Published in final edited form as:
Fam Community Health. 2020 ; 43(3): 200–212. doi:10.1097/FCH.0000000000000264.

Racial differences in the influence of healthcare system factors on informal support for cancer care among Black and White breast and lung cancer survivors.

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Abstract

This retrospective, secondary qualitative analysis investigates whether health system factors influence social support among Black and White breast and lung cancer survivors and racial differences in support. These data come from race- and cancer-stratified focus groups (n=6) and interviews (n=2) to inform a randomized controlled trial utilizing anti-racism and community-based participatory research approaches. Findings indicate social support was helpful for overcoming treatment-related challenges, including symptom management and patient-provider communication; racial differences in support needs and provision were noted. Resources within individual support networks reflect broader socio-structural factors. Reliance on family/friends to fill gaps in cancer care may exacerbate racial disparities.

Keywords

cancer care; social support; institutional racism; racial health disparities; community-based participatory research

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Introduction

Racial disparities in cancer-related outcomes persist across the cancer care continuum.[1–6] Among breast and lung cancer patients, specifically, there is evidence of pronounced disparities at all stages of care. Racial differences in follow-up after abnormal screening and later stages at diagnosis contribute to worse breast cancer outcomes among Black women compared to White women.[7,8] Following a lung cancer diagnosis, Blacks are less likely than Whites to receive curative-intent surgery. In addition, the five-year survival rate for lung cancer is lower in Blacks than in Whites (14% vs 18%), and Black men have the highest lung cancer mortality rate among racial or ethnic groups.[6] Emerging data also indicate that racial disparities exist in cancer survivorship[9]: this includes poorer physical[10,11] and financial health,[12] and lower rates of post-treatment surveillance[13] among Blacks and other populations of color. In short, enduring racial disparities in cancer care highlight a need to take action more broadly about where we intervene and evaluate more critically our approach to doing so.

One abiding aspect of cancer care is the involvement of a patient’s informal social network, i.e., their family members and friends.[14,15] Functional characteristics of these networks, generally referred to as social support (often categorized as emotional, instrumental, appraisal, and informational support), have been shown to positively influence cancer outcomes from prevention to survivorship.[16–19] Structurally, the number of contacts (i.e., range) a patient has and the connections between those contacts can influence the availability of resources and support.[20,21] Interactional characteristics - such as emotional closeness between patients and their support networks, the frequency of their interactions, and the homogeneity of social attributes (e.g., education and income) - can also contribute the type of support available.[22–24]

It is important to situate the ability of family and friends to support a patient with cancer within the proper context. Racism at the macro-level factor can influence functional, structural, and interactional characteristics of support networks.[25] For example, research has shown that populations of color are more likely to experience cancer-related financial problems,[12] including increased vulnerability to financial decline, more financial hardships, and higher financial stress as a result of cancer.[26,27] These challenges - which mirror income and wealth inequalities in the United States tied to generations of racist policies and practices[28,29] - can influence the ability of support networks to provide financial assistance to individuals undergoing cancer care. Ongoing racism linked to inequities in education and career opportunities also contribute to a lack of racial diversity in the medical profession and in cancer care[30,31] potentially limiting patient access to a racially diverse medical workforce at their care institutions and within their support networks. Patient-and-family centered care initiatives to enhance the wellbeing of both patients and family members are becoming more widespread.[32–34] However, few studies have examined relationships between patient/family care and cancer disparities.[35,36]

When considering the causes of racial disparities in cancer care, it is also vital to consider institutional racism.[37,38] Institutional racism is less visible than individual acts of racism, i.e., racial bias or prejudice that can manifest itself as race-based assumptions about others and can lead to differential action towards others based on race.[37] Examples of these individual acts of racism in everyday life include devaluation of knowledge or competence of certain groups, poor service provision in the marketplace, and rude or disrespectful communication based on race.[37] Institutional racism, on the other hand, functions as “the structures, policies, practices and norms resulting in differential access to goods, services and opportunities of society by ‘race’”.[39(p10)] Examples of institutional racism in cancer care include inadequate familiarity and attention to cultural beliefs and practices[40] and racial differences in the receipt of standard[41,42] and supportive care.[43] System changes that improve access and delivery of healthcare can make substantial strides toward reducing health disparities.[44,45] Thus, where racial differences in patient/family experiences exist, implementing system-level changes may be the most effective approach.

The purpose of this qualitative study is to examine the relationship between social support and the cancer care experiences of Black and White breast and lung cancer survivors using anti-racism and community-based participatory research approaches. Our main study questions are as follows: What are the patterns of support by family and friends for cancer care and are there noticeable differences by race? Given the increased focus on family wellbeing, how do survivors describe support provided to family members and are racial differences observed? To what extent do family and friend support reflect racial differences in cancer care experienced by patients and survivors? Attention to these issues can highlight opportunities for system-level changes to improve the quality and equity of patient and family-centered cancer care.

Materials and Methods

We conducted a secondary analysis of qualitative data[46] collected through six focus groups and two interviews during the formative stage of the Accountability for Cancer Care through Undoing Racism and Equity (ACCURE) study. ACCURE’s intervention focused on narrowing noted Black-White disparities in treatment completion for stages I-II breast and lung cancer. Despite differences in trajectories of disease and care needs for these two cancer sites, key similarities are that inequities in treatment for early-stage breast and lung cancer have persisted for decades and standard milestones in treatment exist[47]; consequently, efforts to improve equity in treatment provision could mitigate the influence of treatment disparities on racial disparities in survival.[48,49] The Undoing Racism® framework[50] provided the conceptual foundation for addressing structural factors that obstruct patient engagement in cancer care and ultimately, contribute to racial disparities in treatment completion. This anti-racist framework[51] is grounded in evidence that powerful systems with historically traceable roots exist around the world. These influential systems exert their power on institutions, policies and practices in ways that systematically privilege some and disadvantage others. This approach contends, however, that if/when people are informed about how they benefit from or are hurt by these systems, they can contribute to dismantling and improving these systems. The ACCURE intervention focused on addressing two key principles from the Undoing Racism® framework—transparency and accountability. Barriers to transparency include narrow knowledge, a consequence of training oncology health professionals to play specialized roles and work in silos within specialty units.[52,53]

Barriers to accountability include fragmented power within healthcare systems that inhibits the ability of care providers to introduce system-wide changes.[52,53]

The Undoing Racism® framework was integrated into the study in several ways.[47,54] The design and primary analysis of the formative focus groups and interviews were informed by this framework. This qualitative research was helpful for uncovering issues with transparency and accountability to be addressed in the intervention (see Data Collection section below). Four system-level intervention components were designed to enhance transparency and accountability at the two cancer sites. First, a nurse navigator was trained at each cancer center to use a racial equity lens in their interactions with Black and White cancer patients. Second, a real-time registry linked to patient electronic medical records and appointment data signaled the nurse navigator of patient deviations from standards of care (e.g., missed appointments, unmet treatment milestones). Third, the registry allowed the ACCURE team to aggregate provider-level and practice-level data. Summaries of these data were included in clinical performance reports that were delivered quarterly to physicians by designated ACCURE physician champions. Furthermore, these reports allowed physicians to compare their race-stratified care quality metrics to practice averages. Fourth, quarterly Healthcare Equity Education and Training (HEET) sessions were held at the two cancer center sites. The HEET sessions were adapted from the Undoing Racism® two-day workshop. Eight HEET sessions delivered over two years to medical and administrative staff at the cancer centers also included healthcare-specific content, including data and discussion on health outcomes for black and white lung and breast cancer patients at the cancer sites. The focus groups and interviews were conducted May – September 2013 and informed the Healthcare Equity Education and Training (2014–2016) and nurse navigation (2013–2015) components of the ACCURE intervention.

The Greensboro Health Disparities Collaborative (GHDC) led the design and testing of the ACCURE intervention. GHDC is a 17-year old community-academic-medical partnership founded on principles of anti-racism and community-based participatory research (CBPR).[55,56] Its mission is to advocate for and implement system change to decrease racial disparities in health. ACCURE's Steering Committee included: GHDC members; academic researchers from the University of North Carolina at Chapel Hill and the University of Pittsburgh; The Partnership Project, a nonprofit organization affiliated with GHDC that hosts anti-racism trainings in Guilford County, North Carolina; and providers and staff from two participating cancer centers.

Focus groups and interviews were conducted with Black and White early stage breast and lung cancer patients. The purpose was to determine points along a patient's journey through the cancer care system when patients encountered barriers or facilitators to care quality and to treatment completion, and to determine whether these encounters differed by race. Primary focus group findings highlighted a need for improved communication to increase transparency in care protocols, an opportunity for patient-centered solutions to enhance accountability of the care system to patient needs, and implicit Black-White differences in cancer care.[57] Our previous analyses did not include an in-depth examination of support network involvement as reported here.

Participants and Recruitment

A purposive sample of Black and White breast and lung cancer survivors were recruited at two cancer centers based at a regional hospital and at a university teaching hospital. At study initiation, there were noted racial disparities in cancer health outcomes in the two geographic locations, with higher cancer mortality among Blacks compared to Whites.[58,59] Specifically, in the 5 years prior to the study initiation (January 2007 - December 2012), 79.8% of Black patients vs. 87.3% of White patients completed treatment ($p<.0001$) for stages I and II breast cancer or non-small cell lung cancer.[47] Cancer survivors were eligible to participate in the focus groups and interviews if they: 1) were diagnosed with stage I or II breast cancer (women only) or diagnosed with stage I or II lung cancer (men or women); 2) received cancer care at one of the two cancer centers; and 3) completed treatment in the previous 12 months. Participant incentives included a $20 gift card. The Institutional Review Boards at each institution approved the study.

Data Collection

ACCURE conducted four focus groups and interviews by race and type of cancer at each of the cancer centers between April and September 2013 (Black breast cancer, White breast cancer, Black lung cancer, White lung cancer). The purpose of this stratification was to uncover similarities and differences by race, given expected similarities in treatment protocols by cancer type. The original study design called only for focus groups; however, lack of planned participation at scheduled sessions required us to conduct interviews with a single survivor on two occasions (a White lung cancer survivor and a Black lung cancer survivor). In total, focus groups (n=6) and interviews (n=2) were conducted with 12 Black survivors (n=8 breast; n=4 lung) and 15 White survivors (n=9 breast; n=6 lung). The range of participants in the focus group was 3–5. Prior to the discussion, participants provided informed consent. A person of color (African-Japanese American) facilitated the Black focus groups and interviews, while the White facilitator served as the note taker; the roles were reversed for the White groups and interviews. Details on the CBPR-grounded data collection and analysis used in this study have been reported elsewhere.[57,60]

The interview guides were informed by findings of a previous study – Cancer Care and Racial Equity Study (CCARES) led by the GHDC - and the Undoing Racism® framework. The CCARES study[55,61] reviewed two years of data from a breast cancer registry at a local cancer center to investigate treatment delivery to 853 early-stage breast cancer patients. From the registry, a sub-sample (n=50) black (46%) and white (54%) patients were randomly selected to complete two interviews. During these interviews, patients identified *critical incidents* that had a significant positive or negative impact on their cancer care experience. CCARES findings revealed shortcomings of cancer registry data for recording who and how patients delayed or discontinued their breast cancer care. The CCARES interview findings identified subtle but important racial differences on the impact from patient encounters with the various systems of care. Implications from CCARES findings pointed toward a need for prospective studies that record patient encounters with the various systems of cancer care during treatment to identify systemic causes for less than optimal care for African Americans. This led to the development of the parent study, ACCURE.

The focus groups and interviews were part of an *analysis of power and authority*, a diagnostic tool of the Undoing Racism® framework. An analysis of power and authority aims to uncover the origins and pathways of systems of power that perpetuate racial inequities. Based on this work, we developed our discussion guide to elicit conversations of participant experiences with the following the key systemic barriers of transparency and accountability. We also developed the guide to elicit *pressure point* encounters,[62] conceptualized as encounters during the cancer care journey when patients felt encouraged (or discouraged) to continue their treatment or empowered (or disempowered) by the treatment process, with the ultimate goal of uncovering experiences during treatment that undermine transparency and accountability for quality and completion of care. The guide was developed by a committee of community members, academics and clinicians within the Greensboro Health Disparities Collaborative.

We pilot tested the interview guide with five volunteer breast cancer survivors from Sisters Network Greensboro, NC, the local chapter of the national Sisters Network® Inc. organization. After modifications, the final interview guide (see Appendix A) included questions on the choice of treatment center, treatment decision-making participant interactions with healthcare staff and providers, experiences that participants attributed to their race, and suggestions for improvement of the care system. The discussions were audio recorded and transcribed verbatim, with unique identifiers for each participant to ensure anonymity.

Data Analysis

We analyzed the data using directed content analysis. This process is appropriate for exploring qualitative data where prior research exists, but further exploration is warranted.[63] Two key features of directed content analysis are to begin coding with predetermined codes and then determine whether data that cannot be coded represent a new category or subcategory of an existing code.[63] The final codebook for this study modified the codebook used a the prior analysis.[57,60] We made modifications to the original codebook based on the support network focus of the current analysis. Specifically, we incorporated codes that captured the role of informal support throughout the cancer journey, social support provided by network members, network member health history, and the impact of the survivor’s cancer journey on network members (and vice versa). As the analyses progressed, we developed new codes or sub-codes to capture relevant data that were not adequately represented in the predetermined codebook.

The community and academic partners who conducted data analysis completed extensive qualitative training to prepare them for this work.[60] In brief, the GHDC convened a Coding Coordinating Committee (CCT), which led and designed a process by which academic and community partners were involved in coding and interpreting data. The CCT provided training on the process and goals of the qualitative analysis. This training included information regarding types of coding, differences between methods of coding, methods for assigning codes to qualitative texts, and identifying and interpreting themes. The current manuscript represents the second qualitative manuscript that has been written with community and academic partners from GHDC using this process. The coding and interpretation process was reviewed with individuals involved in this qualitative analysis prior to the start of the current analysis.

We took a number of steps to enhance the rigor of this work.[64] To enhance confirmability, coders were intentionally organized into mixed race, community-academic coding pairs, allowing for examination of personal biases in coding and interpreting data. In addition, the coding pairs responded to guided questions to enhance their reflexivity during the analysis process. To ensure credibility, community-academic pairs submitted their coded texts to the lead author, who entered them into the qualitative software package, Atlas.ti, 7.5.12.[65] The lead author reviewed the code reports generated through Atlas.ti, noted commonalities in text segments, aggregated commonalities to form a broad idea,[66] and then convened the coding pairs to identify emergent themes, subthemes, and representative quotes. Initial drafts of findings were also reviewed, edited and critiqued by the community and academic coauthors and presented during a monthly GHDC meeting for feedback on interpretations, themes, and implications. To ensure the dependability of these data, we recorded the decision-making process for developing the codebook, the coding process of teams, and the development of themes. To ensure transferability, we aimed to provide a description of the experiences of participants at distinct phases of the cancer journey.

Our findings highlight observed similarities and differences by racial group because the investigation of racial differences in cancer survivor experiences and perspectives was a key component of the study design. Thematic differences by cancer site were not detected, thus we do not present comparisons of findings by site. Selected quotes reflect the diversity of experiences and perspectives of cancer survivors that emerged from these data.

Results

During the focus groups and interviews, survivors discussed support network involvement at each point of their cancer journey, from pre-diagnosis (e.g., screening and abnormality detection) through follow-up care. The range of network members described included family (as a broad term), spouses and partners, parents, children, siblings, aunts, uncles, friends, and church members. Four major themes related to apparent racial differences that emerged from our analysis are described below.

Theme 1: Black and White survivors appear to have similarities and differences in social support involvement in cancer care

Both Black and White participants spoke about how social support, particularly from family members, enhanced their emotional health during or immediately after medical visits and improved patient-provider communication. Support network members accompanied Black and White participants to medical visits where they received information about their cancer prognosis and treatment options. The presence of family and friends at medical visits helped participants address the emotional and communication challenges involved with receiving a serious health diagnosis. However, there appeared to be racial differences in both the range of support network members mentioned by participants, and the degree to which participants relied on this network in the context of their medical care.

Compared to White participants, Blacks participants engaged in more extensive discussions of social support. Black participants also described a greater number of members in their support networks and a greater variety in the types of relationships that provided them with social support throughout their cancer journeys. Black participants were more likely to mention communicating with extended family, members of their church, and adult children, in particular. For example, a Black lung cancer survivor—who had overcome a previous cancer diagnosis—described feeling shock and disbelief, and "falling apart" immediately after leaving the doctor's visit where she received her diagnosis:

> "[I thought] if I could just get away somewhere. If I could go to another planet this would go away, because this is just too much…my daughter told me, she said, 'Mommy, you are gonna either live and fight or you are gonna die and then you gonna be by yourself. And you let me know what you wanna do.' I went on in the house. I went through my emotional breakdown. I [listened to gospel music]. At the end…I feel like goin' on."

Though her first inclination was to "run away" from the experience, support from her adult daughter, who accompanied her to the visit, as well as spiritual upliftment, encouraged her to move forward with her treatment.

Support network involvement in medical visits often improved cancer care experiences, especially patient-provider communication. White participants provided examples when network members (often spouses) asked questions, clarified information presented by health professionals, and engaged in discussions with providers in ways perceived as helpful. For example, a White breast cancer survivor indicated that her mother's presence at her chemotherapy treatments after a bad experience helped her make pleasant connections with the health professionals:

> "So, the nurse who administered my chemo after the first one that was a bad experience, somehow we connected. I don't know how—I don't know! Somehow just every time I came for chemo, my mother would come with me. So, my mother was very social, so maybe that was part of it."

Family member assistance with enhancing patient-provider communication was widely reported among Black participants. For example, when a Black breast cancer survivor was discouraged by interactions with her cancer care provider, intervention by her adult son improved communication with her provider:

> "I had my son come, and my son came, and he went in and talked to the doctor, and uh…explained to him the type of person I am, and that, and I have to say he changed…it's been a year…I have to say he's different now. You know, if [the doctor's] more concerned, he will stand there for a minute now and talk."

The survivor had been dissatisfied with the physician's listening skills and lack of concern for her wellbeing. This changed after her son travelled from out of state to meet with the physician.

Theme 2: Black and White survivors discussed differences in support for managing treatment side effects.

Support network members played a key role in helping participants manage cancer treatment challenges. Challenges included managing treatment side effects when assistance by the cancer care system was inadequate, as well as wanting to discontinue treatment. Participants also discussed their reliance on support when connections with providers stopped abruptly at the end of treatment. Both Black and White participants described a need for better education about cancer treatment side effects.

Black participants' discussion focused primarily on using their support networks for information about treatment challenges (e.g., how to manage symptoms), and White participants described greater engagement with information from healthcare systems about treatment-related challenges and side effects. For example, White participants discussed attending educational classes at their institution with members of their support network. As a White lung cancer survivor explained:

> "…the introductory things that they do at the cancer center…again your family's involved. [Facilitator: 'What are the introductory things?'] Well, we went over there one day for about an hour and the lady took us through what was gonna happen, you know, talked about the various treatments, what could happen [with side effects]…"

While to a lesser extent than Black participants, White participants also discussed gaps in information about side effects. For example, a White breast cancer survivor shared:

> "I wish someone had talked to me after the surgery. I could not get out of bed. My husband could not help. I would have liked to know. I had to borrow front closing shirts. I wish I had heard about what would happen after."

A Black lung cancer survivor considered discontinuing treatment after difficulties with side effects, and mentioned a friend in a similar situation:

> "It has been a problem for me…the side effects…that's when I was thinking about quittin' cause another guy, one of my friends, he was talking about stopping and he had [colon cancer surgery]…side effects is hard."

Black participants also discussed learning about side effects from members of their support network as opposed to from healthcare providers. Another Black lung cancer survivor who considered ending his cancer treatment described learning about side effects from friends, which helped him know what to expect, and decreased the negative impact of side effects on his cancer experience.

Participants identified the survivorship phase as especially challenging because attention from medical professionals decreases dramatically after treatment (e.g., surgery, chemotherapy, radiation). A White breast cancer survivor agreed with another participant regarding the importance of a good family support system, sharing that "When treatments end, the support ends…that's when you process it." Though discussed less extensively in the focus groups and interviews, when compared to other phases of cancer care, informal support was helpful during this transition. There was little discussion in the focus groups and interviews about collaboration between the healthcare system, survivors, and personal support to prepare patients for transition from active treatment to maintenance care.

Theme 3: Black and White survivors and their support networks appear to have similarities and differences in psychosocial support from the cancer care system.

The impact of cancer on the survivors' support networks—most significantly family members —was often inadequately addressed by the cancer care system. Survivors described economic consequences and emotional distress for their support network. Economic challenges were conspicuous among Black survivors and their challenges impacted others. A Black survivor shared that she lost her home and job after her lung cancer diagnosis. As a result, she moved in with one of her adult children; other children who had been living with this survivor ended up in alternate housing. Though this was her second cancer diagnosis, she was unaware of care navigator services at the cancer center. Another Black breast cancer survivor moved in with a friend during cancer treatment when she was evicted from her home and had no income. When assistance from a social worker was not helpful, her oncologist intervened to help her secure support:

> "I couldn't get in contact with the social worker from here when I was doing my chemo. I didn't have no income coming in, and they had put me out from where I lived…I was homeless. [The social worker] was saying she can't help me…and never returned my calls until the doctor got on her…My girlfriend opened her arms to me and I was staying there with her."

Black and White participants described emotional distress among family members, especially when first receiving the diagnosis. Participants discussed providing support to family members grappling with emotional challenges of the cancer diagnosis; however, attention to these challenges by the cancer care system varied. A Black breast cancer survivor shared her husband's emotional distress during a delay between diagnosis and education about treatment:

> "It was a little disappointing because I got the diagnosis on a Friday. So I had to wait until Wednesday to find out the specifics, the extent of it, you know where it was. So that was a little frustrating. And then it really taxed my husband…matter fact when we got in the car he was crying."

When the doctor of a Black breast cancer survivor noticed that she was often alone during medical visits, the patient shared that her family could not provide support due to their struggle with her cancer diagnosis. She chose to limit their involvement in her care:

> "My doctor was like, 'Why you're always here by yourself?' I said, 'Because I feel better by myself.' You know, my family…everybody was such a mess, and I just didn't like them discouraging me in any way…I didn't want any of them with me 'cause I didn't, I was going through enough things on my own without going through their pain too."

She did not indicate whether the cancer care system offered support to her family members. In contrast, White participants described assistance for family members from their cancer care institutions, whether the assistance was welcomed or not. A White breast cancer survivor described a helpful encounter that her husband had with medical providers:

> "He was very kind to my family. He was extremely kind to my husband, who really needed somebody to sit down and talk to him. And he did, and my son, also."

Another White lung cancer survivor, who served as a primary caregiver for his wife, described his frustration with receiving unsolicited home assistance and his lack of satisfaction with the services provided.

Theme 4: Blacks and White survivors discussed differences in professional healthcare experience among their support networks.

Access to family and friends with healthcare experience (e.g., physicians, oncologists, nurses), and personal connections with cancer care providers, had a positive impact on participants. Patients felt more prepared and more confident in both treatment decision-making, and the quality of care provided. White participants were more likely than Black participants to report having network members with professional medical experience to call on for advice and support. For example, the spouse of a White lung cancer survivor, a nurse, helped the survivor recognize serious symptoms and seek care that led to his cancer diagnosis. She also helped him make treatment decisions. He also described her assistance with understanding medical vocabulary used by health professionals:

> "My wife is fairly forceful…She was my interpreter…I'm married to a medical person and it helps, you know, 'cause, you know, when you go through this thing, you learn a whole new language."

Another White breast cancer survivor shared that the medical experience of her support network was helpful and affected her attitude toward treatment:

> "I was married to an oncologist, so I had a little bit of a head start in terms of knowledge of breast cancer and the curability of breast cancer, so that gave me a very positive attitude."

In some cases, participants described that the availability of support from family and friends with medical knowledge and expertise decreased their need for supportive services from their care institution.

Discussion

Our study identified racial differences in key social support characteristics during cancer care, including patient-provider communication, access to information about symptom management and treatment options, comprehension of medical jargon, and need for emotional and psychosocial support. We also observed racial differences in healthcare support for the families of patients receiving cancer care. Overall, our findings suggest that improvements to cancer care could enhance cancer patients' experiences and lessen the burden placed on their family members and friends.

Advances in medical treatments, as well as and increased costs, have led to more outpatient cancer care; consequently, patients have a greater need for social support during treatment and recovery.[15,67] Though patients' family members and friends have long provided support beyond what the medical system traditionally provides, firmly establishing where social support from people outside the care system should begin can be challenging. Institutional policies that clarify the support that is reasonable to expect from social support networks, as well as the rights of individuals who serve in caregiving capacities, could increase transparency and accountability in this area. However, racial differences in support availability have to be taken into account. For example, caregiving research indicates that Black caregivers tend to have lower socioeconomic status[68,69] and perform more caregiving tasks than White caregivers.[70] Given the known differences in access to resources and opportunities by race,[71–73] the use of support networks to fill gaps in cancer care could perpetuate health disparities.

Black and White survivors identified deficiencies in symptom management support from cancer care systems, for which support networks proved helpful. Survivors received social support for side effects and symptom management, including information about how to manage symptoms. While assistance from family and friends is often supported by cancer care systems and patients themselves,[74,75] our findings suggest that more information and support from the healthcare system about symptoms would be helpful to survivors—and optimize support provided by family and friends. Support networks also helped to improve the transparency of cancer care, but key racial differences emerged. For example, these data suggested that White survivors had greater access to family and friends with medical experience and White survivors were more likely to discuss how members of their support network clarified medical jargon during appointments. Other research has noted racial differences in support network involvement during care interactions: Black patients are less likely to have a companion during medical visits, which potentially contributes to asking less questions during the interaction.[76] Thus, while there needs to be institutional-level changes to improve access to information about symptoms and side effects, other factors to consider are barriers and facilitators to social support availability.

As observed in our study, patient access to treatment information beyond what is provided by the cancer care institution influenced treatment-related decision-making. Research suggests that individual "choice" or decision-making should not be divorced from social contexts in which choices are made.[77] In this vein, the care and support patients receive from their support networks are key aspects of their social context. Although White survivors described a smaller number of support network members, they benefited from members who had medical backgrounds. Conversely, though Black survivors discussed receiving informal support from various people, they were less likely to discuss individuals with formal medical expertise. This difference could be, in part, a factor of norms and preferences at the individual level regarding help-seeking. Previous research suggests these differences in help-seeking may be observed by race/ethnicity,[78–81] gender and age,[82,83] and composition of the support network.[84] More broadly, differences in patient ability to leverage support network resources to increase access to medical expertise are likely influenced by known racial disparities in socioeconomic attainment,[85,86] and the lack of racial diversity in medical professions.[87,88] This underscores the need for cancer care institutions to employ more people of color and to provide comprehensive and relevant treatment information during the patient decision-making processes.

Another key finding was that Black cancer survivors in our study, and members of their families, experienced unmet needs in emotional and financial support during cancer care. Routine and culturally appropriate psychosocial and mental health assessments,[89,90] and an understanding of broader unmet social needs,[91,92] could help to better identify patients and loved ones who need support for grief, economic issues, and emotional distress—and increase accountability for addressing these issues. A primary benefit of building psychosocial assessments into cancer care is the ability to proactively assess needs and proactively connect people to resources within and outside the healthcare system, with the goal to decrease barriers to complete and timely treatment. Unfortunately, these assessments are not routinely conducted at cancer centers with adult populations.[93] Meeting the psychosocial needs of the "family" is an important component of patient and family-centered care that is often overlooked.[94,95] Opportunities exist to improve the support provided to family and friends to manage their emotional distress and assist with patients' physical and psychosocial challenges. Research shows that the health of patients and caregivers are interdependent,[96–98] and that supporting caregivers of patients with cancer improves patient and caregiver outcomes.[99–102]

Encouragingly, programs and interventions integrating multidisciplinary, medical and non-medical staff, such as social workers, undergraduate students, and legal professionals to help families tackle unmet social needs are getting increased attention.[32,103] In many cases, a social worker, or another healthcare team member, conducts an initial assessment and refers the patient or family member for services.[104] In one model, trained undergraduate students follow-up with patients and families in-person and over the phone, connecting them to resources related to housing, food insecurity, and other concerns.[105] In medical-legal partnerships, lawyers help patients address legal issues that affect their health, such as working with landlords to secure better quality housing.[106] Positive results have also been found in interventions involving navigators (e.g., nurse navigators, patient navigators) to help patients and families overcome barriers to care. Thus, while literature is scant on how addressing unmet social needs impacts cancer outcomes,[107,108] evidence does indicate that unmet needs are linked to poor mental and physical health[109–112] and addressing them leads to increased patient satisfaction.[113,114]

Lastly, it is critical to interpret these findings and implications within the context of Black life in the United States. Blacks in the United States have historically been subjected to injustice and inequality in virtually every aspect of everyday life, including medical care.[29,115,116] Conversely, Whites in the United States have historically benefited from substantial levels of privilege in medical care and other arenas.[117,118] There is a strong tendency towards individualism in the United States (e.g., in medical care, in examinations of racism and privilege),[119–121] that make investigations of institutional racism in cancer care and its interaction with informal support networks quite challenging. This orientation hinders our ability to understand and examine the ways in which systemic racism in cancer care has impacted the collective wellbeing of these networks of support. Research has called attention to the influence of higher levels of mortality in Black families on intergenerational transmissions of health disadvantage.[122] Future research should aim to examine more closely how substandard treatment of Blacks in cancer contribute to intergenerational transmissions of disadvantage among their informal support networks, and whether system-level efforts to improve cancer care also benefit the health of these networks.

Limitations

Our findings are specific to the care systems at two cancer centers (a regional hospital and an academic medical center) and at the time of this report, these data were collected approximately six years ago. Study sites were selected because racial gaps in patient outcomes exhibited at these centers mirrored national cancer data. While our findings likely reflect the experiences of other breast and lung cancer patients, they are not completely generalizable to patients who have received care at other cancer centers and changes that may have occurred since the time of data collection. Additionally, the focus group discussion guide did not include direct questions regarding informal support networks. Though a considerable amount of data emerged on this topic without direct questioning and prompting, which appear to suggest similarities and differences across groups as noted, more pointed questions about family and friend support during the cancer journey could have elicited richer and more nuanced data. Next, in line with the design of the parent study,[47,60] we examined differences in Black/White experiences, and did not pursue an in-depth analysis of within group experiences among Black survivors or focus solely on suboptimal care among Blacks. In addition, lower than expected participation led to two individual interviews in place of two planned focus groups and focus groups with as few as three respondents. Consequently, data collection and interactions between focus group participants were not as extensive as anticipated. We did not collect data on services provided at the two cancer centers, which limits our ability to determine how variations in service offerings influenced study findings. We are also unable to report demographic data on the participants, limiting our ability to examine the findings with additional context. Lastly, we did not directly ask about the race or socioeconomic status of support networks. Future research that captures demographic information regarding the support network of patients would be beneficial in this regard. Despite these limitations, a strength of this research is our CBPR approach. Future research using a CBPR approach to address the challenges highlighted could lead to more applicable and sustainable programming for patients and families in cancer care.

Conclusions

Our findings suggest that institutional improvements in key aspects of cancer care can influence the need for and degree of network support. Moreover, racial differences in patient support reflect the strengths, resources, and limitations of support networks. Future research would benefit from discussions with support network members to learn how to enhance their supportive role. Further discussions with cancer patients that focus on social support may also be helpful to develop services or programs that support both patients and their networks. While our study focused on family and friend involvement, we cannot assume that all patients have access to informal support during their care. Intentional partnerships between cancer centers and community groups could improve support for all patients, but particularly those lacking informal support.

Patients naturally turn to their family members and friends for comfort and support after a cancer diagnosis. We gained several important insights into support network involvement in cancer care from cancer survivors in our study. First, more system-level approaches are needed to formally integrate informal social support into cancer care and give better attention to family members and friends in supportive roles. Second, the desire and need for social support may vary from patient to patient. Any system-level approach to enhance social support in cancer care needs to be flexible and responsive to the individual needs of the patient and the support network. Lastly, improved quality of care throughout the cancer journey could decrease racial variability in needed social support. Better care could also decrease variability in patient outcomes that reflect the unequal capacity of support networks to fill gaps in patient care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgements:

ACCURE was funded by the National Cancer Institute (1 R01 CA150980). Support to the first author was provided by the NCI funded Cancer Health Disparities Training Program (T32CA128582); the Center for Health Equity Research at the University of North Carolina at Chapel Hill; a grant from the National Institutes of Health (P30 AG015281); the Michigan Center for Urban African American Aging Research; and a grant from the National Heart, Lung, and Blood Institute to the University of Mississippi Medical Center (Grant #2R25HL126145 - MPIs Beech and Norris). The funding sources had no involvement in study design, data collection analysis or interpretation, article writing, or decision to submit.

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