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Living with the Double-Edged Sword: A Qualitative Study of Navigating Leukemia within the Cancer Care System

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Abstract

Background

Racial disparities persist in acute myeloid leukemia (AML) treatment and survival; however, little is known about how Black patients experience and navigate cancer care. This study explored the role of cancer care in health outcomes and the experiences of Black adults with AML navigating the cancer care system.

Methods

A qualitative study was conducted with 16 Black adults diagnosed with AML. Participants were recruited using purposive and convenience sampling from a comprehensive cancer center, cancer patient social network, and hospital cancer registry. Semi-structured interviews explored participants' experiences with race, insurance, patient-clinician communication, treatment, finances, and supportive resources. The National Institute on Minority Health and Health Disparities Research Framework guided the study. Data were analyzed using thematic analysis.

Results

Participants ranged in age from 38 to 74 years (M = 57.7, SD = 11.57) and included 10 women and 6 men diagnosed with AML between 1980 and 2022. Five themes emerged: (1) the disadvantage of being Black with AML, (2) the importance of social support, (3) the privilege of receiving high-quality healthcare, (4) the significance of representation in healthcare settings, and (5) the shared experience of isolation. Participants described feeling dismissed, unheard, stereotyped, and disadvantaged when seeking care and perceived race as a barrier to finding a stem cell donor. In contrast, knowledgeable and supportive clinicians, family and community support, social workers, spiritual support, access to comprehensive cancer centers, and Black representation in healthcare settings facilitated cancer care. Participants also described isolation associated with AML and its treatment, with some identifying similarities between AML-related infection precautions and the COVID-19 pandemic.

Conclusion

Black adults with AML described cancer care experiences shaped by perceived racial disadvantage, healthcare interactions, social support, access to high-quality care, representation, and isolation. Findings highlight opportunities to improve patient-clinician communication, provide accurate information regarding contemporary stem cell transplantation options, strengthen supportive resources, and promote equitable healthcare interactions across the AML care continuum.

Background

AML is a rare blood cancer characterized by genetic changes, which lead to the failure of myeloid cell proliferation into functional blood cells (American Cancer Society, 2025a). There are approximately

79,317 people living with AML in the U.S. and the disease currently carries a 5-year survival rate of 32.9.7% (Surveillance, Epidemiology, and End Results (SEER) Program, 2025). In the United States, approximately 4.3 per 100,000 people are diagnosed with AML and 2.7 per 100,000 die per year (SEER, 2025). In 2025, it was projected that there would be 22,010 new U.S. cases of AML and 11,090 deaths annually (SEER, 2025). Despite having a lower incidence of illness, Blacks and Hispanic Whites diagnosed with AML have higher rates of mortality compared to non-Hispanic Whites (Bhavana Bhatnagar et al., 2021). People living with AML experience persistent symptoms such as fatigue and weakness, that are related to low functional blood and bone marrow (American Cancer Society, 2025b). Many survivors are hospitalized for weeks to undergo intense treatment and supportive care while awaiting blood count recovery (Kumar, Henzer, Rodday, & Parsons, 2018). Treatment can often lead to nausea, gastrointestinal discomfort, fatigue, mucositis, and alopecia (American Cancer Society, 2025c). Subsequently, survivors of AML experience unplanned hospital visits to manage neutropenic fever and infections such as pneumonia, bacteremia, and gastrointestinal infections. infections, neutropenic fever, pneumonia (Guerra et al., 2020). In addition to suffering physical symptoms, survivors of AML also report emotional symptoms, including high levels of uncertainty, anxiety, and psychological distress (Albrecht & Bryant, 2019).

Knowledge gaps about how cancer care systems impact health outcomes persist in the literature. Research findings suggest the cancer care system may contribute to racial and ethnic disparities in cancer as evidenced by poor patient-clinician communication, discriminatory health practices, implicit bias, medical mistrust, and unequal access to adequate survivorship care, unequal access to pain therapies, inadequate representation in clinical trials and the rising cost of therapies (Mitchell et al., 2022). Overcoming these interpersonal and societal level challenges (National Institute on Minority Health and Health Disparities, 2024) make navigating the cancer care system difficult while managing the personal and physical burden of AML. There is limited published literature to understand the experience of Black patients with AML navigating cancer care. Little is known about perception of diagnosis, managing financial obligations, insurance coverage, engagement with their cancer care team, healthcare facilities, inpatient and outpatient referrals, accessing emotional, spiritual and psychological support, delays in treatment, resources to better understand AML and the experience of navigating cancer care during the pandemic of COVID-19 (National Cancer Institute, 2025; Wang, Berger, & Xu, 2021).

The purpose of this study was to explore the role of cancer care in health outcomes and better understand navigating cancer care among a sample of adult Black patients diagnosed with AML.

Methods

Theoretical Approach

The National Institute of Minority Health and Health Disparities Research Framework (National Institute on Minority Health and Health Disparities [NIMHHD], 2024) was the theoretical framework used for this

study. The framework models levels of influence which guided the development of the interview guide (Appendix A), including how questions were structured to assess Black patients' perspectives on barriers and facilitators needed to successfully navigate cancer care and how health outcomes were influenced by the domain of the cancer care system (NIMHHD, 2024). Using this framework, the study assessed the perceived impact of individual level influences including insurance and race, interpersonal influences including patient-clinician relationships, community influences including availability and accessibility of services, and societal influences including quality of care. Semi-structured interviews were used to better understand how patients perceived their race, insurance, appointment schedules, transportation, access to community resources, and referrals that enhanced or impeded their experience in the cancer care system.

Study Participants

This study used purposive and convenience sampling to recruit 16 adult survivors of AML, using multiple strategies. Purposive sampling ensured the sample: 1) represented the target population, 2) included individuals who were knowledgeable and willing to share their experience of AML, and 3) included information-rich cases (Palinkas et al., 2015). Recruitment took place between August 2021 and December 2023. A blood cancer clinic within a comprehensive cancer center in central North Carolina served as the initial recruitment site. The study was broadened to include the Leukemia Lymphoma Society patient social network and a large hospital cancer registry.

Recruitment was initiated during the 2020 global pandemic of COVID-19 which imposed contact restrictions from 2020 to 2021 (Wang et al., 2021). Additionally, many patients opted for telehealth visits which decreased their risk of infection as well as relieved them of transportation burdens, but reduced access to potential participants in the clinic. The effects of the pandemic, and challenges with recruitment of Black participants diagnosed with a rare illness and limited financial resources further challenged this study's recruitment (Griggs et al., 2009). A description of the recruitment process is included in Fig. 1. Potential participants were recruited using the following mechanisms: Presentations in the clinical setting to orient healthcare clinicians, nurses and clinical staff to the study, reviewing the clinic schedule weekly to identify potential patients, consultations with methodological research experts to identify innovative recruitment methods, attendance at community events that target survivors of blood cancer, and identifying potential participants within a hospital cancer registry. Most participants were identified and recruited using the cancer registry.

The study was approved by the Institutional Review Board (IRB), including a waiver of written consent. Consent forms included a location to document date/time verbal consent was obtained, contact information for the IRB and study team, participant rights to decline participation and strategies used to preserve participant anonymity.

Eligibility and Enrollment

A blood cancer clinic within North Carolina served as the initial recruitment site. The study was broadened to include the Blood Cancer United's (formerly known as the Leukemia and Lymphoma Society) patient social network and a large hospital cancer registry.

Inclusion criteria for the study were: Individuals who were 18 years or older at time of enrollment, diagnosed with AML (confirmed with the medical record) identified as Black (self-identified reporting black or African ancestry), ability to converse in English (self-report), and willing to consent to an audio-recorded interview. Individuals were excluded if they were under 18 years of age at the time of enrollment, did not have a confirmed diagnosis of AML, did not identify as Black, were unable to converse in English, refused consent to an audio-recorded telephone interview.

Data Collection

Eligible patients were met in the clinical setting or contacted via telephone by the researcher (NRCA) to determine their interest and eligibility. If they were interested, the study consent was read, and participants were asked to confirm verbal consent. A list of study criteria was provided to the cancer registrar to extract eligible survivors who were listed as living according to the most recent updates. The records were extracted by a registrar and uploaded into a secure electronic environment. The list included first and last names, contact telephone numbers, and AML diagnosis. Each participant was contacted at least twice using the listed contact numbers provided by the registry. Participants were asked to completed an interview that would last up to 30 minutes. Study recruitment ended at 16 participants as data saturation was achieved. In most qualitative studies with narrowly defined, homogenous samples, data saturation, a hallmark indicator of adequate sample size attainment-, can be achieved with 9–12 interviews (Hennink & Kaiser, 2022; Vasileiou, Barnett, Thorpe, & Young, 2018).

The interview guide (Appendix A) was developed using a framework developed by Kallio, Pietilä, Johnson, & Kangasniemi, 2016. Kallio et al.'s framework identifies five phases for interview guide development: 1) identifying the rationale for using semi-structured interview to answer a research question, 2) retrieving and using previous knowledge to have a firm grasp on what is known about the question, 3) creating a preliminary interview guide, 4) pilot testing the interview guide to confirm coverage of relevant content and reformulate questions as needed, and 5) presenting the complete interview guide. A thorough review of the literature was conducted, and knowledge of the literature was used to develop the interview guide. The interview guide was evaluated by a team of experts including a hematologist-oncologist, three advanced oncology practice nurses with expertise in survivorship, a nurse scientist with expertise in qualitative methodology and an advanced practice nurse with expertise in cancer disparities.

Interviews were conducted with no maximum time-limit to provide additional time for participants who felt open to sharing details and providing rich data. Participants were asked about: 1) ways race may have impacted their cancer care, 2) challenges with receiving treatment, 3) challenges with attending

appointments, 4) communication with healthcare clinicians, and 5) how finances may have impacted their experience of having AML.

Qualitative semi-structured in-depth interviews were used to facilitate exploration of participants' experiences. This format also enabled the researcher to improvise follow-up questions based on the participant's responses (Kallio et al., 2016). One-on-one interviews facilitated the exploration of more sensitive topics such as challenges with racism, experiencing discrimination based on insurance status, and difficulties with communication. The use of open-ended questions maximized the opportunity for a more rich and detailed narrative (Guest, Namey, & Mitchell, 2013).

An encrypted SONY digital stereo voice recorder was used to record each interview. At the end of the interview, participants were given a $10 gift card for their time and participation.

Methods

Our analysis was guided by Braun and Clark's (2006) method of thematic analysis. The steps of this analysis were: 1) becoming familiar with the data, 2) transcribing audio, 3) determining and assigning themes, 4) reviewing themes, 5) labeling and giving a description or definition of themes, and 6) reporting results. Audio files were reviewed by listening to the complete audio multiple times. Reflexive journaling was used while listening to the recordings. Transcription involved converting the recorded audio file into a useable format (i.e., mp3). The formatted files were then uploaded into transcription software. The software transcription module was used to convert the audio text into a transcription or written form. The transcribed text was read and re-read to ensure accuracy.

Two authors coded and analyzed the data independently (NRCA and RM). The transcribed audio was coded using inductive coding where codes were derived from the data. Codes were organized into categories that provided meaning to the raw data (Basit, 2003). Using published qualitative literature, each code was assigned relative to the cultural and lived experience of Black cancer survivors (Vaismoradi et al., 2013). Each code was reviewed and compared to other codes that have similar meaning. A codebook was maintained and updated to document: 1) selected codes, 2) descriptions of codes, and 3) an exemplar from the raw data (i.e., a segment of the participant's quote). Codes and themes were reviewed for relevance and soundness of derived themes.

Results

Sample

The study sample included 16 adult Black patients diagnosed with AML. There were 99 Black adult patients with AML identified and retrieved from the cancer registry. Among the sample, 9 were deemed ineligible (4 self-identified as White, 4 had no confirmed diagnosis of AML, 1 was incarcerated), 9 were deceased (confirmed via electronic health records or a family member's report), 3 refused participation

in the study (2 male and 1 female), 19 were unable to be reached because no updated contact information was available, and 37 were unable to be reached after at least 3 call attempts (including voicemails and leaving messages with family members). The final study sample included 16 participants who consented, enrolled and completed the telephone interview. There were 6 biological males and 10 biological females who were diagnosed between 1980 and 2022. The sample age ranged from 38 to 74 years (M = 57.7, SD = 11.57). The time to complete interviews ranged between 12.2 and 57 minutes in length (M = 33.3, SD = 13.3). Among 2 independent coders, the interrater reliability of the sample was 96.7% which was coded using two interviews. Interrater reliability was calculated using the percent agreement method (Belur et al., 2021).

Codes and themes were reviewed by NC, ALB, AM, an expert qualitative researcher in qualitative methodologies and clinical disparities among populations with chronic diseases. NC assisted with relevance and soundness of derived themes.

Themes

Five themes emerged from our qualitative interviews: 1) the disadvantage of being Black with AML, 2) importance of social support, 3) the privilege of receiving high-quality healthcare, 4) the significance of representation in healthcare settings, and 5) the shared experience of isolation. They also highlighted the need for spiritual, emotional, financial, and familial support. Access to clean cancer care facilities, knowledgeable healthcare clinicians, a healthcare team that actively listens were listens were perceived as privileges.. Additionally, they underscored the critical role of Black representation in cancer patients and cancer care teams within the cancer care setting.

The Disadvantage of Being Black with AML. Participants reported that being Black and having AML was often considered a disadvantage or barrier to navigating cancer care. The disadvantage of being Black with AML describes social challenges faced by being Black in the U.S. (i.e., racism, historical trauma, discrimination, etc.) compounded with the burden of having AML (i.e., lengthy aggressive treatment, side effect of disease, side effects of treatment, etc.). In addition to managing AML, patients perceived that they faced poor prognosis and low probability of finding a match for hematopoietic stem cell transplant because they were Black. They also shared that Black patients who have limited or no insurance coverage may not be able to access certain treatment options. One participant stated:

"*…it was almost down to they weren't going to be a candidate for the transplant. Now, we already talking about you got your color going against you for finding a match. And now because you don't have a particular socioeconomic level or group or what have you, then that, you know, that plays - it's like a double edged-sword." (Female, Diagnosed in 2017).*

Another participant described her shock of not being able to access

treatment due to her race:

"….the bone marrow transplant became the issue for me and my race and the inability to find a match because of being African American. Like, that was just shocking news, when, when I was told, most likely, I won't find a match……especially needing that, for the potential of being cured… to be told that your color plays a part in you your cure rate, it just sounds really foreign..." (Female Diagnosed in 2005)

Participants also associated the duality of being Black with AML with not being believed. Entering the cancer care system was difficult because of perceived racial profiling or racial stereotypes. Patients voiced feeling "not heard", "not believed", or feeling clinicians "write [them] off" when they initially presented with signs and symptoms of AML (prior to diagnosis) in primary care and emergency department settings. Most participants perceived that these encounters delayed diagnosis, contributed to disease advancement, and may have led to early mortality. Patients shared the following:

"*Because where I had gone prior to [a large cancer institution], I think that the doctor made an assumption that I was probably just there for pain meds or, you know, attention. And so I was I was ignored a lot. And I think by the time I got to the initial hospital, I got to, after my initial experience…somebody [else] had to take me to the hospital*." (Female, diagnosed in 2004)

One participant who was a young adult at diagnosis, shared how she presented to a clinician with symptoms of dizziness. She was assessed for pregnancy and drug use even after she denied any history of pregnancy or drug use. She stated:

"…No, I've never used drugs in my life. But those are the stereotypic things that happen to young African American or black people, when it is really a disease…And I think that is why I was probably misdiagnosed by saying I was anemic, because it just wasn't that different." (Female, Diagnosed in 1990)

The Importance of Social Support. Each participant described the importance of social support from various sources throughout their time navigating cancer care. Social support describes support for needs that are ancillary to cancer care, which include financial, emotional, and spiritual needs. Within the cancer care setting, support from clinicians, nurses, social workers, and chaplains were perceived as a facilitator of navigating cancer care from diagnosis through survivorship. Supportive care from knowledgeable, approachable, non-discriminatory clinicians and nurses was perceived as a facilitator of navigating cancer care from diagnosis through survivorship. One patient stated:

*"So doctor **** was really, really helpful. He, uh, he explained everything, you know. And he'd always ask me if I've had any questions or anything and you know, I couldn't come up with any questions cuz I didn't know what to ask. You know, I didn't know what I was facing, but for the most part, yeah, he was, uh, he was really good. I wish I could pay him."* (Male, diagnosed in 2020)

Support from family, friends and the community was a facilitator of care for all but one patient. One patient diagnosed in 2020 preferred not having visitors because visitors …*"would have been there just to see how bad off [she]I was ….sometimes people who don't know what to say, they always say the wrong thing"*.

Most patients experienced disruptions at work or at home while managing AML treatments and cancer care. Social workers were pivotal in navigating financial and insurance barriers to treatment. Social workers assisted with finding financial resources, support for childcare, and support groups for survivors of AML, and community resources. One participant described the supportive role of a social worker:

"I think she was like a social worker…So you know, the cancer unit. So she already knew what people dealt with. It's almost like she knew everything. I never (pause) I mean because I wouldn't know what to ask or what I needed or what have you. So I was blessed to get someone who not only knew... but cared. and knew....and she cared enough to jumpstart things..." (Female, diagnosed in 2020)

Chaplains within the cancer care setting and pastoral care and counseling from religious leaders outside of the cancer care setting were salient to a positive care experience. Spiritual care and support were perceived as necessary for survival as participants acknowledge God for sustaining life with AML and for providing an opportunity to receive treatment. Two patients described the impact of having spiritual support as follows:

… And, you know, the recreational therapists came in, we talked, the, the chaplain came and we talked. So it was mostly uplifting, positive conversations. The nurses were wonderful, they took good care of me… (Male, diagnosed in 2020)

"… told him, I said, Pastor, the doctor says that I have leukemia. He says. "What did God say?" And from that day on, I never absolutely felt like I was sick. Although I knew I was, it was, like, I just went about my daily duty, believing that God was going to take care of me. And my pastor constantly he would call he would text." (Male, diagnosed in 1999)

The Privilege of Receiving High-Quality Healthcare. Most participants described how "grateful" and "blessed" they were for having the opportunity of receiving cancer care at a large cancer institution. Receiving cancer care at large cancer centers was consistently a facilitator of successfully navigating cancer care. Participants who transitioned from smaller healthcare facilities to larger cancer centers frequently reported improved interactions with clinicians, nurses, and staff, citing enhanced professionalism, communication, and quality of care compared to their experiences in local settings. Quality of care describes the patient's perception of care experienced during diagnosis, treatment and follow-up visits. The perception of how well goals are met, new experiences of cancer and receiving information impacted a participant's perception of the quality of their care. Most participants in this study reported that they received a high quality of care. They were pleased with healthcare delivery, describing it as "great care," and reported experiencing "equal treatment". Participants were very pleased with their care and communication with their cancer care team. Good quality care was perceived as a "privilege". One participant shared her perspective on race and receiving quality care:

"I knew that I had to come to [a large cancer institution] to get proper care…I knew I was getting sick. And I knew that if I really wanted someone to take me serious, because I had to be at [a large cancer institution]. And that's exactly what happened. Maybe I manifested it…[a large cancer institution] just has a good

reputation for a good reputation from Black people. Black people love coming to [a large cancer institution] and, you know, that's, that's where I want it to be in. They lived up to the name of their good quality health care." (Female, diagnosed in 2021)

Another participant described quality care through her clinician's sacrifice of personal time to monitor her treatment:

"Some of my doctors didn't even take vacations because of the severity of my illness, right. So, you know, you asked me several times have asked me several times, how was my care?... I think care was excellent. I think I had excellent care. Again, and I don't think my race played a part in the actual care that I was getting." (Female, diagnosed in 2020)

One participant requested that his clinicians consider continuing annual follow-ups and surveillance of his cancer. He acknowledged appreciation of high-quality care and voiced fear of experiencing AML again.

"*But, you know, I wish that one of the other doctors would be able to at least check me, you know, each year, okay. And the reason why I would like to at least be checked each year because I knew I know what I had to go through, you know? I don't want something like I don't want that to ever come back on me ever again. Yes, sir. Yes.*" (Male, diagnosed in 2002)

The Significance of Representation in Healthcare Settings. Black participants perceived that having patient-clinician race congruency, access to a Black hematologist-oncologist, Black oncology nursing staff, and access to other Black patients with AML were facilitators to navigating cancer care. Participants shared that, despite having high quality cancer care, increased representation of Black hematologist-oncologists, nurses and patients would have enhanced their cancer care experience. One patient described her experience of being a Black woman with a primary care clinician who is a Black woman. She shared that:

"Um, well, my primary care physician, she is a Black woman, and she understands me well, and I, and I could talk to her, you know, I could just freely talk to her and tell her my problems, you know, about, you know, what I want to see done for my health, and she understands, and I feel comfortable doing that, that's so important, you know, yeah. So there was a team around me that included women, it would have been nice to see some Black women included in that team…you want to feel like that your life is important to the person that you're dealing with….I did not have that type of connection with him." (Woman, diagnosed in 2021).

Another participant shared the difference between a having a Black female clinician and a White male clinician. She shared that:

"…when we start looking at how women are treated, and whether or not these drugs have been tested on women or not, and these are questions that I can ask my Black physician or my female physician and she knows exactly what I'm talking about when I started talking about representation, and whether or not we know how this is really going to affect me as a woman, or how this is really going to affect me as a Black

woman…I actually had a White male oncologist…and I really didn't have that feel with him.” (Female, diagnosed in 2017)

The Shared Experience of Isolation. One participant perceived the precautions required to prevent the COVID-19 virus (COVID-19) as a facilitator to her experience of cancer care. She did not report having COVID; however, she compared COVID and precautions (i.e., social distancing, wearing a mask, isolating with active virus, and fear of transmission) related to the virus to AML and protective precautions recommended for patients (i.e., wearing a mask, avoiding crowded areas, abstaining from fresh flowers, and isolating from anyone who is ill). She described how the general population may be able to empathize with patients with AML after having experienced COVID. She shared that:

“…AML, it's sort of like I had COVID, I was dealing with COVID, before COVID existed, it's the same thing you have to really distance yourself from people. I wasn't able to really hang out with friends, wasn't able to go to certain social events, I wasn't able to really go to my kids functions when I wanted to. My immune system was compromised. So that was a big deal. I wasn't able to really be around people in the same way. And I don't think people really understood it. So once COVID-19 started, I think people really start to get it, that if you're immunocompromised, you're dealing with this all the time, not just, you know, I'm dealing with it during flu season…So I think people have a greater understanding of what it feels like, I'm not just telling you, I can't come and hang out with you because I want I don't want to hang out with you. I'm saying it because it could be detrimental to my health.” (Female, diagnosed in 2017)

Discussion

Our qualitative study explored the experiences of 16 Black adult patients with AML while navigating the cancer care system between 1990 and 2022. Our findings contribute to a growing body of evidence documenting persistent inequities within cancer care and provide important insight into the specific barriers and facilitators that shape care experiences among Black patients with AML. Three overarching findings emerged from this study. First, participants described experiences of dismissal, discrimination, and not being heard within healthcare settings. Second, participants perceived race as a barrier to accessing potentially curative treatments, particularly stem cell transplantation. Third, social support from individuals within and outside the healthcare system served as a critical facilitator of cancer care.

Our findings suggest that being Black with AML was perceived as a disadvantage and a barrier to navigating cancer care. Participants described experiences of not being heard, having symptoms dismissed, and being perceived as drug-seeking, all of which negatively influenced their healthcare experiences. These findings provide contextual support for quantitative studies demonstrating that Black patients with AML experience lower survival rates, lower receipt of chemotherapy, and lower utilization of stem cell transplantation compared with White patients (Bierenbaum et al., 2012; Bradley et al., 2011; Dong et al., 2024; Eisfeld, 2024; Freeman et al., 2016). Bradley et al. (2011) found that uninsured patients were most likely to be Black and were four times more likely to forgo chemotherapy, while Black patients with Medicaid or no insurance experienced higher mortality than patients from other

racial groups. Although quantitative studies have identified disparities in treatment and survival (Bierenbaum, et al., 2012, Bradley et al., 2011), our findings offer insight into potential mechanisms that may contribute to these inequities. Experiences of dismissal and discrimination may undermine trust in healthcare clinicians, delay timely evaluation of symptoms, and discourage future engagement with healthcare services. Given that AML often presents with non-specific symptoms and requires prompt diagnosis and treatment initiation, feeling unheard by healthcare clinicians may have particularly important consequences for treatment outcomes. These findings are consistent with prior qualitative work among Black patients with colorectal cancer who reported experiences of dismissal, discrimination, and inadequate communication during cancer care encounters (Garrett et al., 2024). Collectively, these findings suggest that disparities in AML outcomes may be influenced not only by structural barriers to care but also by the quality of interactions patients experience throughout their cancer journey.

A particularly important finding was participants' perception that race reduced their likelihood of receiving a stem cell transplant or finding a suitable donor. Historically, Black patients have faced lower probabilities of identifying fully matched unrelated donors because of underrepresentation in donor registries and greater genetic diversity among individuals of African ancestry (Gragert et al., 2014). However, advances in transplantation over the past two decades have dramatically expanded donor availability and access to potentially curative therapy. The development of haploidentical transplantation, expanded use of cord blood transplantation, and improvements in graft-versus-host disease prophylaxis have made transplantation feasible for nearly all patients with an appropriate clinical indication, even when a fully matched unrelated donor is unavailable (Hwang et al., 2022;). Therefore, the perception among some participants that they could not undergo transplantation because they were Black is particularly concerning. While these perceptions may reflect historical realities, especially among participants diagnosed during earlier treatment eras when donor options were more limited, they may also reflect communication gaps regarding contemporary transplant practices. Importantly, participants appeared to interpret racial disparities in donor matching as evidence that transplantation was unattainable rather than understanding that alternative donor strategies may provide viable treatment options. This distinction is clinically meaningful because perceptions of transplant ineligibility may influence treatment expectations, willingness to pursue referral, decision-making, and overall hope regarding prognosis. Our findings therefore highlight an important opportunity to improve patient-clinician communication surrounding transplant eligibility, donor availability, and evolving advances in transplantation. Ensuring that patients receive accurate and understandable information regarding treatment options may help reduce misconceptions, support informed decision-making, and improve confidence in care planning.

Another notable finding was the central role of social support as a facilitator of cancer care. Participants described receiving support from family members, friends, faith communities, and healthcare clinicians that helped them navigate the emotional, logistical, financial, and spiritual challenges associated with AML treatment. These findings are consistent with literature suggesting that social support serves as a protective factor that helps individuals cope with cancer-related stress and improves engagement with

care (Bottaro et al., 2023). For patients undergoing intensive AML treatment, which often requires prolonged hospitalizations, frequent clinic visits, and substantial caregiver involvement, social support may be particularly important for maintaining treatment adherence and quality of life. Participants frequently described supportive individuals as helping them access resources, overcome barriers, and persevere through difficult treatment experiences.

Interestingly, despite reporting negative experiences prior to diagnosis, participants generally described receiving high-quality care once they entered specialized oncology settings. Access to high-quality cancer care was often characterized as a privilege, blessing, or fortunate circumstance rather than an expectation or right. This finding may reflect broader concerns regarding healthcare inequities and perceptions that access to quality care is not equally available to all patients. While participants reported positive experiences with oncology teams, earlier experiences of dismissal and discrimination may have influenced their expectations of care and contributed to broader feelings of medical mistrust. Previous studies have shown that experiences of discrimination can contribute to mistrust in healthcare systems (Armstrong et al., 2013; Williamson et al., 2019). Mistrust may influence patient engagement with healthcare services, including cancer screenings. Consequently, efforts to improve equity in AML care should address not only access to treatment but also the quality of communication and interactions that occur throughout the diagnostic and treatment continuum.

Finally, participants described unique challenges associated with navigating AML during the COVID-19 pandemic. COVID-19 precautions were often compared with precautions routinely required to protect immunocompromised patients with AML from infection. One participant noted that the pandemic helped others better understand the social isolation, physical separation, and anxiety frequently experienced during cancer treatment. While previous qualitative studies have primarily emphasized heightened fear, uncertainty, and psychological distress associated with COVID-19 among patients with cancer (Rodriguez et al., 2023; Treiman et al., 2022), our findings suggest that the pandemic also created a shared frame of reference through which some participants felt their experiences were better understood by others. At the same time, participants recognized that their immunocompromised status placed them at heightened risk for COVID-19 infection and adverse outcomes, further compounding the challenges of cancer treatment.

Taken together, these findings suggest that disparities in AML care are shaped by more than treatment availability alone. Participants' narratives highlight the importance of equitable healthcare interactions, accurate communication regarding treatment options, and access to supportive resources throughout the cancer continuum. Interventions designed to improve communication about transplantation, address discriminatory healthcare experiences, and strengthen social support systems may represent actionable strategies for reducing disparities and improving outcomes among Black patients with AML. Given the curative potential of contemporary AML therapies and transplantation approaches, ensuring that all patients receive accurate information, equitable treatment, and opportunities to participate in treatment decision-making remains a critical priority.

Limitations

Our study provides data about understudied experiences of Black patients with AML who are navigating cancer care. The findings provide detailed empirical data for Black patients' perspectives of navigating cancer care. The qualitative data from our study may provide support for informing quantitative studies addressing racial disparities in cancer care. However, there are several limitations of this study.

One study limitation was obtaining our sample from a single large comprehensive cancer center. All patients were treated at the same center; therefore, generalizability of our findings is limited to the experience of Black patients receiving treatments in similar settings. Another limitation is that our study was retrospective, whereby patients were asked to recall and reflect upon past experiences. In some cases, these experiences occurred over 10 years prior to the interviews. While they shared detailed accounts of their experiences, our findings are subject to possible recall bias based on the retrospective nature of the interview.

A unique challenge for our study included the recruitment of an underrepresented sample of patients with a rare disease in the setting of the COVID pandemic. We had to overcome difficulties achieving sufficient enrollment to achieve thematic saturation. Finding patients who met the inclusion criteria and were willing to enroll was challenging. This was likely due to the rarity of illness, the average age of patients with AML (over 65 years), impact of COVID-19 (more patients opting for virtual healthcare services), decreased interest in discussing cancer treatments, busy work-life schedules, and no updated contact information. Each participant was contacted at least twice using the listed contact numbers provided by the registry. This study uniquely utilized multiple methods for recruitment including engagement with community support organizations, accessing established databases, and using multiple interview strategies to accommodate participants' availability. These strategies may be useful for future studies conducting qualitative work with hard-to-reach populations.

Conclusions

Despite the study's generalizability being limited to large academic cancer care setting, the findings highlight several cancer care challenges for Black patients. These findings can be used to promote practice changes to improve health and quality care outcomes in similar cancer healthcare facilities. Our study provides evidence for intervention studies in the primary care and emergency department settings to improve communication between Black patients and clinicians. Studies are needed to develop a blood cancer diagnosis pathway, which may provide a standardized way to escalate care for patients who present with signs and symptoms of blood cancers. A diagnosis pathway may trigger a cascade of assessments and tests when patients present to primary care or emergency departments settings with specific signs and symptoms of blood cancers. This mechanism may mitigate patients' more negative encounters of feeling unheard, not believed and dismissed. This mechanism may also reduce the time to diagnosis for patients with undiagnosed AML which may reduce survival disparities.

Additional studies are needed exploring the experiences of patients navigating cancer care after receiving treatment in a variety of healthcare facilities: Community centers, regional hospitals, home health infusion and ambulatory care clinics.

Abbreviations

AML
Acute Myeloid Leukemia

Declarations

Ethics approval and consent to participate

This study was approved by the Duke University IRB (protocol # Pro00106597). Participants provided informed consent to participate.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Author Contribution

NCA, ALB, TWL, and AM conceived the study. NCA drafted the manuscript. The interview guide was designed by NCA, AL, and AM. NCA, TWL, ALB, AM, and NC participated in recruitment. RM and NCA transcribed and coded data. NC managed the project. NC and TN ensured that funding for the study was secured. TN, TWL, NCA, AM, and AL reviewed and revised the manuscript with substantive feedback. All authors contributed to the review and approval of the final version of the manuscript.

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Data Availability

The audio-recorded and transcribed data analyzed within this study are not publicly available due to the need to protect identifiable and sensitive participant data. Requests for de-identified data may be submitted to the lead author. All requests will be reviewed and approved by the authorship team and the ethical review board prior to release.

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Figures

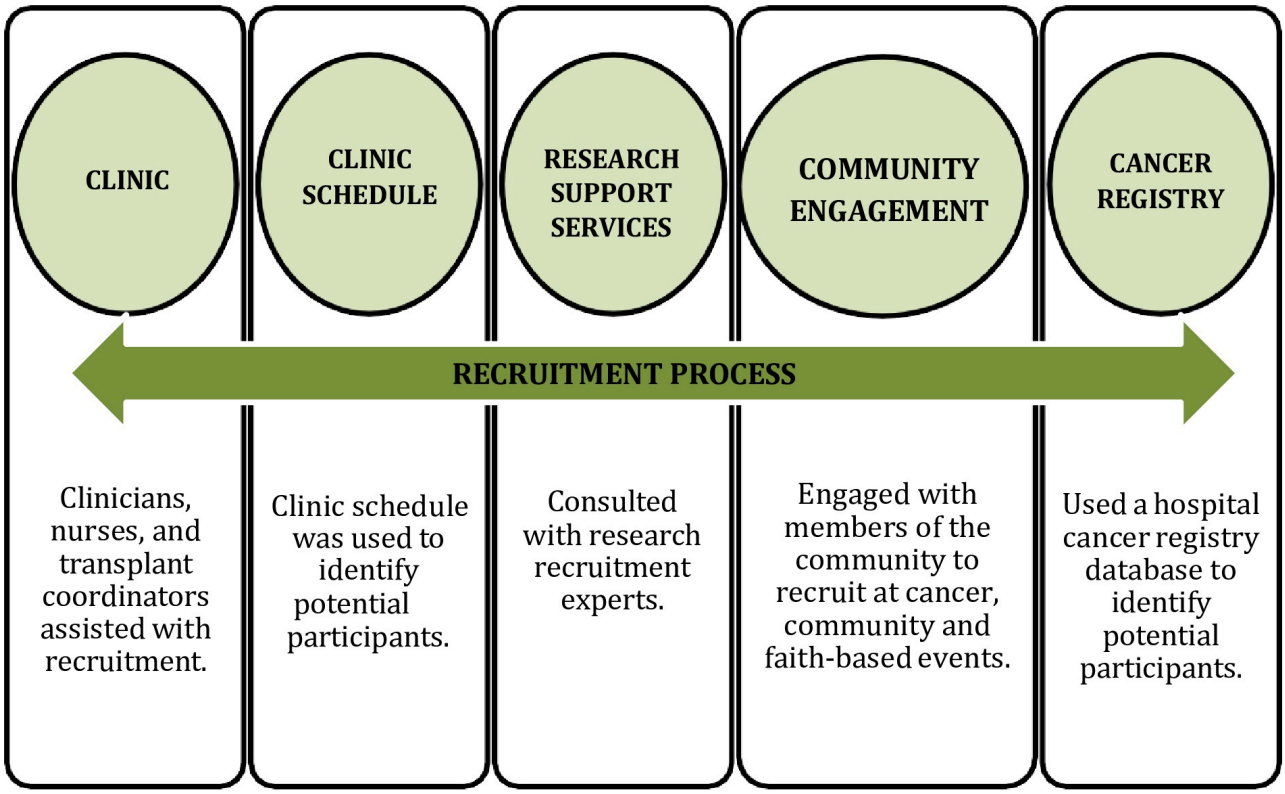


Figure 1: A graph of strategies used to recruit a sample of adult Black patients diagnosed with AML

Figure 1

See image above for figure legend

Supplementary Files

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