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## ***'It's like you don't have a roadmap really': Using an antiracism framework to analyze patients' encounters in the cancer system***

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### **Abstract**

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**Background:** Cancer patients can experience healthcare system-related challenges during the course of their treatment. Yet, little is known about how these challenges might affect the quality and completion of cancer treatment for all patients, and particularly for patients of color. Accountability for Cancer Care through Undoing Racism and Equity is a multi-component, community-based participatory research intervention to reduce Black-White cancer care disparities. This formative work aimed to understand patients' cancer center experiences, explore racial differences in experiences, and inform systems-level interventions.

**Methods:** Twenty-seven breast and lung cancer patients at two cancer centers participated in focus groups, grouped by race and cancer type. Participants were asked about what they found empowering and disempowering regarding their cancer care experiences. The community-guided analysis used a racial equity approach to identify racial differences in care experiences.

**Results:** For Black *and* White patients, fear, uncertainty, and incomplete knowledge were disempowering; trust in providers and a sense of control were empowering. Although participants denied differential treatment due to race, analysis revealed implicit Black-White differences in care.

**Conclusions:** Most of the challenges participants faced were related to lack of transparency, such that improvements in communication, particularly two-way communication could greatly improve patients' interaction with the system. Pathways for accountability can also be built into a system that allows patients to find solutions for their problems with the system itself. Participants' insights suggest the need for patient-centered, systems-level interventions to improve care experiences and reduce disparities.

### Keywords

cancer health disparities; systems-level interventions; community-based participatory research; racial equity

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It is well documented that cancer patients can experience healthcare system-related challenges during the course of their treatment (Institute of Medicine 1999, 2008). Poor patient-physician communication and lack of emotional and instrumental support have been commonly reported by breast cancer patients (Carroll et al. 2010; Kranick et al. 2010; Roberts et al. 1994). Lung cancer patients have reported high levels of unmet physical, psychological, and informational supportive care needs (Li and Girgis 2006; Sanders et al. 2010). In addition, navigating cancer care across multiple providers and clinical settings have been noted as burdensome for cancer patients (Freeman and Rodriguez 2011).

Systems-level challenges warrant greater attention given racial/ethnic disparities in cancer care. Compared with White cancer patients, Black cancer patients are less likely to be diagnosed at early stages (Bradley, Given, and Roberts 2001; Howlader et al. 2013; DeSantis, Naishadham, and Jemal 2013), undergo guideline-concordant treatments (Samuel et al. 2014; Lathan, Neville, and Earle 2008; Keating et al. 2009), report trust and shared decision-making with providers (Siminoff, Graham, and Gordon 2006; Gordon et al. 2006), and receive palliative and supportive care (Cleeland et al. 1994; Payne, Medina, and Hampton 2003; Smith, Earle, and McCarthy 2009). Despite decades of documenting racial disparities in cancer survival, Black breast cancer patients continue to initiate treatment later

(Gorin et al. 2006) and be treated less completely than their White counterparts (Voti et al. 2006; Hershman et al. 2005; Bickell et al. 2006; Berry et al. 2009). Moreover, Black lung cancer patients are more likely than Whites to make a decision, either independently or mutually with their physicians, to not pursue surgical resection, which is the only reliable curative treatment (McCann et al. 2005; Farjah et al. 2009; Cykert et al. 2010). Reasons for racial variations in quality and completion of cancer care are not well conceptualized or documented, and they vary by type of condition, socio-demographic variables, economic factors, and various cultural preferences, attitudes, and reservoirs of knowledge about disease etiology, prevention, and treatment (Rimer 2000; Van Ryn and Burke 2000; Tejada et al. 2017; Haozous and Knobf 2013). Despite the clear need, interventions that address systems-level challenges to enhance equity, quality, and completion of cancer treatment are missing from cancer prevention and control research. This paper shares findings from formative work aimed to understand patients' cancer center experiences, explore racial differences in experiences, and inform systems-level interventions.

## Background

### Background on ACCURE Partnership and Intervention

To address this gap, our community-academic-medical partnership implemented and evaluated Accountability for Cancer Care through Undoing Racism and Equity (ACCURE), a systems-change intervention aimed at reducing race-specific gaps in treatment initiation and completion among early stage Black and White breast and lung cancer patients. Funded by the National Cancer Institute (NCI), ACCURE utilized a community-based participatory research approach (CBPR) (Schaal et al. 2016; Oh et al. 2016; Israel et al. 1998) with guidance and governance provided by the Greensboro Health Disparities Collaborative (GHDC), a 15-year old CBPR partnership of community, academic, and medical organizations. GHDC's mission is 'to establish structures and processes that respond to, and build the capacity of, communities and institutions in defining and resolving issues related to racial and ethnic disparities in health' (Schaal et al. 2016; Yonas et al. 2006; Yonas, Aronson, Coad, et al. 2013; Yonas, Aronson, Schaal, et al. 2013). GHDC is committed to using an antiracism approach informed by the Undoing Racism (UR)<sup>®</sup> framework (The People's Institute for Survival and Beyond 2015). All members of GHDC have completed a two-day antiracism training based on that model. The foundation of this training is to provide participants with a common understanding of antiracism language and to establish a lens for analyzing the structure of power in US institutions and systems. ACCURE, GHDC's second NCI-funded study, built on findings from prior research, the Cancer Care and Racial Equity Study (CCARES), which, using critical incident analysis, an innovative interviewing technique, with Black and White cancer survivors, identified systems-level gaps, such as lack of race-specific data related to treatment completion (Yonas, Aronson, Schaal, et al. 2013).

ACCURE was developed by the GHDC as an intervention to respond to the systems-level gaps identified in the literature and our CCARES research findings. ACCURE included four innovations with the goal of reducing gaps in treatment initiation and completion between Black and White cancer patients and tested the intervention in two cancer centers, one a

regional cancer center in the south and the second a large academic cancer center in the northeast. Innovations included, first, a nurse navigator, specially trained in utilizing a racial equity lens to work with Black and White breast and lung cancer patients to identify and address practical, emotional, and communication issues. The goal was for the navigator to serve as a two-way conduit between the patient and the cancer care system to address issues during the full continuum of care. Second, a real-time patient registry was developed to alert the navigator when patients did not reach timely treatment milestones (e.g., attending appointments, completing radiation treatments), allowing the navigator to address issues early enough to prevent compromises of quality and completion of care. The registry also aggregated provider-level and practice-level data, allowing clinicians to examine race-stratified care quality metrics (e.g., time between diagnosis and first treatment, percentage of early stage lung cancer patients referred for lobectomy) of their own patient panels as compared to practice averages and to published literature. Third, the nurse navigator collaborated with specific Physician Champions at each site for each cancer type to bring these race-specific clinical performance reports to the attention of practitioners to ensure equity in quality and completion of care. Finally, ACCURE offered quarterly Healthcare Equity Education and Training (HEET) sessions for medical and administrative staff members at each site. These interactive sessions were designed to introduce the staff to: systems-level issues of transparency and accountability, a racial equity lens, and concepts of unconscious bias and its effect on patient care.

### **Principles of Undoing Racism<sup>®</sup> Informing ACCURE**

The concepts of antiracism are at the core of ACCURE and its focus on systems-level change to reduce gaps in cancer care and outcomes between Black and White patients. Antiracism training has grounded our partnership in the history of racism in the US and the laws, policies, and procedures which have perpetuated a system of power that advantages some (White people) and disadvantages others (primarily people of color). The legacy of this structural racism is evident in all of the systems that affect people's lives and opportunities (e.g., education, criminal justice, healthcare) and the disparate outcomes (e.g., achievement gap, mass incarceration, health disparities) that disproportionately burden people of color (Hayes-Greene and Love 2016). The antiracism framework promotes understanding and a common language, and also provides a racial equity lens and tool (the analysis of power and authority) to gain understanding of how power shapes our institutions/systems as a first step towards generating systems-level strategies to intervene.

In particular, ACCURE draws on the antiracism principles of transparency (technocratic protocols and narrow knowledge) and accountability (technical language and fragmented power) which affect how systems operate, and the roles of gatekeepers who can impede or advance access, resources, policies, and procedures which affect how individuals experience and are treated in institutions or systems. ACCURE's intervention components were designed with an antiracism lens to address specific exposures and circumstances that make cancer care vulnerable to institutional racism (James et al. 1984; Geronimus 2000), interrupt the pathways through which these occur (McEwen 1998; Wadhwa et al. 2001; Lu and Chen 2004), with the explicit goal of changing structures that obstruct transparency and accountability. The absence of transparency and accountability in a system can lead to

unequal access to information and resources, therefore exacerbating racial inequities (The People's Institute for Survival and Beyond 2015).

### **Practices of Undoing Racism<sup>®</sup> Informing ACCURE Focus Group Analysis**

In the research described here, we drew on a critical practice within the UR<sup>®</sup> framework, an analysis of power and authority. The goal of this analysis is to examine the relationships between communities and institutions, and facilitate a critical analysis of structural racism by addressing issues of transparency and accountability, which affect equitable treatment. According to the People's Institute for Survival and Beyond (PISAB), which initiated these principles and practices, 'the world is controlled by powerful systems with historically traceable roots. Once people are shown how they benefit from or are oppressed by those systems, they can work together to change the system' (Shapiro 2002, 100). PISAB's analysis of power and authority process also brings to light the role of gatekeepers within systems who can grant access to resources and who have power over the individuals who enroll in the system.

To inform intervention development, particularly the Healthcare Equity and Education Training sessions for providers and staff at our partner cancer centers, ACCURE conducted a formative study engaging Black and White cancer survivors in an examination of the cancer care experience. The goal of this investigation, carried out through focus group discussions, was to explore patients' perspectives on treatment and identify places in the cancer care system where patients encountered critical incidents, also referred to as pressure points (Yonas, Aronson, Schaal, et al. 2013), that influenced the quality and completion of their cancer treatment.

Once the focus group data were collected, we sought to apply the principles and practices of antiracism by using the analysis of power and authority as a tool and a lens to analyze the transcripts and identify pressure points, or encounters within the care and treatment experience of Black and White breast and lung cancer patients at two different cancer centers, that affected their ability to navigate the cancer care system and complete their care plan. In doing so, we focused on the UR<sup>®</sup> principles lack of transparency (e.g., obtuse vocabulary/jargon, inconsistent information, impersonal communication modes, inflexible protocols, unclear procedures) and lack of accountability (e.g., unclear procedures for collecting and monitoring information on standards of care and for decision-making, not knowing about deviations from standards of care) from the cancer care system to the patients.

Few studies have applied CBPR principles (Israel et al. 1998) to examine patient perspectives on their cancer care experiences. Moreover, no studies to our knowledge have examined these experiences through an antiracism lens. This paper reports on the findings from the focus groups we conducted with cancer patients and analyzed with an antiracism lens. In this paper we: (1) describe our approach to applying the Undoing Racism<sup>®</sup> framework's analysis of power and authority (Schaal et al. 2016) as a tool to understand the experiences of Black and White stage 1-2 breast and lung cancer patients at two cancer centers; (2) discuss our findings on pressure points during care that influenced the quality and completion of their cancer treatment; and (3) highlight race-specific differences that are

critical to attend to if we are to improve transparency and accountability for equity in cancer care experiences.

## Methods

### Participant Selection and Data Collection

To elicit experiences of cancer patients during their journey through the cancer care system, we conducted eight focus groups with non-Hispanic Black and White breast and lung cancer survivors. Patients were recruited through their oncologists at the Cone Health Cancer Center (CHCC) and UPMC Hillman Cancer Center (UPMC CC). The CHCC is part of a regional hospital system and UPMC CC is a university teaching hospital. The requirements for participation were: (1) diagnosed with stage 1-2 breast (women only) or lung cancer (women and men); (2) received cancer care at CHCC or UPMC CC; and (3) completed treatment in the previous 12 months. Four race and cancer type specific focus group sessions were conducted (i.e., Black patients with breast cancer, White patients with breast cancer, Black patients with lung cancer, and White patients with lung cancer) at each cancer center for a total of eight focus groups.

The goal of the focus groups was to probe patients' experiences for pressure point encounters in which they felt encouraged (or discouraged) to continue their treatment and empowered (or disempowered) by the treatment process in order to understand systems-level protocols, procedures, and encounters that affect patients' treatment experiences, decisions, and completion rate and, ultimately, differential outcomes (Table 1). We used a journey diagram (Figure 1) to jog their memories in recalling aspects of their treatment and interactions with the cancer system and as a tool for our analysis of power and authority within the cancer care system.

Our uniquely inclusive CBPR process explicitly addressed racial equity and power sharing at each step of the project, a process described thoroughly elsewhere (Schaal et al. 2016). ACCURE's community, academic, and medical partners collaborated to develop the analysis of power and authority materials, including the journey diagram and focus group guide. Two community members were selected by GHDC as racially concordant facilitators for the focus group sessions. A person of color (Japanese-African American) facilitated sessions with Black participants at each cancer center, while a White moderator took notes. They reversed roles for the sessions with White participants. Sessions were audio-recorded and transcribed verbatim. The Institutional Review Boards at the University of North Carolina at Chapel Hill and the University of Pittsburgh approved the ACCURE study.

### Focus Group Analysis using the Analysis of Power and Authority

To analyze the data in adherence to our CBPR and antiracism principles, each step involved racially diverse community, academic, and medical center partners from GHDC working together (Schaal et al. 2016). All members of the team had been through antiracism training. A Coding Coordinating Team (CCT), a subgroup of community and academic members of the GHDC that included people of color and White representatives, developed guidelines and protocols for analyzing the transcripts. To ensure that community, academic, medical,

and racially diverse perspectives were included in the analysis, volunteer coders were solicited from the GHDC membership. The CCT developed a codebook, conducted qualitative analysis training with GHDC members, and organized GHDC volunteers into diverse coding pairs who: reviewed an assigned transcript together; assigned topical codes to relevant text; and defined and assigned interpretive codes to relevant text (Schaal et al. 2016). The CCT reviewed coded transcripts, created a consolidated codebook that included topical and interpretive codes, applied these codes to all transcripts, and produced code reports of extracted text.

Informed by the antiracism framework's analysis of power and authority, the CCT reviewed these code reports to identify the pressure points encountered by cancer care patients along the cancer journey and generated a matrix for Black and White participants, respectively. This matrix provided detailed descriptions of patients' experiences on both challenging and uplifting interactions. From that matrix, the CCT literally mapped these experiences, both positive and negative, onto the journey diagram (Figure 1) as a way to visualize encounters at the systems level. Subsequently, the CCT used the patient encounter journey diagram to generate conversations first with GHDC members and ultimately with cancer center providers and staff about how these systems-level encounters did or did not exhibit transparency and accountability and what affect these experiences might have on cancer patients.

## Results

A total of 27 breast and lung cancer patients participated in eight focus group sessions. Of the 27 participants, 12 were Black and 15 were White. Table 2 shows the breakdown of the participants by race, cancer type, and cancer center.

Six overarching, interrelated themes emerged across racial and cancer groups (Table 3): (1) fear was disempowering and discouraged continuation of care; (2) uncertainty and lack of information were disempowering and hindered care; (3) trust in the medical team was crucial to continuing care; (4) communication was empowering when providers shared information and were also good listeners; (5) navigating complex, impersonal healthcare systems was often confusing, overwhelming, and disempowering; and (6) in these impersonal systems, small interpersonal interactions were enormously important in helping patients feel cared for or disregarded. When patients were asked during their focus group discussions whether they felt they were treated differently due to their race, few explicitly described experiences of differential treatment. Despite these commonalities, implicit differences emerged in Black and White participants' descriptions of their cancer care experiences and pressure points they encountered along the way. We describe these commonalities and differences across four phases of care: diagnosis, course of treatment, daily grind in a complex system, and when treatment ends. These phases were where our patients' pressure point experiences clustered. Table 3 exhibits how the six overarching themes manifested within these four encounters.

## The Diagnosis Encounter

The moment of delivery of the diagnosis of cancer is a stressful experience for cancer patients. Black and White participants in this study shared the ways they received this news at two different cancer centers. At one cancer center, this news was largely delivered in person, while at the other it was routinely delivered by telephone without regard for whether the patient was at home or work or had a supportive individual with them. The reactions of participants to these different modes of communicating difficult, life-changing news highlighted ways that patients experienced pressure points at the outset of the cancer journey. Both Black and White breast cancer patients expressed dismay when such critical information was delivered by telephone, especially at work. Receiving such news in locations or circumstances where they did not have a safe space to express themselves emotionally or a caring source of support at their side was overwhelming and disempowering. These impersonal modes of communicating critical information at the beginning of the cancer journey typify a system not accountable to patients' needs for establishing trust with the cancer care system; and exemplify how the system lacked transparency in its two-way communication by not considering how the mode of delivering critical information may impact the patients' experience in receiving that information. For the cancer centers, this represents a missed opportunity to begin establishing trust through transparency in communication and accountability for the important nature of this first communication.

**Racial Differences**—Although both Black and White patients expressed dismay at receiving their cancer diagnosis by phone, Black patients reported concerning delays in communication. For example, one Black breast cancer patient received a voice message about her biopsy results on a Friday and had to wait five days until she could speak with her provider regarding the results. Delayed information and uncertainty were exceedingly stressful for her. Another Black breast cancer patient described a delayed diagnosis because the technician administering her mammogram did not listen to her. The patient's primary care physician (PCP) found a small mass underneath the patient's right arm and scheduled a mammogram. The patient informed the technician about this mass, identified its location, and was assured that the mammography would detect a mass if present. She later discovered from her surgeon that the area of concern was not included in the field of the image, so the mammogram was negative. Subsequently, she was retested with an ultrasound-guided biopsy that ultimately confirmed the breast cancer diagnosis originally suspected by her PCP. The Black breast cancer patient described her anger about this delay in diagnosis and, therefore, treatment:

I was angry for a while because the doctor [mammography technician] that was here at [hospital]...I thought that she would've listened to me better. If...she would've listened to what I was trying to tell her about the spot here...then I probably would not have had to go through that... So, if she would've listened maybe we could've stopped it before, but she just wouldn't listen.

This patient felt strongly that her breast cancer would have been diagnosed more quickly and treated sooner if the mammography technician had listened to her and investigated her concern. Through its lack of accountability, missing the mass so that her diagnosis and

treatment were delayed, the system in effect failed this patient. The technician served as a gatekeeper whose control of the interaction (i.e., not accepting the patient's insights and communication of the issue) resulted in inadequate follow through and critical delay in diagnosis and treatment. While only two among many, these experiences demonstrate how lack of two-way transparent communication interferes with the patient-provider relationship and lack of system accountability has potentially serious consequences for patient diagnosis, treatment, and care.

### The Treatment Encounter

The issue of transparency also arose in regard to building trust and facilitating two-way communication during the course of treatment. Once diagnosed, the participants found the processes before and during treatment to be challenging and stressful due to the lack of information and uncertainties of what to expect. Patients experienced difficult treatments, which caused problematic fatigue and noxious side effects. The pressure points they described most often were interactions with physicians as gatekeepers, which either successfully facilitated care, or failed to do so. Both Black and White patients reported that the information they received was sometimes inadequate and often too overwhelming to understand clearly. In addition, pain and side effects were not always satisfactorily managed or addressed. For example, a White breast cancer patient's crippling pain was dismissed for over a year before her doctors agreed to discontinue a medication that caused her suffering. A Black participant described her skin pain during radiation treatment as follows:

And so...I had start burning real, real bad and I couldn't stand to have anything on me...so I wanted to stop, but...because of him being a nice doctor...he heard me... 'Cause this one day I, I said 'I refuse to go'...when they called me to go I said, 'I'm not going! I'm burning.' ...And so they called the doctor down and he came and he said, 'You're a feisty little thing.' He said, 'And I'm gonna listen to you and I'm giving you a week off.' ...and when I came back...I only had three more days to go...and I was ready to...deal with it even though...it was still painful, but I was ready to deal with it.

Clear, transparent communication and careful listening on the part of the provider was essential in creating a space for patients to question, disagree, and provide input. Our participants made it clear that patients want regular, open, clear communication and to know what to expect in terms of treatment and appointment schedules. Black and White patients both described challenging interactions with doctors when they did not feel they were listened to or consulted. Pivotal pressure points and causes for distress for cancer patients included: (1) waiting and uncertainty about aspects of their treatment; (2) inflexibility in scheduled care plans; (3) lack of preparation for and communication before procedures or treatments; and (4) unexpected changes for which patients were not well informed. These pressure points are all indicators of the lack of transparency within the cancer care system.

In spite of these negative experiences, our analysis of pressure points in the cancer care system revealed that patients were grateful for the amount and quality of support from their cancer care teams. Overall, patients felt included in the decision-making process regarding their treatment. Some patients established trusting relationships with physicians, nurses, and

support staff, even to the point where the cancer care team members and the patients themselves used humor to communicate and to bring joy to an otherwise difficult situation. There were several instances where physicians used much-appreciated humor to build rapport with patients and put them at ease.

**Racial Differences**—Whereas White patients' main issues concerned not receiving adequate post-operative care information, such as reconstructive surgery information for breast cancer patients, Black patients expressed more concern about how standard procedures or the implications of procedures were not always fully explained to them. For example, they described experiencing delays in the scheduling of surgery, as well as delays in receiving pathology or staging results after a lumpectomy. Although they tried to advocate for themselves, there was no mechanism in place to ensure the system and the procedures initiated were transparent or to hold the system accountable for timely communications.

Although patients of both races at both cancer sites expressed that their pain and side effects were not always satisfactorily managed or addressed, Black patients felt particular dissatisfaction with how their cancer treatment-related symptoms were managed. Pain and symptom control were issues for Black patients in multiple settings and from multiple causes during the course of their cancer treatment. Issues mentioned by Black patients included painful venipuncture, radiation skin problems, medication side effects, and invasive un-anesthetized procedures. When they did receive information about potential side effects, some Black patients suggested, it was insufficient, inaccurate, or late, resulting in undue pain and suffering from treatable side effects.

One Black lung cancer patient described the experience:

I was disappointed mostly in the side effects...that...is the part that really got me, ...I didn't think that you could go through all of that, because, they would tell you a certain part of it...and a few other things that wasn't mentioned... They gave me some...prescription to get the right medication, but there are certain things that I called in about... they weren't givin' me the right information I needed...at the time.

A Black breast cancer patient described a particularly harsh experience:

Cause I had a boil to come up...the provider said 'let me take a look at it' and then the next thing I knew he asked for something and he immediately lanced it. He didn't prepare me. He didn't tell me what he was doing. Nothing. And I had to actually literally grab my pants because I was getting ready to cold cock him... That's how bad it was.

Insensitivity to or even disregard for patients' pain tolerance, as the boil experience suggests, has the potential to sever the patient-doctor relationship at a time when patients are particularly in need of support and empathy. Failure to prepare patients for procedures and treatments led to excess pain and unmanaged side effects among Black patients. The lack of transparency manifested in these experiences disempowers and discourages patients, increasing the potential for discontinuation of care.

Although it is important to acknowledge how individual interactions between patients and providers influence patient health outcomes, it is critical to understand these interactions from a systems perspective. For example, the inflexibility of the protocols and procedures for scheduling surgery/treatment appointments and managing pain and symptoms reflect the failure of the *system* to maintain the transparency necessary for optimal care. Patients' experiences during treatment played a critical role in how and when they followed their treatment plan. Racial differences that emerged from our analysis of the system suggest that some Black patients were not receiving the care they needed in a timely or sensitive manner.

### The Encounter of the Daily Grind of Navigating the System

Navigating a large, complex, impersonal system without clear mechanisms for transparency and accountability was overwhelming and disempowering for the participants. Challenges faced by participants included medical and non-medical issues reflecting a lack of transparency, such as: (1) not having well-coordinated care, which led to confusion about which provider to call for which issues; (2) problems with acquiring information or support from billing offices; and (3) lack of support from social workers even in times of dire need for transportation, financial, or psychosocial support. Furthermore, these patients' challenges were a reflection of how the cancer care system can provide uneven, haphazard care. Some patients shared how they were not aware that educational and social support resources were available at their cancer center, while others had been connected with an array of resources and services. Although communication was clear at times, it was not always transparent, and the mechanisms in place did not hold the system accountable. Breast cancer participants provided one example of how such differential access to resources was experienced by patients. Some told of receiving a *'black bag'* full of breast cancer resources and information at the onset of diagnosis, while others had never heard of or been offered such a resource.

Another dominant theme among the participants was the importance of small interpersonal interactions. Participants acknowledged the crucial role their physicians played in encouraging them to initiate or continue treatment. Patients valued their interactions with staff and described them as *'welcoming'* and *'like old friends'* who *'knew their names.'* A Black lung cancer participant summed up the kind of experience expressed by participants:

So...between the cancer center, the therapist that they have there...the smallest person, even the greeters when you come in the door...they go above and beyond their job. Because I think you have to be a special kind of person to work there, you just can't be like a regular doctor's office, because they are compassionate, they understand people are going through some serious stuff, mentally, physically, and emotionally.

Despite these positive interactions, both Black lung and White breast cancer patients also described negative experiences with nursing staff and oncologists at both cancer centers. Seemingly minor interactions were perceived as critically important in making patients feel comfortable, encouraged, or empowered. Both Black and White patients gave examples of the challenges they encountered, for example, in negotiating the financial/ billing system. Patients also described stress-inducing experiences with the oncology center, including long initial visits, lack of return calls from the scheduler, and difficult interactions with *'rude'*

staff or a doctor who had no *'bedside manner.'* Patients recognized during those encounters that the quality of care was sub-optimal but did not know who was in charge or where to voice a complaint. The mechanisms for accountability of the system to the patients were not clear. A White breast cancer patient described the frustration of such an interaction she had at the front desk:

...And I actually left here in tears one day because of the rudeness of the people that worked here. It wasn't the nurse, it was like mainly the...people at the desk... and I don't know whether it was a bad day, it was just everyone was so rude. And I felt that, well you know I thought it was unprofessional, but you know if any place where you need to be kind and caring, it should be here because not only are the patients under a lot of stress, but their families are under stress. And I actually did call somebody about this and reported it.

Similarly, a Black breast cancer patient described a pressure point encounter with a White woman at the front desk:

I could get food down more and better than I had. But...there was another woman that told me about the mints and the...Lemonheads...up there at the chemo place. And when I come in there for my treatment...I would grab a handful and throw them in my purse. There was this one lady up there at that desk, she knew I was coming. Every time I came she would move 'em... And I asked her where's the Lemonheads at? {imitating lady at front desk} 'Oh, they haven't put any out today.' ...She was at the front desk on floor three. ...I went back to where the chemo people were, they always had their Lemonheads out, so I grabbed a handful of them... But for her to move them Lemonheads that really like, just took me...

**Racial Differences**—The examples above speak to individual incidences experienced by both Black and White patients. While these occasional negative experiences were dwarfed by the participants' overall positive impressions of the cancer centers, the tenor of incidents described by Black participants raise questions about whether innocuous interactions may be related to unconscious bias (Hall et al. 2015; Nolan et al. 2014; Burgess et al. 2006), a critical underpinning that may affect the quality of patient care. Whereas the White patient experienced a kind of universal rudeness from the front desk staff, the Black patient experienced a very targeted and intentional denial of a small bright spot in her chemotherapy treatment experience. While she did not explicitly describe this as an example of when she was treated differently due to her race, it emerged from our analysis as a potential racial microaggression. Microaggressions, or 'brief and commonplace daily verbal, behavioral, or environmental indignities, whether intentional or unintentional, that communicate hostile, derogatory, or negative racial slights and insults toward people of color,' (Sue et al. 2007, 273) could affect patients' treatment experiences whether or not they recognize them as racially-motivated. The very staff members whose role was to facilitate the patients' care journey were in fact preventing patients from progressing smoothly through the system; an example of how a gatekeeper controlling access to resources and procedures can affect the quality of care and patient experience. Moreover, each patient's response raises interesting questions about who feels empowered within the cancer system. In this case, the White patient felt empowered enough to complain and report the rude behavior. The Black patient

acknowledged that she found this behavior distressing, but she did not describe taking any action. From our antiracism lens, these encounters suggest the privilege a White patient may feel (and the reluctance a Black patient may feel) in challenging the negative treatment within a system that is not accountable to all of its patients.

In a few cases, cancer treatment-related side effects were so severe that patients reported going to the emergency department (ED) to seek care. Navigating the ED system was frustrating for cancer patients, especially the Black patients who reported more negative experiences. Black breast and lung cancer patients reported receiving inadequate information and care from the ED medical staff. There was a lack of coordination and transparency between the ED triage and the cancer care system. One Black lung cancer patient said that he was told to go to another section of the hospital after reporting to the ED located near his cancer center. Unlike a White patient who described feeling empowered during her ED visit, a majority of Black patients spoke about their experiences in the ED as a challenging and frustrating aspect of their cancer journey because they were not able to navigate the ED to receive the care they needed to manage residual pain from cancer treatment. They felt they were given insufficient treatment that only temporarily managed their pain. When they were told to schedule visits with their cancer care teams, it felt like a dismissal since it was not clearly communicated that this was the path to long-term pain management resolutions.

Navigating the cancer center system is a difficult journey for many patients, so the guidance and service that patients received from oncology and other hospital staff had a powerful effect on their overall experience. Many patients expressed how attentive and caring the cancer center staff was, while others, particularly Black patients, shared incidents of microaggressions that left them feeling disempowered by the very gatekeepers who were in place to assist them. This attests to the need for cancer center staff to engage positively with patients and for systems to be in place so that when patients, regardless of race, do not feel welcomed, respected, or well supported, they know where to go to address those issues.

### **The Encounter When Treatment Ends**

The participants' cancer-related experiences extended beyond their cancer care team since they often interacted with other areas of the hospital post-treatment, including the ED, radiology, and support groups. There were reports from both Black and White patients about positive experiences they had with receiving a post-treatment MRI (magnetic resonance imaging) and visits to the ED. One White patient emphasized how empowered she felt when she received the care she needed in the ED. A Black patient shared that she was able to advocate for herself in the ED when she insisted that the medical staff not use the port, which had been inserted for use during her cancer treatments. Another Black patient reported how appreciative she was when the person conducting her X-rays allowed a break in the scan to increase her comfort.

Yet, several patients felt the strong support they received during treatment completely dissipated once they finished their chemotherapy or radiation. This left patients feeling abandoned and ill-prepared to navigate the post-treatment issues they experienced, such as continued radiation-induced skin changes, side-effects from anti-estrogen medications, and persistent residual effects of chemotherapy. Post-treatment care was a major concern for

Black and White breast cancer patients. Patients found the system was not set up to provide continuing transparent communication after their active treatment ended, although they were expected to attend scheduled follow-ups. As one White breast cancer patient explained, *'When treatments end, the support ends.'* In the same regard, a Black breast cancer patient shared:

If I had to change something or suggest a change, it would be after treatment. I found that to be very difficult. Matter fact I fell apart... After treatment it's like what do you do? Where do you go? ...And some real high anxiety like over-the-chart anxiety issues came up after my treatment. Just like out of nowhere, which I later found out it was very typical, very normal, but I'm like I didn't know what to do... And so it wasn't until I saw...the [physician assistant] that you know if it's certain things you just call the center... You know if you got a headache, your leg hurt, your head you know go to my primary physician. But anything else so...I'm still not real clear on that.

This uncertainty about whom to contact (e.g., primary care or cancer care physician) to address post-treatment medical needs left many patients confused about who should be their primary provider following completion of cancer treatment. At one cancer center, patients mentioned that chemotherapy classes were offered. They appreciated these classes because they provided information about what to expect during treatment. Patients desired to have similar resources that offered more widespread support post-treatment. They desired reliable sources to contact to address their questions and to assist them with navigating the medical system after the completion of active cancer treatment.

The care of cancer patients extends beyond the actual cancer center. Patients need flexible and compassionate care from gatekeepers in all sections of the hospital that they interact with. Even after the patients' care plans have been completed, they experience residual medical issues for weeks or months related to their cancer treatment. All cancer patients need well-defined instructions on steps to take when they have pain or symptom management concerns after treatment ends.

## Discussion

Our analysis of power and authority focus group findings provide important considerations for how cancer centers in the US can improve transparency and accountability for quality and completion of treatment within their system. As one patient eloquently described the challenges of navigating the cancer system for her treatment and care, *'it's like you don't have a roadmap really.'* Our findings shed important light on what the experience of treatment was like for cancer survivors and suggest critical areas where cancer systems could change their procedures and policies, as well as better educate and prepare gatekeepers, to improve care for all patients. As described by our patient participants, most of the pressure point encounters were related to lack of transparency, such that improvements in communication, particularly two-way communication could greatly improve patients' interaction with the system. Pathways for accountability can also be built into a system that allows patients to find solutions for their problems with the system itself. Seen through an antiracism lens, the experiences these participants shared about their

diagnoses, treatments, and dealings with complex cancer centers suggest eight patient-centered systems-level interventions that could address common pressure points and potentially improve cancer center experiences for all patients:

- (1) Participants said learning of their diagnosis was enormously stressful. The stress was intensified for those who had received the news by telephone, because it was impersonal, and did not allow for the opportunity to absorb information or formulate questions. Following-up with patients in person after diagnostic imaging and procedures would address this problem.
- (2) Some participants found a first visit with a multi-specialty oncology clinic to be informative, streamlined, and reassuring, but others found that approach overwhelming because of the length of the visit and the sheer amount of information conveyed by multiple providers. Centers might offer options for the first visit format based on patient preferences.
- (3) Systematizing provision of informational resources, triaging for social service needs at regular intervals, and documenting these interventions in the electronic health record could help to ensure every patient has access to needed support services.
- (4) While reducing wait times might be difficult, appointments might be made less stressful by allowing patients to wait in common spaces, rather than in gowns in exam rooms.
- (5) Our participants reminded us that procedures clinicians consider minimally invasive are often aversive experiences for patients. Protocols that limit venipuncture attempts and appointment systems whereby patients might have their intravenous lines placed or indwelling catheters accessed by known, trusted phlebotomists and nurses might reduce the distress associated with these procedures.
- (6) Protocols for timely communication among ED staff, on-call oncologists, and patients might alleviate some of the stress associated with unexpected complications that result in visits to the ED.
- (7) Health systems can establish clear protocols to communicate the plan for follow-up or identify community resources for survivorship education and support for every patient transitioning out of active treatment. Our participants' concerns align with a growing conversation about the need to provide survivorship care plans for all patients that are post-treatment.
- (8) Finally, consistent policies that *explicitly* address the mechanisms patients have to address institutional problems should be clear. Guiding patients through the system with accessible policies will clearly establish the institution's commitment to accountability to patients.

Our findings have been crucial to informing ACCURE's groundbreaking intervention components and to engaging cancer center providers and staff in the effort to increase their own cancer care systems' mechanisms of transparency and accountability. Using the

analysis of power and authority tool for this formative research also emphasized the importance of using an antiracism lens to understand and intervene on racial inequities in health. In order for this type of analysis to be effectively used, community and academic researchers must gain the shared understanding, language, and lens offered by an antiracism training to fully comprehend and appropriately apply the analysis of power and authority to research. Efforts should be made to increase access to antiracism trainings to enable more researchers to learn about this framework for examining systems. A limitation of this formative study is our findings are specific to the care systems at two cancer centers and may not be transferrable to other cancer centers. Nonetheless, our two partnering cancer centers were specifically selected as ACCURE sites to reflect a range of cancer centers in the US (i.e., those that are affiliated with regional hospitals and academic medical centers), as well as the racial gap in patients' outcomes exhibited in cancer centers across the country (DeSantis, Naishadham, and Jemal 2013; Samuel et al. 2014; Lathan, Neville, and Earle 2008; Keating et al. 2009; Smith, Earle, and McCarthy 2009; Cykert et al. 2010; Farjah et al. 2009). Hence, our findings are likely relevant to other cancer centers.

A major strength of this formative research is the central role that our community partners in the GHDC played in holding academic and medical center partners accountable and transparent throughout the research and intervention process. The GHDC members led the effort to pinpoint pressure points that might be related to differential treatment by race, discussed preliminary findings, and once the findings were finalized, suggested ways to incorporate them into the larger project, fine-tune ACCURE navigators' work goals, and shape content of the Healthcare Equity and Education Training sessions for cancer center providers, staff, and administrators. Another strength is that our team included cancer survivors whose perspective was essential, and feedback was taken into account at every step of the research process. Our CBPR approach to planning, data collection, analysis, interpretation, and writing of this manuscript integrated multiple perspectives throughout the process, including Black and White cancer survivors, community members, healthcare workers, and academic researchers.

Our analysis of power and authority of the cancer care system has shown that:

- (1) There are several key pressure points along the cancer care continuum where patients encounter barriers to care and feel disempowered. These pressure points are where the healthcare system can be improved to facilitate more empowering experiences for patients.
- (2) The Undoing Racism<sup>®</sup> framework's analysis of power and authority serves as an effective tool for analyzing pressure point encounters and identifying equity issues within the healthcare system.
- (3) The concepts of transparency and accountability provide a starting point for the fields of public health and medicine in general, and cancer health disparities in particular, to understand and address how structural issues contribute to persistent cancer disparities.

In sum, our findings from patients' encounters with the cancer care system underscore the need for new ways to ensure transparency and accountability for cancer care through clear,

two-way communication systems and well-integrated policies and procedures that serve as a roadmap to guide patients, clinicians, and staff through the cancer care journey. The use of the antiracism framework to achieve systems change may assist in eliminating Black-White inequities in the quality and completion of cancer treatment.

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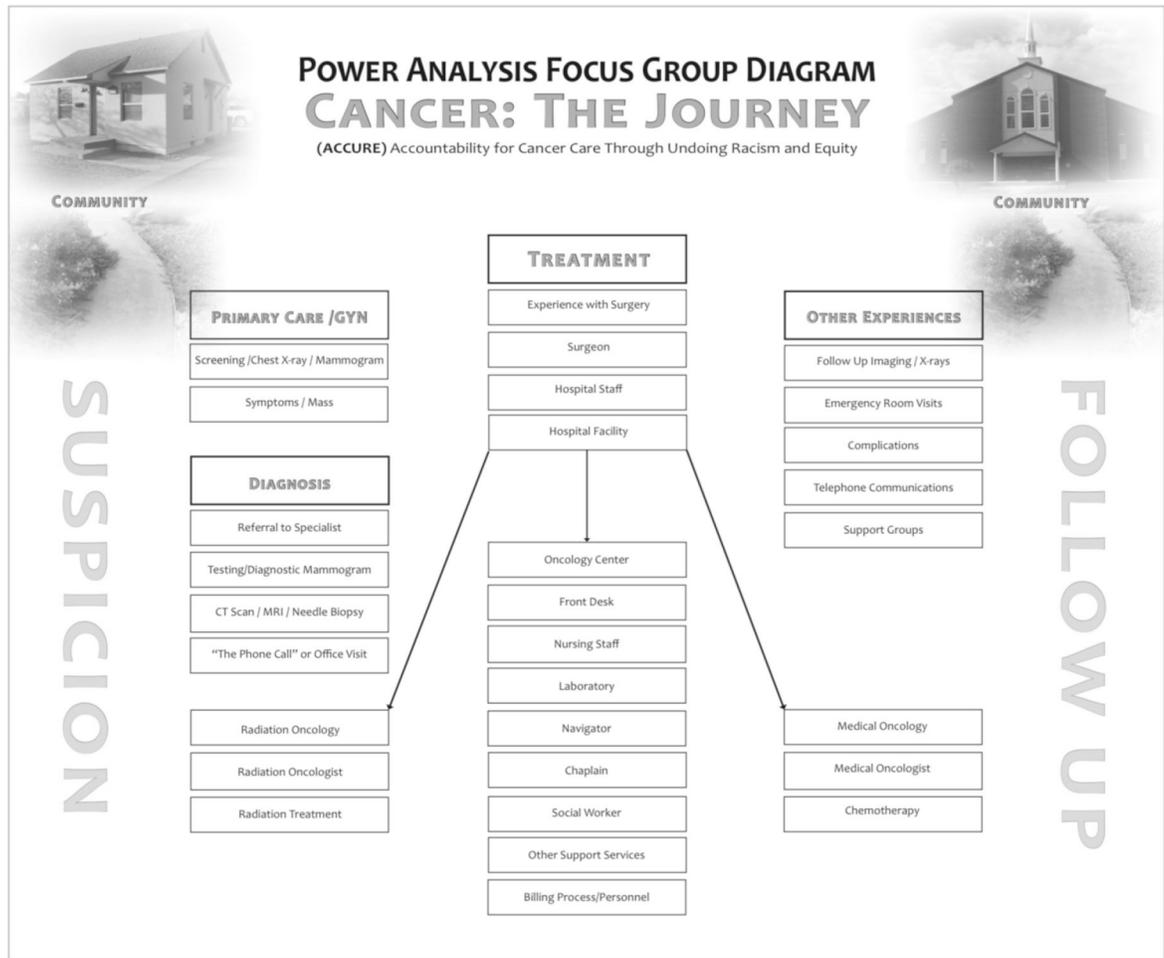
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**Figure 1.**  
 Cancer Journey Diagram<sup>a</sup>

<sup>a</sup>The cancer journey diagram, developed by GHDC and Sisters Network Greensboro NC, a local affiliate of a national African American breast cancer survivorship organization, was a focal point for analysis of power and authority discussions and data analysis. It depicts a patient’s journey through cancer care, beginning in the community, from diagnosis through therapy and return to the community following treatment.

Table 1.

## Analysis of Power and Authority Focus Group Guide

| #            | Question and Additional Prompts   |
|--------------|---|
| Introduction | We've put together this diagram to jog memories of the 'journey through the cancer care system.' Each person's journey is a bit different, but we can hopefully use this as way to remind us of all the different parts of the system. You can also let us know as we go along if we need to change or add anything to this diagram to better reflect the treatment experience at your cancer center.   |
| 1            | We can start with a quick walk through the diagram to review the many important points in a cancer treatment process. We show progression from initial testing through diagnosis to the cancer center and through treatment. At each point there are multiple medical and non-medical experiences that can influence the quality of your experience. For example, I would like to hear your experiences with services, paper work, unfamiliar medical vocabulary, rules and regulations, schedules, preparation and follow-up procedures, or experiences when medication side effects may not have been explained. There may be: <ul style="list-style-type: none"> <li>• Points (encounters with the medical system) where you felt 'stuck'; that you did not know how to move forward in the system</li> <li>• Points where you were sent 'back and forth'; or going in circles like a merry-go-round</li> <li>• Points of particular confusion</li> </ul> {STOP to allow time for the participants to add to the diagram and reflect on these points.} |
| 2            | Now that we've got the system mapped out and you are thinking about your experiences, let's begin by describing: <ul style="list-style-type: none"> <li>• What led you to start your cancer treatment at your cancer center instead of another place?</li> <li>• What made it easy or hard for you to DECIDE to start your treatment at your cancer center?</li> <li>• And then, tell me about particular points in this journey, or situations, where you felt EMPOWERED (meaning that you fully understood the plan, your opinions were respected, that you were a full partner in your own cancer treatment)?</li> <li>• What about that experience made you feel empowered?</li> </ul>  |
| 3            | And what about experiences in the journey or situations where you did NOT feel EMPOWERED / that you were a full partner in your own cancer care? <ul style="list-style-type: none"> <li>• What about that experience made you feel disengaged, discouraged, and/or disappointed?</li> </ul>   |
| 4            | Tell me about times when you felt you had a part in making decisions about your care. <ul style="list-style-type: none"> <li>• How was your participation 'invited'?</li> <li>• How welcome do you think your participation was in that instance?</li> </ul>  |
| 5            | And what about times when you felt you were NOT allowed to participate in making decisions about your care? <ul style="list-style-type: none"> <li>• What happened to make you feel like you weren't allowed to participate?</li> <li>• Were there times when you did not feel welcome to participate in decision-making but you did/tried to participate anyway? What happened?</li> </ul>   |
| 6            | Were there any incidents or points along this journey that made you want to stop treatment? Tell me about that... <ul style="list-style-type: none"> <li>• Did you tell any medical staff that you wanted to stop treatment? What happened?</li> <li>• Why did you decide to continue?</li> <li>• How do you think the cancer care system should handle issues like this?</li> </ul>  |
| 7            | Describe any incidents or points along this journey that really built up your courage to continue your care. <ul style="list-style-type: none"> <li>• Tell me more about that...</li> </ul>   |
| 8            | Were there barriers to YOU for getting the best care? <i>{Give a long pause for silence to wait for answers before giving these examples: any challenges regarding paper work, unfamiliar medical vocabulary, rules and regulations, schedules, preparation and follow-up procedures.}</i> Tell me about those. <ul style="list-style-type: none"> <li>• Did you know of anything or anyone in the cancer center system that might have been able to change that situation?</li> <li>• How were those barriers dealt with, or were they?</li> </ul>   |
| 9            | Do you feel you were treated differently (positively or negatively / better or worse) because of your race or other elements of your cultural or ethnic background? If so, what gave you this feeling or impression?  |
| 10           | What was helpful to you in getting the quality of care YOU needed? <ul style="list-style-type: none"> <li>• What was helpful about the way the procedures/services were organized?</li> <li>• How did this help you?</li> </ul>   |
| 11           | What were the points in this system that made your experience especially difficult or frustrating? <ul style="list-style-type: none"> <li>• (If answers are personal—family, relationships, work, etc.) Did you know of anything or anyone in the cancer center system that might have been able to help with that situation, or anyone you could go to for advice?</li> <li>• Did you communicate these struggles to your providers? How?</li> </ul>   |
| 12           | Based on your experience with cancer diagnosis and treatment system, if you had the power to improve the system, what would you change?   |

**Table 2.**

Analysis of Power and Authority Participant Profile By Race, Cancer Type, and Cancer Center

| <b>Race</b> | <b>Cancer Type</b> | <b>Cone Health Cancer Center<br/>(Regional Hospital)</b> | <b>UPMC Hillman Cancer Center<br/>(Teaching Hospital)</b> |
|-------------|--------------------|--|---|
| Black       | Lung               | 3  | 1 <sup>a</sup>  |
|             | Breast             | 4  | 4   |
| White       | Lung               | 5  | 1 <sup>a</sup>  |
|             | Breast             | 5  | 4   |

<sup>a</sup>Conducted as one-on-one in-depth interview using the same focus group questions

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**Table 3.**

Encounters in the Cancer Care System Where the 6 Overarching Themes Manifested

| THEMES  | ENCOUNTERS       |                  |                    |                       |
|---|------------------|------------------|--------------------|-----------------------|
|   | <i>Diagnosis</i> | <i>Treatment</i> | <i>Daily Grind</i> | <i>Treatment Ends</i> |
| <b>1: Fear</b> was disempowering and discouraged continuation of care   | X                | X                | X                  | X                     |
| <b>2: Uncertainty</b> and lack of <b>information</b> were disempowering and hindered care                               | X                | X                | X                  | X                     |
| <b>3: Trust</b> in the medical team was crucial to continuing care  |                  | X                | X                  |                       |
| <b>4: Communication</b> was empowering when providers shared information and were also good listeners                   |                  | X                | X                  |                       |
| <b>5:</b> Navigating complex, <b>impersonal</b> healthcare systems was often confusing, overwhelming, and disempowering | X                | X                | X                  |                       |
| <b>6: Small interpersonal interactions</b> were enormously important in helping patients feel cared for or disregarded  | X                | X                | X                  |                       |

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