetuating this deficit. As studies have shown, the experience of discrimination when seeking treatment is linked to a wide array of disastrous health outcomes. Reflecting on many of the stories shared above, the reality of discrimination is ruinous. It is imperative that inventions aimed at improving health outcomes for Black Americans are implemented immediately and are culturally responsive to the unique disparities in care experienced by Black Americans.

Social Support: What does this action plan seek to accomplish?

Alternatively, receiving social support while undergoing treatment has been linked to astounding health benefits. As such, the primary focus of this action plan is the expansion of the social support networks available to Black women cancer patients and survivors. Social support consists of both structural and functional aspects (Gudina et al., 2021). Structural support incorporates the composition of a social network or various sources of support such as family, church, or support organizations (Gudina et al., 2021). Functional support includes the provision of specific resources such as wigs or hats for individuals who have recently lost their hair or types of support such as emotional -well-being support (Gudina et al., 2021).

Given the beneficial health outcomes social support utilization has, creating an intervention directly focused on providing social support for Black women may be one method to overcome the gross health disparities experienced by this demographic. Many of the stories shared above highlight how impactful community, education, and awareness have been in fighting this disease. Highlighting the structural aspect of social support, creating space within organizations dedicated to facilitating support with other community partners may encourage preventative behaviors and build trust, two negative health outcomes associated with discrimination experienced in healthcare.

Furthermore, facilitating a more community driven approach underscores the importance of the ecological systems. An ecological approach emphasizes the interdependent social contexts including interpersonal relationships, neighborhoods, culture, community organizations and the physical environment itself (Weiss & Lorenzi, 2009). It is clear throughout these stories that community, culture and interpersonal relationships all intersect to construct a social support network valuable to its members.

Assessments: How will this action plan accomplish its goals?

As a component of the proposed action plan an assessment has been embedded into the program design. The comprehensive needs assessment will be conducted for the purpose of discovering the “gap” between what is currently available and what should be available in response to participant needs. This program was designed in response to a contextual reality experienced by Black women cancer patients and survivors, therefore their needs must be assessed to remain relative.

Culturally responsive evaluations encourage contextual knowledge and meaning guided by values such as social justice, equity, and change (Acree & Chouinard, 2020). Accordingly, as a feature of this action plan, assessments will be conducted by program participants, facilitators, and key stakeholders all of whom are aware of the contextual cultural experience promoting the necessity of this intervention.

Goals & Objectives

The overall goals of this action plan will be to:

1. Increase the emotional support and well-being of Black women cancer patients and survivors.
2. Expand the social support networks available to Black women cancer patients and survivors.

The mid-term goals are to:

1. Create program activities to meet needs determined through research and stakeholder feedback.

2. Increase awareness through outreach to promote membership.

Figure 3.1. *Logic Model*

Inputs	**Outputs**		**Outcomes -- Impact**		
	Activities	*Participation*	*Short*	*Medium*	*Long*
Time Funding Stakeholder input and assistance Facilitator input and assistance Community space provided by the organization Church groups Community Partners	Conduct research pertaining to best practices for social support network formation both in person and online	Facilitator and key elected stakeholders	Learn what unique needs black women cancer patients and survivors need in a social support network	Create program activities to meet needs determined through research and stakeholder feedback	Increase the support and wellbeing of black women cancer patients and survivors
	Conduct comprehensive needs assessment to determine gaps in current offerings	Facilitator and key elected stakeholders			
	Workshop to implement changes determined by needs assessment	Organizational stakeholders, facilitator, and key elected stakeholders	Determine current level of mental health and wellbeing	Increase awareness through outreach to promote membership	Expand the social support networks avaliable to black women cancer patients and survivors
	Focus groups for direct stakeholder information gathering	Program participants			
	Weekly stakeholder social support meetings	Program participants			
	Monthly Newsletter	Program participants, organizational stakeholders, external community members			
	Monthly Community Outreach Events	Church groups, sorority groups			

Inputs

Inputs included in this logic model incorporate the resources and locations needed to implement this intervention. Resources primarily consist of participant labor and community or digital space to facilitate research and meetings. This action plan will develop throughout implementation to incorporate more inputs as new information arises. The external stakeholders, including church groups and community partners, were added in response to the information gathered over the course of data collection and the importance of maintaining an ecological systems understanding of intervention. Incorporating the suggestions for improvement provided by the participants indicated that outreach and education were two much needed targets. The addition of church and community groups as external participants and spaces to spread awareness and promote membership is in direct response to these findings and the theoretical framework employed throughout this study.

Outputs

Outputs included in this logic model incorporate the persons, and tasks needed to implement this program. This section is divided into two parts listing the activities recommended as stated above and the persons suggested to perform them. The assessment indicated is a key component of ensuring a culturally responsive intervention which properly incorporates the needs of the program participants.

The Comprehensive Needs Assessment proposed for this action plan was developed by the Office of Migrant Education for the purpose of discovering the “gap” between what is currently available and what should be available (“Comprehensive

Needs Assessment", 2001). This needs assessment utilizes a portfolio style assessment conducted through multiple stages of data collection and deliberation.

The CNA uses a three-phase model of assessment to ascertain the need or discrepancy between the current state of the targeted item and the desired state of the targeted item ("Comprehensive Needs Assessment", 2001). The stages 1. Explore "what is", 2. Gather & Analyze Data and 3. Make Decisions, each have several sub-stages involving the creation of management plans, data sources and proposing action plans for progression ("Comprehensive Needs Assessment", 2001). Due to the tiered approach of this needs assessment, each stage can be revisited and adjusted as new information arises creating a continuous cycle of improvement which is in alignment with the goals of Black emancipatory action research and consistent with an evolutionary based organizational change plan ("Comprehensive Needs Assessment", 2001).

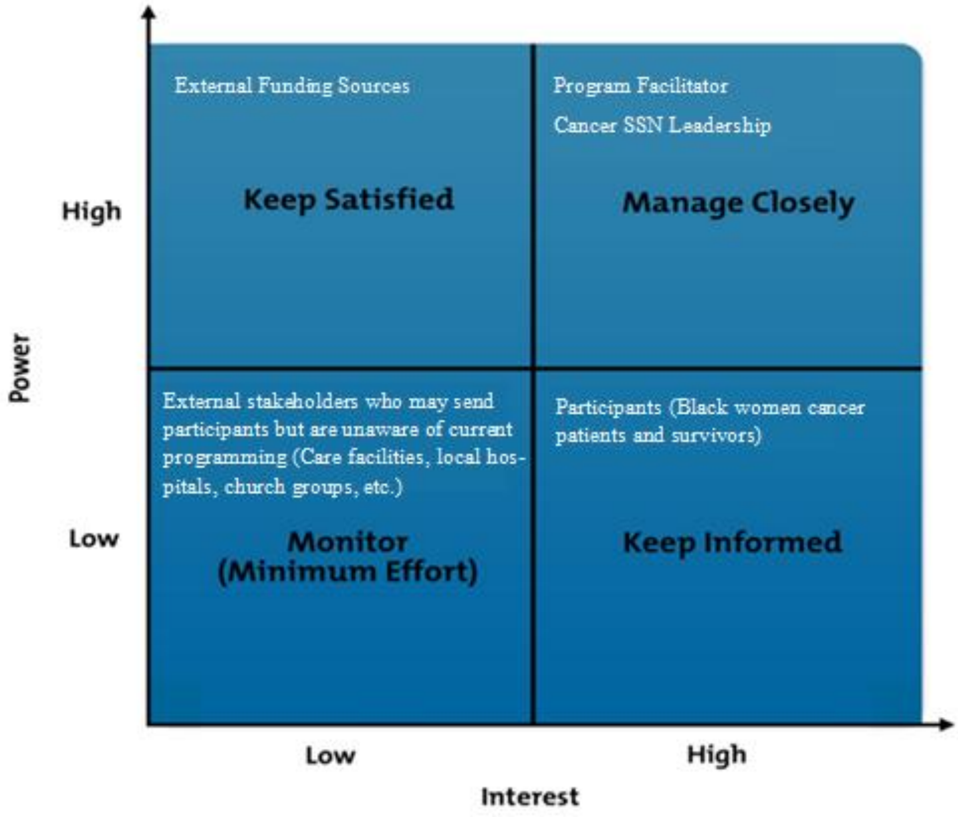
Two additional outputs include both a monthly newsletter and monthly community outreach events. These additions are in direct response to the information gained through interview and are proposed to disrupt the conspiracy of silence surrounding critical illness within already established community spaces.

Outcomes

Outcomes included in this logic model incorporate both the goals of the program itself and a tentative timeline to completion. The short-term outcome of this program is gaining the knowledge from the assessment as a guide for future program development. From this knowledge, the intermediate outcome of developing program activities to meet the needs determined through research and shareholder feedback can evolve. Currently, the activities proposed to meet these needs include weekly stakeholder meetings, focus groups, monthly newsletters, and community outreach, however these activities could evolve once better information has been discovered. The long-term outcomes of this program are the stated goals of this program which are to increase the emotional support and well-being and to expand the social support networks available of Black women cancer patients and survivors.

Stakeholder Analysis

Figure 3.2. *Stakeholder Engagement Model*



Program Facilitator

The program facilitator is the founder and CEO of Cancer SSN, and as such, is the primary stakeholder. This organization was born from her own experiences fighting cancer and a devotion to her community. She personally facilitates, organizes, markets, and operates all the programs for Cancer SSN. Due to her position, she is highly invested in the organizational outcomes and has an enormous amount of internal power. Her guidance is an invaluable resource for the successful implementation of this action plan.

Cancer SSN Leadership

The board of Cancer SSN consists of 4-6 individuals who share a similar experience of frightening cancer and who serve on a volunteer basis. The board has the most oversight in instituting new programs, changing support group themes, creating new policies, procedures or structures and instituting outreach with external community members. Due to their position within the organization, the similarity of their experiences, and participation in the organizational programs, they have both internal power and interest in outcomes. They too are primary internal stakeholders and are key resources for information gathering.

External Funding Sources

Cancer SSN receives funding from both private donors and corporate sponsors. Private fundraising is typically conducted through silent auction, individual solicitation through go fund me, individual events such as the Wine-A-Thon or Purses with a Purpose, or member donation. Corporate sponsorship is infrequent and primarily happens around breast cancer awareness month. External funders have high power, due to their financial contributions but low interest in organizational programing due to lack of membership. They are secondary external stakeholders.

Program Participants

The program participants of Cancer SSN are individuals who have either personally fought cancer or who are caregivers to individuals impacted with cancer. Being from the affected community, this group has the largest relationship with the social justice issues that Cancer SSN was created to disrupt. Approximately 30 individuals, primarily Black women 40 or above on average, regularly attend the two monthly support groups. Due to their participation in the program, their own similar experience and organizational mission they are primary stakeholders with high interest in organizational outcomes but with little institutional power. With their corporation, this intervention will utilize their experiences through the needs assessment, focus groups, and direct feedback to better realize future initiatives.

External Stakeholders (Community Partners)

The external stakeholders include any group who may partner with Cancer SSN to drive membership or promote the organization and include various other non-profit entities such as local hospitals or health organizations, community centers, or church groups. As there exists such a limited number of organizations specifically targeted towards disrupting disparities in this community, Cancer SSN provides a service many external stakeholders have come to appreciate through not participate in directly. Being external to the organization with their own organizational mission, participants and outcomes, the external stakeholders have both low interest and low power within the Cancer SSN.

Analysis of Implementation

Communication is key for successfully implementing these goals. Cancer SSN interacts with several different stakeholders each with their own unique needs and positional power within the organization. To successfully implement these goals, each stakeholder identified must be addressed at different frequencies and with different strategies in relation to their own needs.

Communication

Figure 3. Stakeholder Communication Plan

Stakeholder	**Topic/Issue/Idea**	**Approach**	**Format**	**Communication Tool**	**Frequency**
	What do you want to communicate?	*What is the best approach given stakeholder interests & power?*	*What type of format will work best for the stakeholder?*	*What is the best means through which to communicate?*	*When and how often will you communicate?*
Program Facilitator	Goal progression	Direct communication / formal structured reports	Written report	Direct communication	Monthly
Cancer SSN Leadership	Goals and initiatives, Overview of assessment results	Formal meeting	Presentation	Formal meetings	Bi-annually
External Funding Sources	Goals and initiatives, Positive program outcomes	Formal structured reports	Written (summary) report	Formal meetings and Social media	Quarterly

Program Participants	New program initiatives	Direct (informal) communication	Verbal communication and infographic	Direct communication	Monthly
External stakeholders / community partners	New program initiatives	Social media posts	Infographic / Email blasts	News/Social media	Monthly

Figure 3. explores the method by which information pertaining to the stated goals of this logic model will be delivered. Each identified stakeholder will receive individualized information relative to their investment within the organization, power, and need. The frequency of this communication is conditional on their position within the organizational structure.

In particular, the goal of spreading awareness for the purpose of driving new membership is communicated directly to program participants and external stakeholders though the promotion of new program initiatives. Combining direct informal communication with a large social media presence is one way of spreading awareness about the positive things happening at Cancer SSN in an accessible and cost-efficient way.

The goal of providing status reports for the purpose of determining future opportunities is realized through the communication of goal progression and initiatives to the program facilitator, leadership, and funders. This information is similarly shared relative to their power and investment in the organization and is communicated at a frequency relative to their need.

Engagement

Figure 4. Engagement Strategy

Stakeholder	**Point of Contact** *Name*	**Interests** *Interests related to program outcomes*	**Power** *Type of power and ability to impact action plan & implementation*	**Engagement Strategy** *Type and frequency of communication.*
Stakeholder #1	Program Facilitator	Invested interest. Will be the person primarily tasked with implimenting suggestions	High power. They facilitate the program.	Continuous direct communication
Stakeholder #2	Cancer SSN Leadership	High interest. Program functions under SSN leadership.	High power. They okay the existence of the program, evaluation plan and program changes. They also control funding allocation.	Formal structured communication. Primarily in the form of reports and status updates.
Stakeholder #3	External Funding Sources	Moderate interest. Need to know if program is worth funding	High power. They fund the programs	Formal structured communication. Primarily in the form of reports and status updates.
Stakeholder #4	Program Participants	High interest. Participating in program	Low power. They have no organizational power outside of program participation.	Continuous direct communication
Stakeholder #5	External stakeholders/ Community partners	Moderate interest. Need to know if program is worth referral	Low power. These are external stakeholders.	Infrequent structured communication. Primarily in the form of annual reports and advertisements.

Figure 4. explores the engagement strategies that will be implemented at Cancer SSN relative to each stakeholder. Each stakeholder holds different organizational power which is important in determining the best ways to engage for the purpose of promoting the best outcomes. Those with high organizational power but lower daily interaction such as the leadership board require more formal and direct discussion as to best convey the needs of the organization while also respecting the boundaries of their position.

Individuals who do participate daily in the programs offered by the organization however, such as program participants and the program facilitator, are able to receive more direct informal engagement. These are individuals who by virtue of their interaction have freedom to share their thoughts and feelings in a safe space without being confined by the boundaries of position. Through respect, program goals can be directly communicated throughout their in-person interaction.

Analysis of Future Implementation

Black emancipatory action research centers participants in a radical act of self-actualization through love, healing, and acceptance. Healing however, particularly from the trauma caused through combating critical illness is not completed swiftly. Coupled with the ever-changing realities of modern health care this action plan holds space to move at its own pace despite timeline estimations.

It is with good intentions that the long-term goals of this action plan will be implemented over the course of approximately two years from outset. Initial communication with program participants and program facilitators can be implemented within the first two months as they are direct and in person due to their position within the organization. This communication serves to promote the first goal of this action plan which is to promote awareness and membership.

However, data to inform the second goal of development and improvement will take time to collect. The comprehensive needs assessment will require several stages of negation, including committee section and research, before completion. Though a lengthy process which may take several years, implementation of a program specifically tailored to the unique lived experience of all its participants is the ultimate manifestation of a labor of love.

Anticipated Results of the Change Process

As explored previously, organizational change is cyclical following a natural process of organizational evolution followed by a period of organizational revolution (Mosca et al., 2021). Therefore, it is natural to anticipate unrest through the change process as the confines of the organizational structure adjust to new initiatives. Emancipation is not easy nor peaceful despite the best of intentions. Coupled with the reality of the limitations of capacity, and the overwhelming stress of fighting critical illness, I anticipate that implementing organizational change will take time.

Many incarnations of the proposed action plan, each with its own activities and suggestions, will likely be proposed as Cancer SSN works to implement the goals of this program. That said, discourse is a fundamental aspect of collaboration and an element often missing in physician relationships as reported by the women who contributed to this study. It is with love and respect for the community created within this organization that these discussions are likely to be had.

Implications for Practice and Future Research

The following section provides an account of the implications of this study integrating not only participant experience but also supporting literature. It is within this context that future recommendations for continued study are suggested.

Implications for Practice

This study sought to discover what the unique needs are of Black women cancer patients and survivors within Cancer SSN. Overwhelmingly, the answer to this question centers the necessity of representative experience within social support spaces. The notion of seeing yourself in other community members was repeated throughout these stories underscoring the point that universal programing is neither wanted nor utilized by Black women cancer patients and survivors. The principal reason for this, as explored throughout these narratives, is that programming designed to support “everyone” cannot properly account for the diversity of experience, including relative struggles created through structural racism, personal history, cultural expectations, importance of prayer or financial limitations experienced by this demographic.

Utilizing an ecological systems theory approach further underscores the importance of community awareness when creating social support systems. A network of peers not only has the ability to provide comfort, but also cultural awareness, all too important when caring for another person. It is the unspoken, intersectional experiences of being both Black and a woman which color all other requirements in a culturally responsive social support network targeted to this demographic. While the respondents each had vastly different experiences through diagnosis, treatment, and recovery, each highlighted a disinterest engaging with other support groups not representative of their cultural background.

Furthermore, this study highlights the role the "conspiracy of silence" plays in limiting the ability of Black women cancer patients and survivors to quickly find community. Though trailblazers who prioritize the importance of education and unwavering vulnerability through the sharing of their experiences exist, they are in the clear minority as evidenced by the many instances of shock reported about uncovering the cancer status of other close community members which went otherwise unknown.

The lack of open communication underscores not only a deeply embedded culture of distrust but also a consistent fear of reprisal. Stories reporting the callus and cruel statements of family, friends, and co-workers highlight the burden of fearless honestly. The double impact of cultural tradition coupled with personal risk, further alienates Black women cancer patients and survivors by limiting their ability to safely find community in a loving environment outside of already established relationships.

This reality has many implications for future interventions and future research. The action plan proposed purposefully includes the addition of newsletters, social media, and community engagement as strategies to raise awareness. However, overcoming cultural expectations and historical precedence is no small feat, and to suggest that change will happen swiftly is unlikely.

Recommendations for Future Research

This study would benefit from being conducted with a wider demographic of respondents. Cancer SSN is a small local organization, and as such, is confined by the limitations of its resources. Future research with a wider demographic of respondents would not only present a wider range of experience but may uncover other needs not explored in this study.

Other areas of exploration this study did not engage include how other minority groups such as, Latino, Asian, LGBTQIA+, Native American, etc. may also benefit from culturally responsive social support programing. It would be beneficial to explore how other minority groups experience universal programming in relation to their own unique needs.

Conclusion

Critical ethnography is a powerful tool for storytelling. Collecting someone's life history as it relates to their health is humbling, informative, invasive, vulnerable, heart wrenching and a million other words too emotional to be considered appropriate for academia. The stories shared within this study are but a small sample of the millions of unique experiences Black women have had fighting cancer.

I was diagnosed with AML, a type of Leukemia, on December 14, 1999, at 11 years old. Though I began displaying symptoms many years in advance, for whatever reason, my physicians caught it late. I am incredibly lucky to have had access to a major hospital system in a large metropolitan area as without it, I may not have been here today to conduct this study. I myself underwent chemotherapy. Lost my hair. Experienced the messiness of critical illness firsthand.

I share this now to fight the stigma of silence and as a testimony to the vulnerability the participants in this study displayed in allowing me to share their stories. May this work serve as an informed beginning towards change, fully acknowledging intersectional experiences, the importance of community and chiefly, the radically emancipatory power of love.

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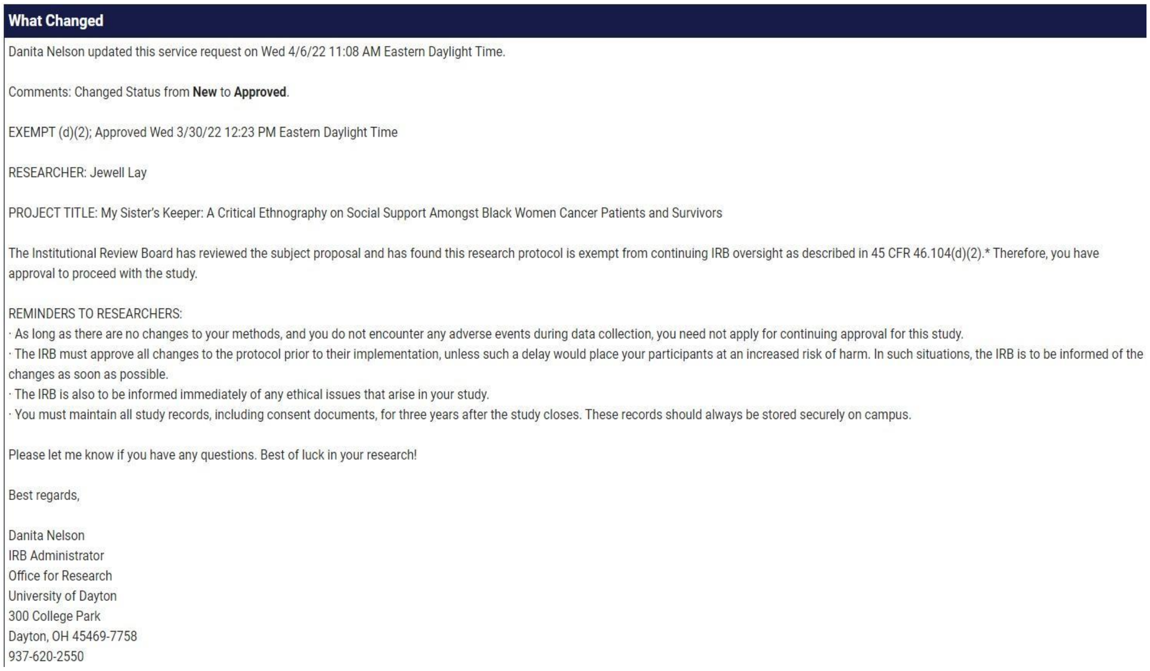
APPENDIX A

IRB APPROVAL



What Changed

Danita Nelson updated this service request on Wed 4/6/22 11:08 AM Eastern Daylight Time.

Comments: Changed Status from **New** to **Approved**.

EXEMPT (d)(2); Approved Wed 3/30/22 12:23 PM Eastern Daylight Time

RESEARCHER: Jewell Lay

PROJECT TITLE: My Sister's Keeper: A Critical Ethnography on Social Support Amongst Black Women Cancer Patients and Survivors

The Institutional Review Board has reviewed the subject proposal and has found this research protocol is exempt from continuing IRB oversight as described in 45 CFR 46.104(d)(2).* Therefore, you have approval to proceed with the study.

REMINDERS TO RESEARCHERS:
· As long as there are no changes to your methods, and you do not encounter any adverse events during data collection, you need not apply for continuing approval for this study.
· The IRB must approve all changes to the protocol prior to their implementation, unless such a delay would place your participants at an increased risk of harm. In such situations, the IRB is to be informed of the changes as soon as possible.
· The IRB is also to be informed immediately of any ethical issues that arise in your study.
· You must maintain all study records, including consent documents, for three years after the study closes. These records should always be stored securely on campus.

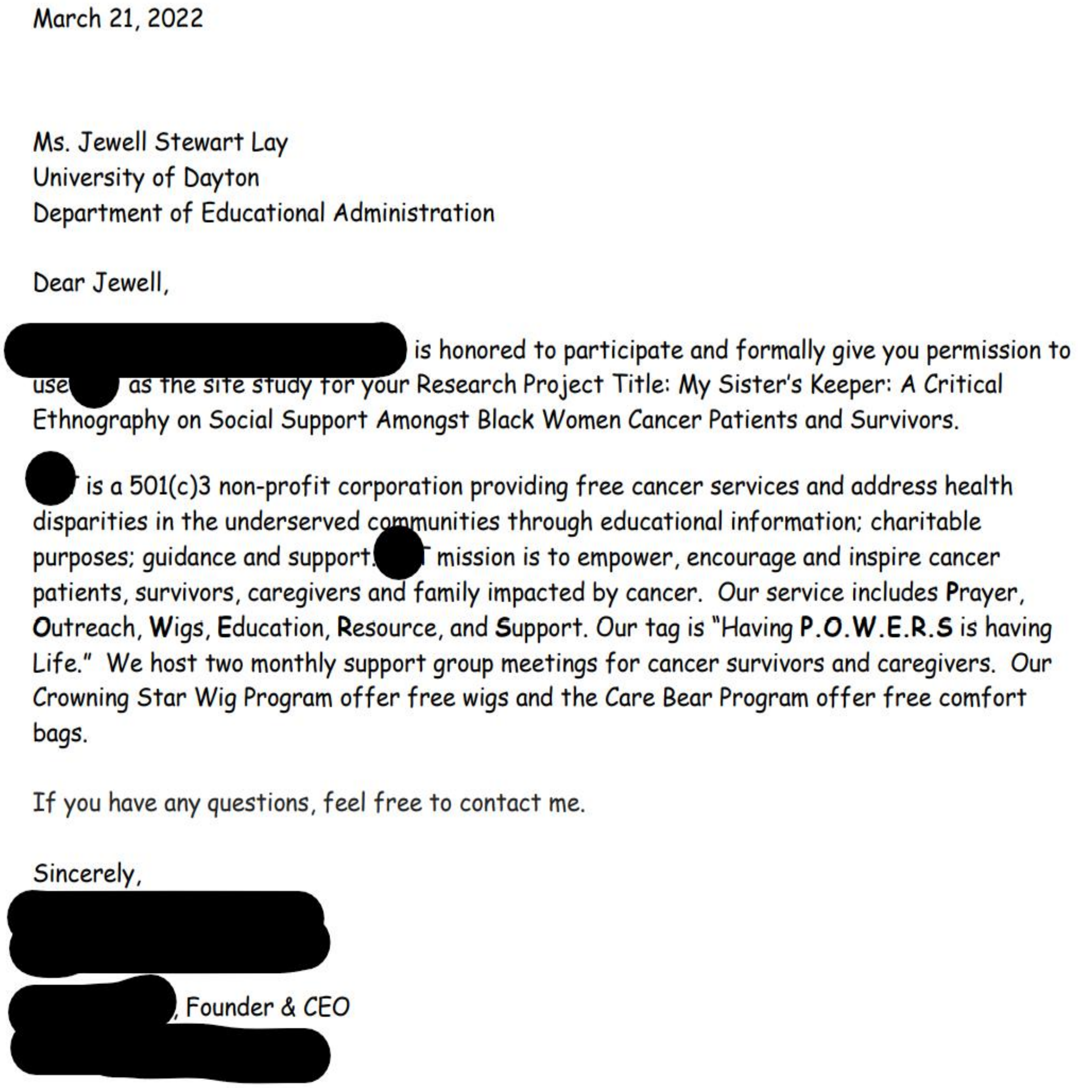
Please let me know if you have any questions. Best of luck in your research!

Best regards,

Danita Nelson
IRB Administrator
Office for Research
University of Dayton
300 College Park
Dayton, OH 45469-7758
937-620-2550

APPENDIX B

SITE APPROVAL



March 21, 2022

Ms. Jewell Stewart Lay
University of Dayton
Department of Educational Administration

Dear Jewell,

[redacted] is honored to participate and formally give you permission to use [redacted] as the site study for your Research Project Title: My Sister's Keeper: A Critical Ethnography on Social Support Amongst Black Women Cancer Patients and Survivors.

[redacted] is a 501(c)3 non-profit corporation providing free cancer services and address health disparities in the underserved communities through educational information; charitable purposes; guidance and support. [redacted] mission is to empower, encourage and inspire cancer patients, survivors, caregivers and family impacted by cancer. Our service includes **P**rayer, **O**utreach, **W**igs, **E**ducation, **R**esource, and **S**upport. Our tag is "Having **P.O.W.E.R.S** is having Life." We host two monthly support group meetings for cancer survivors and caregivers. Our Crowning Star Wig Program offer free wigs and the Care Bear Program offer free comfort bags.

If you have any questions, feel free to contact me.

Sincerely,

[redacted]

[redacted], Founder & CEO
[redacted]

APPENDIX C

Interview Questions

Research Questions:

What are the unique needs of Black women cancer patients and survivors within Cancer SSN?

How can Cancer SSN expand the social support networks available to Black woman cancer patients and survivors?

How can Cancer SSN increase the support and well-being of Black women cancer patients and survivors?

Interview Questions:

1. Tell me about your feelings on going to the doctor before you were diagnosed?

    Did you ever have an experience which made you feel uncomfortable/unheard with your healthcare provider?

    If so, tell me about it.

2. How did you feel when you were first diagnosed?

    Did your healthcare provider fully explain what your treatment would involve?

3. Tell me about how you supported during your diagnosis/treatment?

    Community, family, church, healthcare team?

    What kinds of support do you find valuable?

4. Do you feel like your healthcare providers understand your needs?

    Tell me about how your healthcare providers made you feel comfortable/uncomfortable voicing your concerns/questions?

    Have you ever experienced discrimination from your healthcare provider?

    If so, tell me about that experience and how you navigated it.

5.Tell me about your experiences developing social support in your community.

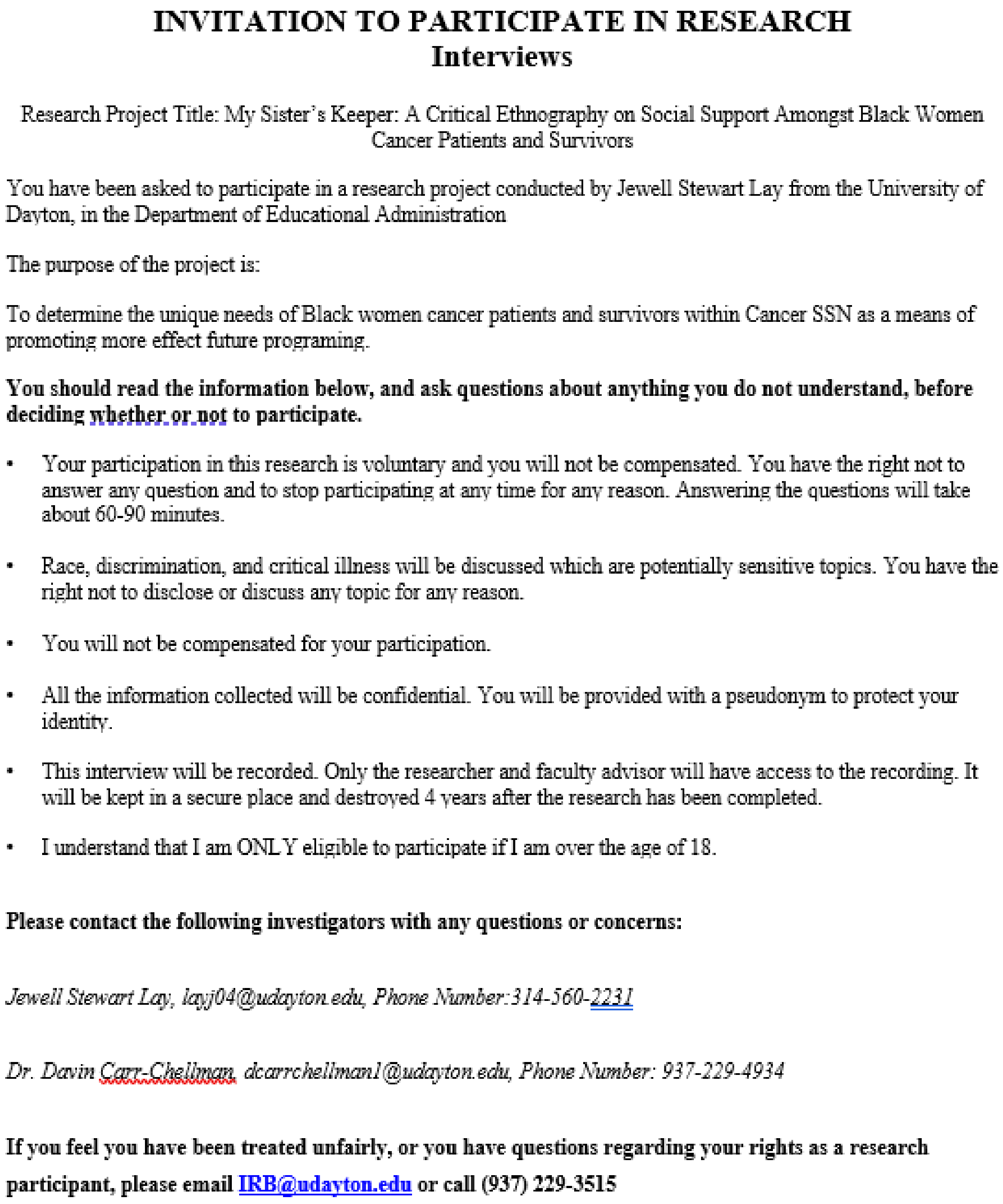
    Do you receive/provide functional support (resources) to other cancer patients/survivors?

Do you receive/provide structural support (community) to other cancer patients/survivors?

6. Tell me about what find valuable/unvaluable in the support groups currently offered by Cancer SSN?

7. If you could increase the functional support (resources) or structural support (community) offered by Cancer SSN, what would you change?

APPENDIX D



INVITATION TO PARTICIPATE IN RESEARCH
Interviews

Research Project Title: My Sister's Keeper: A Critical Ethnography on Social Support Amongst Black Women Cancer Patients and Survivors

You have been asked to participate in a research project conducted by Jewell Stewart Lay from the University of Dayton, in the Department of Educational Administration

The purpose of the project is:

To determine the unique needs of Black women cancer patients and survivors within Cancer SSN as a means of promoting more effect future programing.

You should read the information below, and ask questions about anything you do not understand, before deciding whether or not to participate.

- Your participation in this research is voluntary and you will not be compensated. You have the right not to answer any question and to stop participating at any time for any reason. Answering the questions will take about 60-90 minutes.
- Race, discrimination, and critical illness will be discussed which are potentially sensitive topics. You have the right not to disclose or discuss any topic for any reason.
- You will not be compensated for your participation.
- All the information collected will be confidential. You will be provided with a pseudonym to protect your identity.
- This interview will be recorded. Only the researcher and faculty advisor will have access to the recording. It will be kept in a secure place and destroyed 4 years after the research has been completed.
- I understand that I am ONLY eligible to participate if I am over the age of 18.

Please contact the following investigators with any questions or concerns:

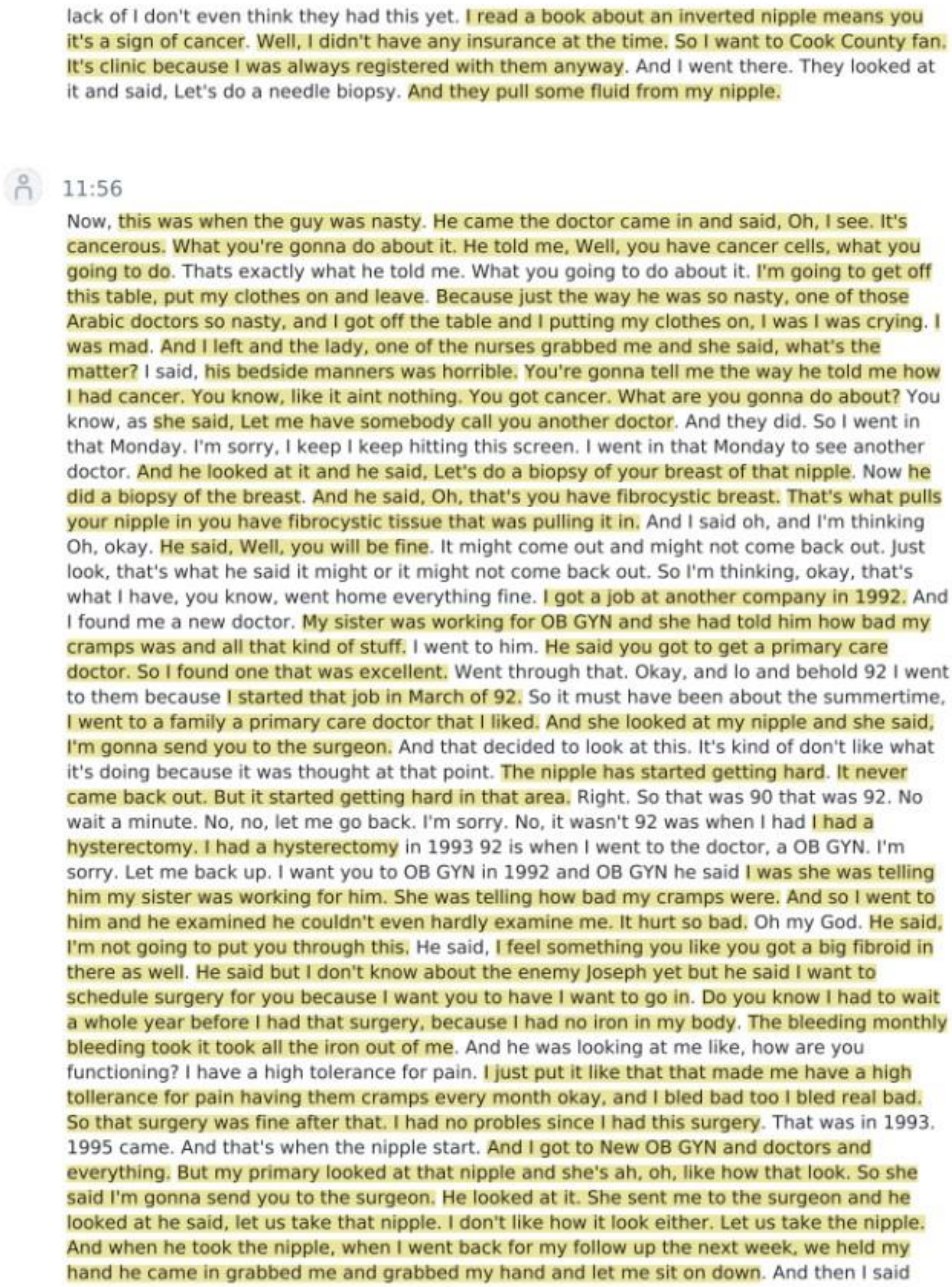
Jewell Stewart Lay, layj04@udayton.edu, Phone Number:314-560-2231

Dr. Davin Carr-Chellman, dcarrchellman1@udayton.edu, Phone Number: 937-229-4934

If you feel you have been treated unfairly, or you have questions regarding your rights as a research participant, please email IRB@udayton.edu or call (937) 229-3515

APPENDIX E

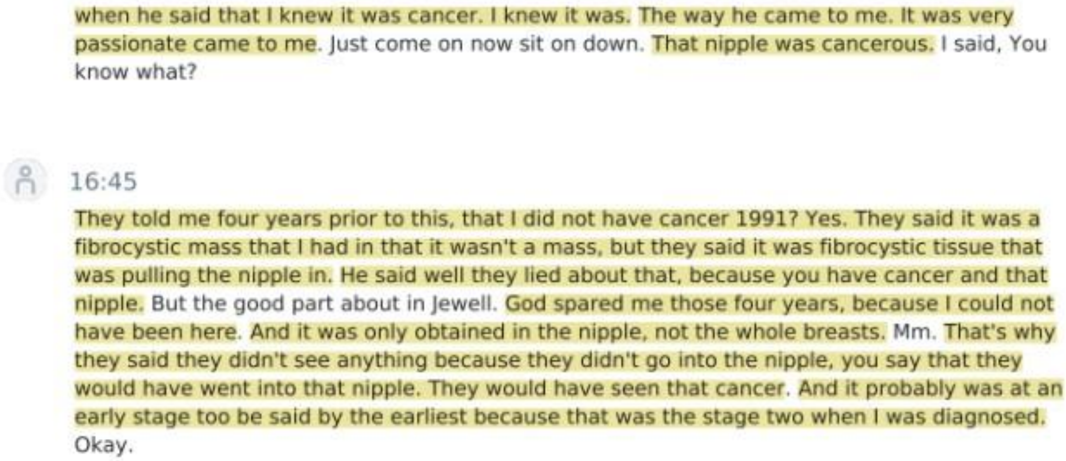
CODING EXAMPLE



lack of I don't even think they had this yet. I read a book about an inverted nipple means you it's a sign of cancer. Well, I didn't have any insurance at the time. So I want to Cook County fan. It's clinic because I was always registered with them anyway. And I went there. They looked at it and said, Let's do a needle biopsy. And they pull some fluid from my nipple.

11:56

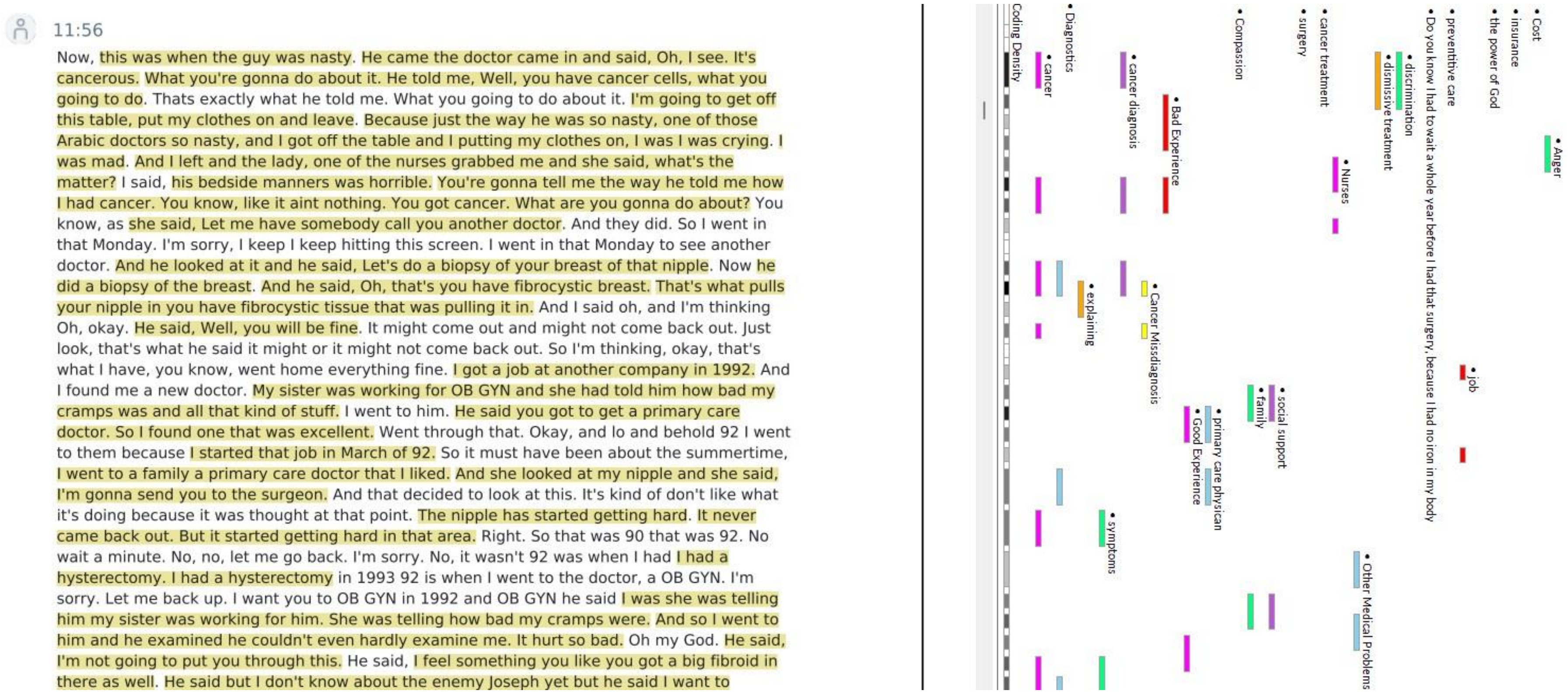
Now, this was when the guy was nasty. He came the doctor came in and said, Oh, I see. It's cancerous. What you're gonna do about it. He told me, Well, you have cancer cells, what you going to do. Thats exactly what he told me. What you going to do about it. I'm going to get off this table, put my clothes on and leave. Because just the way he was so nasty, one of those Arabic doctors so nasty, and I got off the table and I putting my clothes on, I was I was crying. I was mad. And I left and the lady, one of the nurses grabbed me and she said, what's the matter? I said, his bedside manners was horrible. You're gonna tell me the way he told me how I had cancer. You know, like it aint nothing. You got cancer. What are you gonna do about? You know, as she said, Let me have somebody call you another doctor. And they did. So I went in that Monday. I'm sorry, I keep I keep hitting this screen. I went in that Monday to see another doctor. And he looked at it and he said, Let's do a biopsy of your breast of that nipple. Now he did a biopsy of the breast. And he said, Oh, that's you have fibrocystic breast. That's what pulls your nipple in you have fibrocystic tissue that was pulling it in. And I said oh, and I'm thinking Oh, okay. He said, Well, you will be fine. It might come out and might not come back out. Just look, that's what he said it might or it might not come back out. So I'm thinking, okay, that's what I have, you know, went home everything fine. I got a job at another company in 1992. And I found me a new doctor. My sister was working for OB GYN and she had told him how bad my cramps was and all that kind of stuff. I went to him. He said you got to get a primary care doctor. So I found one that was excellent. Went through that. Okay, and lo and behold 92 I went to them because I started that job in March of 92. So it must have been about the summertime, I went to a family a primary care doctor that I liked. And she looked at my nipple and she said, I'm gonna send you to the surgeon. And that decided to look at this. It's kind of don't like what it's doing because it was thought at that point. The nipple has started getting hard. It never came back out. But it started getting hard in that area. Right. So that was 90 that was 92. No wait a minute. No, no, let me go back. I'm sorry. No, it wasn't 92 was when I had I had a hysterectomy. I had a hysterectomy in 1993 92 is when I went to the doctor, a OB GYN. I'm sorry. Let me back up. I want you to OB GYN in 1992 and OB GYN he said I was she was telling him my sister was working for him. She was telling how bad my cramps were. And so I went to him and he examined he couldn't even hardly examine me. It hurt so bad. Oh my God. He said, I'm not going to put you through this. He said, I feel something you like you got a big fibroid in there as well. He said but I don't know about the enemy Joseph yet but he said I want to schedule surgery for you because I want you to have I want to go in. Do you know I had to wait a whole year before I had that surgery, because I had no iron in my body. The bleeding monthly bleeding took it took all the iron out of me. And he was looking at me like, how are you functioning? I have a high tolerance for pain. I just put it like that that made me have a high tollerance for pain having them cramps every month okay, and I bled bad too I bled real bad. So that surgery was fine after that. I had no probles since I had this surgery. That was in 1993. 1995 came. And that's when the nipple start. And I got to New OB GYN and doctors and everything. But my primary looked at that nipple and she's ah, oh, like how that look. So she said I'm gonna send you to the surgeon. He looked at it. She sent me to the surgeon and he looked at he said, let us take that nipple. I don't like how it look either. Let us take the nipple. And when he took the nipple, when I went back for my follow up the next week, we held my hand he came in grabbed me and grabbed my hand and let me sit on down. And then I said



when he said that I knew it was cancer. I knew it was. The way he came to me. It was very passionate came to me. Just come on now sit on down. That nipple was cancerous. I said, You know what?

16:45

They told me four years prior to this, that I did not have cancer 1991? Yes. They said it was a fibrocystic mass that I had in that it wasn't a mass, but they said it was fibrocystic tissue that was pulling the nipple in. He said well they lied about that, because you have cancer and that nipple. But the good part about in Jewell. God spared me those four years, because I could not have been here. And it was only obtained in the nipple, not the whole breasts. Mm. That's why they said they didn't see anything because they didn't go into the nipple, you say that they would have went into that nipple. They would have seen that cancer. And it probably was at an early stage too be said by the earliest because that was the stage two when I was diagnosed. Okay.



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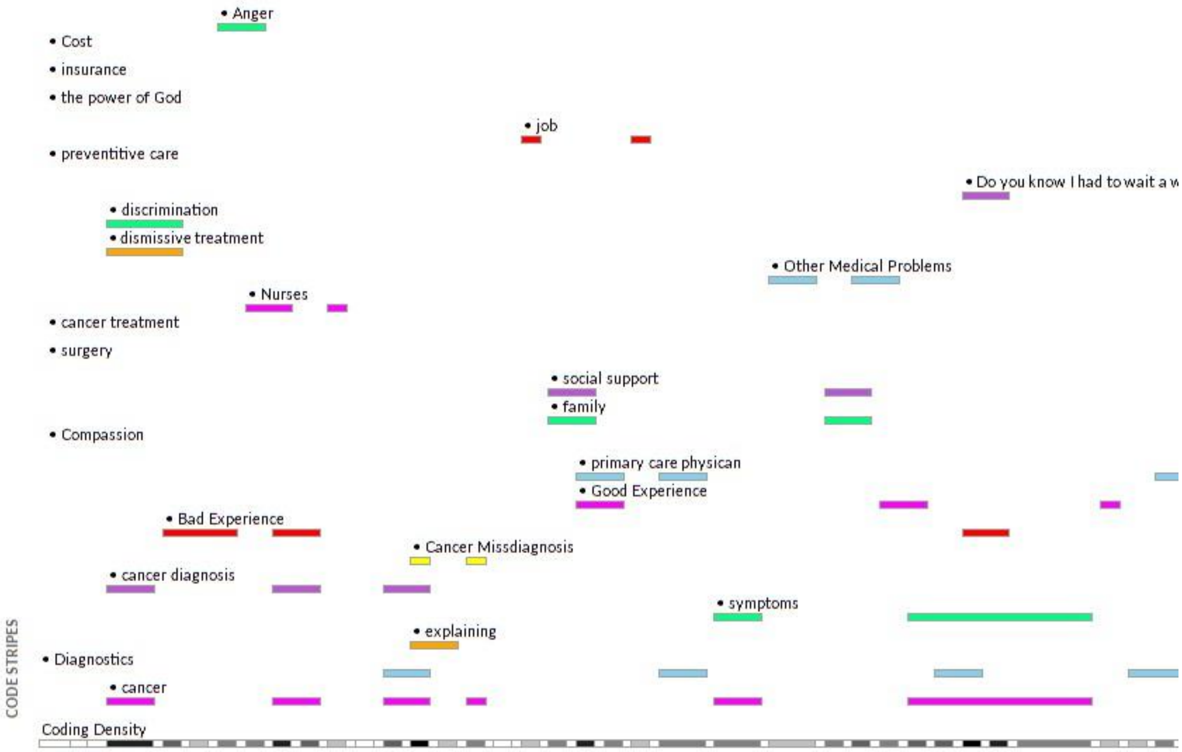
• Anger
• Cost
• insurance
• the power of God
• job
• preventitive care
• Do you know I had to wait a w
• discrimination
• dismissive treatment
• Other Medical Problems
• Nurses
• cancer treatment
• surgery
• social support
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• primary care physican
• Good Experience
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• Cancer Missdiagnosis
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• symptoms
• explaining
• Diagnostics
• cancer
CODE STRIPES
Coding Density

APPENDIX F

EXAMPLE CODE HIREARCHY