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Experiences of racism in healthcare and medical mistrust shape cancer prevention and control behaviors among Black residents of Black Hawk County, Iowa: a qualitative study

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Abstract

Background: Non-Hispanic Black Iowans have substantially higher incidence of and mortality from cancer than their non-Hispanic White (NHW) counterparts in all but the oldest age groups; rates are particularly high in Black Hawk County, which contains the city of Waterloo, a highly segregated city with a documented history of redlining and distinct racial differences in the social drivers of health.

Objective: To gather perspectives on race, racism, healthcare, and engagement with cancer prevention and control behaviors, among Black individuals living in Black Hawk County, Iowa.

Methods: We conducted semi-structured interviews with 20 individuals (10 male, 10 female); questions included experiences in healthcare, and feelings towards the healthcare system; trust of the healthcare system; experiences of racism or other perceived biases within healthcare; and, how experiences of racism/bias, and/or feelings towards the healthcare system impact desire or ability to participate in cancer prevention and control activities.

Results: Almost all interviewees reported both positive and negative experiences in healthcare. Nine themes emerged from analysis of the interviews: everyday racism and racism in healthcare; medical mistrust; need for more Black healthcare professionals; communication with healthcare

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Consent to Participate: All study participants reviewed a study information sheet and gave verbal consent prior to interview. Verbal consent was deemed preferable to written consent for this study, due to the minimal risk associated with participation. A waiver of documentation of consent was approved by the University of Iowa Institutional Review Board.

professionals; need to break down cultural stigma around cancer; need and desire for community education around health and cancer; ability to choose; self-advocacy; and social support.

Conclusions: There are substantial barriers for Black individuals engaging with cancer prevention and control behaviors in Iowa. Multi-level interventions are needed to address structural, healthcare facility, and individual-level barriers to care; interventions may build on existing resiliencies within the community.

Keywords

Racism; cultural stigma; Midwest; cancer screening

INTRODUCTION

Social drivers of health, which may account for up to ~80% of differences in health outcomes,[1] are directly related to systemic and structural racism (i.e., racism that is embedded throughout systems, laws, policies, and practices).[2] Mechanisms include racial residential segregation, which serves as a foundation for disinvestment in infrastructure, including medical infrastructure, residential infrastructure, and transportation.[3] Disinvestment results in unsafe living environments, increased stress, and difficulties in accessing medical care, which in turn creates unequal opportunities for the pursuit of health.[4] These structural and social inequities disproportionately affect Black communities in the U.S., resulting in observed disparities in a wide array of health outcomes.[5]

Cancer disproportionately affects Black communities in the U.S., with Black people having the highest death rate and shortest survival in the U.S. for most cancers.[6] Cancer incidence and mortality rates are highest for Black Americans throughout the Midwest (i.e., WI, IA, NE, IL, MO) and into the Deep South (i.e., LA, MI, OK, AR), with the highest incidence and mortality in Iowa and Wisconsin.[7] In Iowa, the non-Hispanic Black population has substantially higher incidence of and mortality from cancer than their non-Hispanic White (NHW) counterparts in all but the oldest age groups, and higher cancer mortality than every other race group.[8] The causes of these disparities are likely multifactorial, including structural racism, as well as social drivers of health (i.e., conditions in the environments where people live).[9] For example, the city of Waterloo, Iowa has a documented history of redlining[10] and racially-restrictive housing covenants,[11] which forced and perpetuated segregation. In 2018, Waterloo was rated as the worst city in the U.S. for Black Americans [12] with striking differences in social drivers of health including unemployment, median income, and homeownership.[13] Social and structural drivers of health may directly impact cancer incidence and mortality disparities, such as through differing access to insurance to pay for cancer care, screening services to diagnose cancers at earlier stages, cancer treatment, or culturally sensitive healthcare.[14, 15] Furthermore, they may also affect downstream factors such as individual-level cancer preventive behaviors including nutrition choices, physical activity, tobacco use, healthy weight maintenance, and stress.[9]

The purpose of the present study was to gather perspectives on racism, healthcare, and engagement with cancer prevention and control behaviors, among Black individuals living in or around Waterloo, Iowa (i.e., in Black Hawk County). Our rationale for this work

was that by better understanding community perspectives on cancer screening, treatment, and clinical trials, interventions designed to address barriers to engaging with healthcare and cancer prevention/control may be more responsive to community needs, and therefore stand a higher chance of success. While this study focuses on the experience of Black Iowans living in Black Hawk County, we anticipate that these findings may be more broadly applicable, given the historical and modern prevalence of social and structural drivers of health that create health disparities affecting minoritized communities across the U.S.

METHODS:

Ethics

This study was approved by the University of Iowa Institutional Review Board. All study participants reviewed a study information sheet and gave verbal consent prior to interview. Verbal consent was deemed preferable to written consent for this study, due to the minimal risk associated with participation. A waiver of documentation of consent was approved by the University of Iowa Institutional Review Board.

Approach

Our research process was informed by the principles of community-based participatory research (CBPR).[16] In 2022, the Holden Comprehensive Cancer Center at the University of Iowa was awarded a National Cancer Institute Community Outreach and Engagement Cancer Center Supplement to engage with members of Iowa's Black community to understand cancer concerns and needs. We brought together community members in the City of Waterloo, Iowa, to comprise the Black Hawk County Health Equity Steering Committee. Among the priorities identified by this committee was racism experienced in healthcare by Black Iowans, and its potential relationship to cancer disparities. This priority became the foundation of the present study. Our research questions were developed in collaboration with one of the members of the Black Hawk County Steering Committee, who joined our research team as a community collaborator (AV). We finalized four primary research questions that we wished to answer during the process of our interviews: 1) What are community members' experiences with the health care system and their perception of the health care system? 2) What factors influence community members' trust in the health care system? 3) What are community members' experiences and perceptions of racism in the health care system? 4) What factors influence community members' participation in cancer prevention and control activities?

We chose a qualitative descriptive study design, using semi-structured interviews. The interview guide was developed iteratively by AW, AV, and SN; each interview question was selected to directly address one of the above defined research questions. We paid specific attention to literacy and language to ensure that questions would be understood by all potential participants. Interview questions are given in Table 1.

Recruitment

Eligibility criteria for this study included being a resident of Black Hawk County, Iowa, identifying as Black or African American, and ability to complete the study interview

in English. Eligible individuals were initially identified by our community collaborator (AV), who utilized her existing community connections to share information regarding the study and the need for potential participants. Further interviewees were identified using the snowball sampling method. This study aimed to recruit n=20 individuals; including ten individuals identifying as male and ten female; although recruitment was not strictly stratified by age, we did aim to include a roughly equal mix of people in the following age categories: <40y, 40–59y, and 60+y. We offered \$30 to compensate each participant for their time.

Interview procedures

All interviews were conducted using videoconferencing technology (Zoom Video Communications, Inc, San Jose, CA). Before beginning each interview, participants were read the study information sheet and asked permission to have their interview recorded; an electronic copy of the study information sheet was also provided to each participant electronically ahead of the interview so that participants were able to review, discuss with friends and family, and bring any potential questions to the scheduled interview. All interviews were completed by one academic researcher (AW) and the community collaborator (AV). The community collaborator led the interview, asking all questions, and the academic researcher was the primary notetaker; both asked follow-up probing questions. On average, interviews lasted around 64 minutes. Interviews were digitally recorded using two handheld audio recording devices along with zoom recording. Recordings were then transcribed using Rev, a secure online transcription service; all identifying data was removed from transcripts by the researchers before analysis.

Data Analysis

Qualitative data were analyzed using a multi-phase thematic analysis.[17] All qualitative analysis was conducted using Dedoose version 9.0.86 (SocioCultural Research Consultants, LLC, Manhattan Beach CA). Two study team members (AW and SN) developed a list of *a priori* codes, informed by conversations with the Black Hawk County Health Equity Steering Committee, and the theory of fundamental causes.[18] Additional emergent codes that arose from reviewing the data were defined based on an initial review of 4 transcripts (AW, SN), and the codebook finalized. All transcripts were then (re)coded using an iterative process: initial coding was completed by AW; SN then reviewed all transcripts and codes, and flagged codes for discussion where there was any disagreement; AW and SN then discussed any discrepancies until consensus was reached. Themes were identified through an iterative process of data visualization and reduction (AW, SN), first condensing overlapping codes, and removing unused codes, then reviewing all codes to determine areas of co-occurrence and possible data reduction. Preliminary themes were presented to AV for discussion and finalization. Themes were then presented to the Black Hawk County Health Equity Steering Committee for review and feedback.

Positionality:

This research was conducted by individuals who hold identities and experiences that necessarily impact the way they engage with research and interpret research findings: their positionality.[19] The research team actively acknowledged and considered their relative

position to the participants of this interview study throughout its conduct. Relevant identities of this research team include Black woman (AV, AW), White woman (SN, RH, NA), academic faculty (SN, RH, NA), student (AW), and community member (AV).

RESULTS

Demographic characteristics

We interviewed twenty individuals; per inclusion criteria, all interviewees were current residents of Black Hawk County, Iowa or had lived in Black Hawk County for multiple years, and who self-identified as Black or African American. Half of the study participants were male and half were female. Four participants were aged 40 years or less, while eight were between the age of 40 – 59, and eight were above the age of 60 years. No additional demographic information was collected from participants.

Interview findings

Almost all interviewees reported both positive and negative experiences in healthcare. Nine general themes emerged from analysis of the interviews; of these, six we considered barriers to engagement in the healthcare system, and three we considered facilitators. Barriers included: everyday racism and racism in healthcare; medical mistrust; need for more Black healthcare professionals; communication with healthcare professionals; need to break down cultural stigma around cancer; and need and desire for community education around health and cancer. Facilitators included: ability to choose; self-advocacy; and, social support.

Everyday racism and racism in healthcare: In interviews, we identified mentions of racism experienced within everyday life (including historical trauma), and experiences of racism specifically within the healthcare setting. Individuals reported that both types of experience impacted their desire and ability to engage with healthcare, including through medical mistrust and healthcare avoidance. One participant talked directly about their perception of healthcare providers in their community, and their belief that internalized bias may impact quality of care; *“I know the doctors know the health disparities. I know the doctors know how they treat all their patients. So if they have patients that don’t look like them and they don’t treat those patients like they treat their other patients, then that’s something that they need to work on themselves because they took an oath when they said that they were going to do this work, they meant for everybody.”*

Participants reported a lack of recognition or addressing of historical trauma within healthcare in their community; described how they felt systemic racism was embedded in the healthcare system; and perceived that implicit biases impact the way non-rationally concordant physicians provided care. Some individuals described stereotypes of Black patients that they had encountered in their healthcare experiences, such as not being offered pain management when clearly in pain during a medical procedure. Individuals also described racism “blanketed under kindness:” showing up as microaggressions, or physicians’ lack of knowledge about how to treat patients that do not look like them, perhaps due to lack of experience. One interviewee described the following experience while having a biopsy: *“I had found a kind of lesion on my shoulder and... he had to take a biopsy, but he*

made the comment ‘I’m not sure how it will heal on Black skin compared to the White skin.’ And so he kind of talked about how that lesion may possibly look or scar. So that’s kind of why I was thinking, ‘oh, he hasn’t had much experience with Black individuals.’” Experiences of everyday racism or racism in healthcare were described by almost all of our study participants, perhaps indicating its importance in shaping engagement with the medical system among this community.

Medical Mistrust: Medical mistrust can be defined as an absence of trust that health care providers and/or healthcare organizations genuinely care for patients’ interests, are honest, practice confidentiality, and have the competence to produce the best health outcomes.[20] It is a response to systems and experiences of oppression.[21] We specifically asked our study participants whether they trusted the medical system, as well as their reasoning for their trust (or lack thereof). Many interviewees reported that while they might trust individual providers, they did not trust the medical system, including healthcare institutions and health insurers: *“I trust individuals. I don’t trust the institution.”* In part, this was because healthcare is not independent of the society within which it exists, and therefore seen as containing the same structural and systemic biases: *“So, my trust of medical of healthcare is the same as society. It’s not independent. It’s not like if racism and sexism and bias and all of these things exist in society, it permeates healthcare as well in the same way.”* Some specifically referred to historic medical research abuses (e.g., the Tuskegee Syphilis Study) as shaping their perspectives, and specifically impacting their desire to participate in cancer clinical trials: *“No, I do not [trust the medical system]. Historically they have proven through time and time again, that people such as myself are tools of experimentation, and that having not only taught to me, but I’ve done research myself of how people of color have always been physically instruments to poke and prod. And so I would find foolish to trust entirely the motives of the medical community.”* Very few of our participants expressed a willingness to participate in clinical trials: *“I can’t not think of how that has gone poorly for people before me, even with medical advancements, people of color have still been on the short end of the stick when it comes to healthcare and medical care. So I could not in good faith believe that being a part of medical trial would be to my benefit.”* However, some said that they might change their mind if they were put in the situation of being directly asked to participate in a clinical trial: *“I don’t think I would want to be in one those clinical trials. I mean, I do want to see research grow further and study and stuff, but at the same time, I don’t know. But you never know. I can’t say until I’m in that position. You know what I’m saying? Your mind could change quick.”*

Individuals also expressed that their community has very specific mistrust of the providers in their home community of Waterloo, causing many to seek care outside the community (see theme: Ability to Choose). This may be driven by the tight-knit nature of the community, and the sharing of information such that if one person has a bad experience, they will share that experience with others.

Need for more healthcare professionals of color: Individuals in our study reported very few instances of racial concordance with healthcare providers. When participants did report seeing a racially concordant provider, they felt heard, they were able to better

communicate, and were more trusting. One participant described their experience with a racially concordant provider in the local community: *“Not only did they listen to me, they were more attuned with what was going on with me than I would even be aware of. I could go to them with concerns and they may say historically this is something we experienced, and I would be able to identify what they’re talking about... So there was kind of a familiarity that I had with them that I wasn’t able to identify with other physicians.”* Individuals expressed that non-concordant providers did not share their same experiences and understanding towards the medical system: *“I was taken back at how many physicians in the room were not aware of the Tuskegee airmen experiment.”* This lack of shared experience and understanding affected individuals’ trust in their providers, and may have limited communication between patients and providers.

Communication with healthcare professionals: Participants who did have trust in their provider or healthcare system often stated they had a long-term relationship with their doctor; that they felt like their provider cared about them and took the time to learn deeply about their medical issues. In general, those who reported good communication with providers also reported that they received high quality medical care. One participant described discordance between the communication they wanted from their physician, versus their experience: *“There was not a conversation about the illness. There was no real explanation of what was going on. The only way I can explain it is when you go to a restaurant and the waitress takes your order and gives your food. Yep, that was okay that she gave your food. But then you go to another restaurant and she has a conversation, how are you doing? It’s a nice day. That experience is totally different than the other experience. And that’s kind of how I would look at those is it was very... I don’t know, just generic and mechanical.”*

Some participants expressed that they had experienced a lack of depth of communication, with unclear or inadequate explanations for tests ordered or medical options presented. Participants reported that physician lack of communication around medical decision-making may lead to lack of patient understanding and frustration. This frustration was described by one participant, who felt their physician had not well communicated why they did not recommend the participant (their patient) for a cancer screening test: *“And I feel like why do we have to fight with you guys? I understand there’s age guidelines. I understand there’s things, but you know that things are changing. People are catching things at a younger rate. People are dying younger. Run the test. If the signs and symptoms are there, run the test. What harm is it going to do? Come back negative? But that’s not what’s been happening, has it?”* Further, it was evident that trust and action are two separate concepts: one can trust one’s provider, but this trust has to be verified in the actions the provider takes (i.e., following up on the things one says one will do for the patient).

Cultural norms around healthcare and cancer: Almost all interviewees discussed cultural norms in which they only seek medical care as a last resort and if critically necessary. For a variety of reasons including mistrust, historical violence toward Black people within the medical system, and prior negative experience, participants talked about preferring to turn to their own community for health-related needs rather than the medical

system. One participant described: *“But as history has it, most people don’t want to go to the doctor. Why is that? It’s just from years ago, I suppose, just something that they try to self-diagnose self and take care of self, which always don’t come out or then it gets too bad and too late and then they go to the doctor.”* We heard that this lack of trust may be related to racism, both within and towards the community: *“...[M]y parents’ generation, there’s a mid-generation where they don’t trust Black doctors, even Black people because racism is so indoctrinated that the images that White people get that make them think that Black people are less than. Black people have been fed those same images, too, so there’s many Black people that feel a Black doctor wouldn’t be as good as a White doctor themselves.”* In addition, lack of comfort with engaging with the medical system may have roots in childhood access and insurance: *“But then I look at my husband and there has to be damn near bone poking out of his body before he goes to a doctor because he didn’t come up in an environment that had insurance all the time.”*

Because of the stigma associated with cancer itself, many participants noted that cancer wasn’t something that was talked about in the community: *“It’s something that’s not taught in our community. I don’t really hear about it as much, unless it’s a family member who may have cancer, who had cancer, but it’s just never brought up to me.”* Interviewees reported that, in part, stigma may occur because there was a perception in the community that once they heard of a friend or family member being diagnosed with cancer, this was often followed by news of that individual’s death. Thus, many in the community hold a (mis)perception that a cancer diagnosis is always fatal. However, there were indications this lack of desire to talk about cancer may be generational, with the older generations less likely to discuss their diagnoses than those who are younger. One participant described this phenomenon: *“Because of the education. I mean, growing up, man, everybody who had admitted they had cancer, they ended up dying. Usually, when a person died, you wouldn’t even know they had cancer until they was dead... Probably up until about 10 years ago, you hardly ever heard men saying or somebody, ‘Hey, I got prostate cancer.’ Black men just wouldn’t say that’s what it was. Now, I’ve had a number of my friends that say, ‘Hey, man, I got prostate cancer. I’m glad I got it caught early. I got screened early. I’ll be fine.’”*

Further, individuals expressed their community may hold attitudes of fatalism in who does or does not develop cancer, which may contribute to individuals’ desire (or lack thereof) to the stigma surrounding cancer. One participant noted: *“I think that Black people have a general, ‘Oh, you don’t know what’s going to happen because some people get it, some people don’t.’ It seems like crap shoot more than a preventable situation.”* Another participant described this as a lack of agency in the context of community attitudes towards cancer screening: *“Are you going to vote? No. Why? What different does it make? They going to do what they want to do?” Well, that’s the way they feel about screening for cancer. “What different do it make? If I got it, I got it.”* It was noted that educating community members could be one way to address fatalism regarding cancer, and to support community members in both talking about cancer, and engaging in cancer prevention and control behaviors.

Need and desire for community education around health and cancer: Many participants, especially those who were younger, expressed a desire to talk about cancer

within their community. Yet, despite this desire, individuals reported that they did not always feel like they were equipped with the knowledge to have such conversations. Thus, they identified a need for community education around cancer, citing that education may address both lack of knowledge, and cultural stigma surrounding cancer. Every individual interviewed shared that there was a lack of knowledge around cancer, either their own, within their circle of family and friends, or in the broader community. Individuals reported a lack of knowledge about the causes of cancer; where or when to get cancer screening; knowing how and when to self-check; and, the purpose and benefit of clinical trials in cancer treatment. Information did not necessarily have to be provided by healthcare or providers; indeed, several participants noted faith-based organizations as trusted partners in information sharing in the community. Participants also noted a general need for information on how to engage with their healthcare providers, including what questions to ask their provider about cancer and cancer prevention activities (e.g., screening).

Ability to choose: This theme encompassed several independent but interrelated concepts. First, participants noted the importance of health insurance in determining what healthcare providers one can see, and what healthcare (prevention, treatments, etc.) one is able to access. The lack of insurance and/or ability to choose on low-cost plans may impact healthcare participation even when an individual has insurance; individuals without a history of insurance may be hesitant to engage even after acquiring the coverage to do so. Insurance-related ability to choose was strongly related to poverty and socio-economic status. One participant noted: *“It’s very limited. With Title 19, I feel like we don’t have too many options. Me myself, you really don’t get no background, none of that. You just select someone, and that’s just what I did. I just basically, okay, whoever you got open.”* Some also lamented the lack of choice, specifically regarding the ability to get low-cost or free screenings in-community, particularly for those of low income.

Ability to choose also encompassed seeking care outside of the community when desired. While most participants reported seeking routine or primary care within their home community, almost all individuals who had more serious medical issues (including cancer, and other chronic disease management) reported that they chose to seek care for those issues outside of the community. Two facilities, both located <2 hours from Black Hawk County, were identified as places that people looked to for complex medical care: *“So when dealing with cancer, we’ve seen too many people of color die here in Iowa by sticking to [named local hospital]. And so it has become a consensus with the people I know and the people in my close-knit community that when it comes to our life and cancer, we are not going to leave it in the hands of [local] doctors. We are going to go to [named facility outside the community] if we can, if our insurances will allow.”* This ability to choose was closely linked with medical mistrust; and with specific mistrust of Black Hawk County and/or Iowa providers. As another person phrased it: *“No, you need to stop dealing with local, go to [named facility outside of the community],” because the reason why I said [aforementioned facility], they have a lot more resources, they have a lot more experience in dealing with a variety of things.* Participants shared that their community understood that the resources, and the best doctors, were more likely to be found outside of their local community.

Self-advocacy: Multiple participants reported the need to self-advocate during receipt of medical care (not necessarily directed specifically at cancer care); this involves self-trust and self-awareness: *“[that] is when I start to be more aware of my health. I figured out that I needed to be my best advocate at that time, and I was not going to let somebody tell me how I was feeling or was not feeling”*. In some cases, participants reported feeling like they had to work hard to get the care they felt that they should have received initially. Sometimes, participants reported the need to be firm in the face of resistance from their healthcare provider: *“My [relative] has a brain aneurysm, and she had to fight with them to get a referral to [facility outside the community].”*

Participants also identified the need to self-educate: *“Immediately I just look for information. The man gave me a procedure. I came home and got on my computer. “Now, what did he just do to me and why?”*. Education was identified as a way of creating confidence to engage in decision-making with one’s provider: *“But I feel I know what to ask a doctor and I know how to talk to a doctor to get what I need.”* Individuals also identified that being educated on a topic, and bringing questions to medical appointments may have affected the quality of care received: *“I think the ones with my sister were very good. And I think the reason why they were is because of the questions I asked them. They didn’t know where I got my questions from, but they knew my questions were knowledgeable questions. They knew that there was somewhere somehow that I would not have asked those questions if somebody hadn’t been talking to me.”* Having personal experience in healthcare was noted to support the ability to advocate for self and others, and some individuals identified that sharing knowledge as a responsibility of those with the education: *“We need to be better advocates for ourselves. And by doing that, really pulling out the Black medical voice and calling on the Black medical community to see that as a charge and a responsibility for them...”*

Social support: Our interviews indicated that the ability to self-advocate and support one another in pursuit of high-quality, culturally-competent healthcare was a strength of this community. Having friends or family with experience or knowledge (including connections working in healthcare, or experiences with cancer) was reported to support and navigating the healthcare system. One individual reported how having a friend who was a doctor was invaluable in helping her self-advocate to get the right care *“it was my friend who’s a doctor who told me, she was like, “Yeah. No, you cannot be stuffing yourself full of antibiotics.” She was like, “No, don’t take that.” She was like, “Find you an OB-GYN and get in.” And my friend is Black, and she’s a doctor in the city.”* Support systems also provide logistical support, including transportation to appointments, and caregiving. Further, individuals noted the importance of having a system to support difficult journeys; several individuals mentioned support groups that had been founded within the community to support those going through similar experiences.

Having a social structure in place also was noted to reinforce healthy behaviors: *“being around healthy people, all my friends are healthy,”* as well as support conversations around health: *“And my golfing buddies, we all talk about health. That’s pretty important to us.”* Several individuals noted this specifically in the context of cancer screening: *“I do know I have to believe that people in my community want to get screened. I partially believe*

people in my community want me or you to say “[Name redacted], did you do your monthly self-breast exam? Did you go get your mammogram? Did you go have your annual Pap or what?”” While individuals recognized the importance of social support to their own health journeys, they also reported the desire to do the same for others *“Just like the importance of maybe doing the footwork like you would do for an election, you may have to do the footwork for healthcare the same way... Getting out there and saying, “Hey, what can we do to help? Do you need rides? Do you need help getting things set up for you to go to the doctor? Do you even have healthcare? Is there someone that you have that can help you in these things?”*” Individuals that we interviewed expressed that the tight-knit nature of the community, and the desire to help one another were key factors supporting the resiliency of the community.

DISCUSSION

This qualitative study examined perspectives of and experiences within healthcare among Black residents of Black Hawk County, Iowa. These interviews speak to experiences and needs of a minoritized population living and receiving healthcare in a majority White community; while relatively racially diverse for Iowa (which in 2022 was estimated 90% White, 4.4% Black, 6.9% Hispanic), Black Hawk County remains overwhelmingly White (83.5% White, 9.8% Black, 5.0% Hispanic).[22] Further, this study may provide an example of how engaging and partnering with minoritized communities experiencing health disparities can lead to a deeper understanding of community-identified needs and solutions to begin to address those disparities.

Overall, findings from this study indicate that while many Black individuals in Black Hawk County have positive experiences in healthcare, there remain substantial barriers to engaging with healthcare, including cancer prevention and control. Barriers included a lack of trust in medical professionals which may lead to healthcare avoidance; this lack of trust have roots in everyday experiences of racism, as well as racism experienced in healthcare. Opportunities to actively train and/or recruit healthcare providers from diverse backgrounds who are racially concordant with their patients may address some of these barriers. Further, while participants noted that they were unlikely to participate in clinical trials, they might be willing to change their minds if their doctor recommended it. Recommendation from a doctor is a leading predictor of clinical trial participation;[23] yet, Black Americans may be less likely to have discussed clinical trials with their providers,[24] and less likely to convert that discussion into trial participation.[25] These results may indicate the ongoing need to initiate conversations around clinical trials with minoritized communities to increase diversity of trial participation and generalizability of results.

Despite challenges associated with accessing medical care, our participants highlighted several areas of resiliency among this community, including willingness to advocate for self and others; and willingness to seek healthcare that meets their needs. Strengths-based approaches can be a key component of community-based participatory research,[26, 27] and resiliency-focused interventions have demonstrated some success across multiple health-based contexts.[28] These findings demonstrate that the Black community in Black Hawk

County, Iowa, has many resiliencies that could provide a foundation for addressing known cancer disparities.

Our interview findings are in general agreement with a diverse body of literature that explores barriers and facilitators to engaging with healthcare, or cancer prevention and control behaviors, among Black and African American individuals. Song and colleagues explored African American cancer patients' perspectives on patient-provider communication, noting that honest, respectful communication is critical for this population that may exhibit high medical mistrust.[29] Another study showed stark differences in reports of patient-provider communication between Black and white breast cancer patients, with White women praising longstanding positive relationships with providers, and Black women sharing experiences of disempowering, paternalistic interactions.[30] Several studies have linked medical mistrust to experiences of racism, including the history of medical and research malpractice mentioned by several interviewees in our study.[31, 32],[33] Somayaji and colleagues explored how this mistrust, coupled with fear and fatalism around cancer, impacts African Americans' desire and willingness to participate in cancer research.[34] As implied from our findings, experiences of racism also shape one's desire to engage in cancer prevention and control behaviors: Sharif-Marco and colleagues showed significant associations between everyday racism with prevalence of smoking, binge drinking, no walking, and having overweight or obesity; as well as between racism experienced in the healthcare setting and not being current for screenings for breast cancer, colorectal cancer, and prostate cancer. General consistency of findings across studies in different settings, using different methods, and focused on different outcomes may highlight overarching challenges that may benefit from structural or societal-level interventions. For example, taken together, the current literature may indicate that efforts to address implicit bias and dismantle structures that perpetuate racism, particularly in the healthcare setting, will be critical to repairing medical mistrust, addressing the stigma associated with cancer in Black and African American communities, and eventually, eliminating cancer disparities that affect this community.

This study had strengths and limitations that should be considered in its interpretation. A primary strength of this work was its community-engaged nature: the topic of focus for the work was initially identified by the Black Hawk County Health Equity Steering Committee, and the research questions were developed in collaboration with our community partners, who were integrally involved as members of the research team including through data collection and interpretation. The results of this work were shared back with the local community through presentations and information sheets, with specific suggestions for action items that could be pursued by the community or in collaboration others (e.g., academic partners, healthcare institutions). Limitations included our convenience/snowball sampling method, which may mean our study sample may not have been fully representative of Black residents of Black Hawk County: whilst we stratified our sample by sex to ensure an equal representation of those identifying as male and female, we did not collect any other detailed sociodemographic information (e.g., income, education level), so we are unable to determine whether our interviewees under or over represent certain segments of the population based on additional characteristics.

CONCLUSIONS

Black Americans are disproportionately affected by cancer and have worse cancer outcomes. Systems of oppression and the history of racial trauma associated with medical care and research may impact African Americans' desire to engage with the healthcare system, and especially those providers who do not share their same life experiences. Yet, despite evident mistrust of the healthcare system, our interviewees identified a need and desire to improve patient provider communication and the barriers associated with racism in the healthcare system in Black Hawk County, Iowa. The participants of this study show how resilience can lead to better health by building social support networks and sharing information within the community. Further research is necessary to understand provider and healthcare experiences of providing care in this diverse community, and to develop multi-level interventions to address both individual-level barriers to engaging with healthcare, as well as systemic and structural factors that create and uphold disparities affecting Black Americans.

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Data Availability:

A copy of the qualitative codebook is available from the corresponding author on request.

Abbreviations:

CBPR	Community-Based Participatory Research
NHW	Non-Hispanic White

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Table 1.

Interview questions asked to participants in the present study, Black Hawk County, IA, 2022.

Interview question	Corresponding research question
<i>Icebreaker</i>	
Tell me about your earliest memory of going to the doctor, or seeing another healthcare provider. Is this a positive memory? Why or why not?	None
<i>Healthcare experiences</i>	
How often do you see a doctor or other healthcare provider these days?	1: What are community members' experiences with the health care system and their perception of the health care system?
Can you tell me about a time when the healthcare system worked well for you?	1: What are community members' experiences with the health care system and their perception of the health care system?
How would you define "good healthcare"? What does that look like to you?	1: What are community members' experiences with the health care system and their perception of the health care system?
Can you tell me about a time you felt you were treated badly by the healthcare system?	1: What are community members' experiences with the health care system and their perception of the health care system?
Can you tell me about experiences of family and friends within healthcare?	1: What are community members' experiences with the health care system and their perception of the health care system?
Do you trust the medical/healthcare system? Why or why not?	2: What factors influence community members' trust in the health care system?
<i>Cancer prevention</i>	
What keeps you (or people in your community) from getting screened for cancer?	4: What factors influence community members' participation in cancer prevention and control activities?
What helps you and your community to go to the doctor and do things like get your cancer screening?	4: What factors influence community members' participation in cancer prevention and control activities?
<i>Cancer diagnosis and treatment</i>	
Have you, or anybody you're close to been through cancer treatment?	None; essential background
Did you/they have a positive experience with the healthcare system during the process of cancer treatment?	4: What factors influence community members' participation in cancer prevention and control activities?
Did you/they have any negative experiences with the healthcare system during the process of cancer treatment?	4: What factors influence community members' participation in cancer prevention and control activities?
<i>Clinical trials</i>	
During your cancer treatment, were you ever offered to take part in a clinical trial? <i>If no cancer experience:</i> Would you ever consider participating in a clinical trial? Why or why not?	4: What factors influence community members' participation in cancer prevention and control activities?