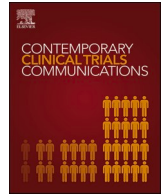


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Examining recollections of Black women with breast cancer who participated in clinical trials: A grounded practical theory study of patient-provider communication

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ABSTRACT

The presence of strong barriers to research participation for Black women is indisputable. However, existing evidence supports the possibility of equal levels of participation among members of minoritized populations in past breast cancer (BC) clinical trials (CTs), demonstrating that while these participation barriers undoubtedly exist but are not insurmountable. This work aims to investigate patient-provider conversations to try to illuminate how providers can better engage Black women in communication that will positively influence their perceptions of breast cancer clinical trial participation. Fourteen women (N = 14) who self-identified as Black, Black American, or African American and who had previously or were currently involved in a BC CT participated in the grounded theory-guided study. These women were recruited through emails and social media platforms and interviewed regarding their communication with their medical providers and their pathway to CT participation. Findings revealed three primary categories: 1) participants reported the following provider types as most effective communicators: attentive, matter-of-fact, warm, or above-and beyond; 2) participants frequently received no information about CTs from their providers; and 3) cultural constructs including faith, word of mouth, and storytelling are important to the recruitment of these Black women to BC CTs. Our findings demonstrate the importance of healthcare providers adjusting their communication to meet one of the preferred provider archetypes of communication styles, understanding and incorporating cultural constructs in their communication, and providing information about BC CTs to Black women. Through improved patient-provider communication, healthcare providers may positively influence Black women's perceptions of and participation in BC CTs.

Before 2003, representative participation in cancer clinical trials (CTs) was approximately equal among women and across members of racialized populations. However, Duma et al. [1] posited that during the period spanning 2003 to 2016, those participation percentages steadily and noticeably declined due to a variety of barriers prohibiting the participation of minority communities in CTs. The authors offered a list of these barriers that were likely responsible in part for this shift, including longstanding distrust of science and medical personnel, cost, fear, cultural background, religious beliefs, etc. More and more often, variations of this list are added as an afterthought to the conclusions of breast cancer (BC) CT research. Many of these studies have fallen short of engaging in a meaningful way with an appropriate percentage of minoritized population members and note this shortcoming as a few

lines in the limitations section without thoroughly examining why these barriers exist.

We believe that Duma et al. [1] were correct in their conclusions—representative participation is possible, but only if changes are made to the way researchers engage with and recruit women of color. This starts with ceasing to attribute the cause of the problem to the minoritized individuals who are subjected to the existing disparities. Instead, the focus must be on improving the medical research community's understanding and efforts to reduce the barriers. This study aims to better understand the motivators, barriers, and facility of Black women's paths to participation in a BC CT and their thoughts about the communication surrounding the recruitment processes of that journey. Additionally, this work seeks to outline strategies that can actively

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encourage behaviors that increase Black women's awareness and interest in participating in BC CTs. We begin by examining the possibly most significant barrier on the list—this group's general lack of knowledge about CTs.

1. Black Women's lack of knowledge about clinical trials

Individuals cannot participate in activities about which they are ignorant. Studies have clearly established that Black women do not receive the exposure to information about CTs necessary to be able to participate in them [2,3]. Previous research has shown that creating awareness of CTs can improve recruitment rates within minority groups. Wallington et al. [4] immersed themselves in the community to hold six nontherapeutic cancer CTs targeting low-income Black women. Their recruitment methods considered the importance of a culturally competent research team, ease of access to the studies, and efforts to engage Black population members in clinical research. These six CTs were widely successful; a total of 559 participants enrolled, demonstrating a 62 % escalation in Black enrollment over other clinical research conducted through their grant [4].

Another community-based project, the STAR study, began in 2016 and focused on increasing the participation of Black women in a BC genetics study [5]. The STAR researchers had success reaching out to Black women in Memphis, Tennessee, to educate, recruit, and retain them as participants in a cancer genetics research study. This is a particularly important research focus because Memphis has one of the highest BC mortality rates for Black women in the United States [6]. Many Black women in Memphis recruited to the STAR study reported that they had never been asked to participate in medical research of any kind before [5].

Takeshita et al. [7] distributed and analyzed surveys from University of Pennsylvania health system outpatient visits across three years and found that patients sharing racial/ethnic concordance with their physicians scored their primary care provider higher on their surveys compared to patients who did not have racial/ethnic concordance with their providers. As we see differences in race concordant physician/patient interactions with more effective therapeutic relationships and improved healthcare, we also see similar differences in race concordant research recruitment.

As an example, the Our Breast Health Study [8] found that partnering with community organizations focused on Black sexual minority women resulted in a recruitment rate of these group members to their study that was 26 times more successful than recruitment of non-sexual minority Black women. The study took an intersectional approach to research recruiting. Each research team member shared at least two of three focused identities (gender, sexual, racial) with the participants and relied on community partners to bring credibility and trust to the study [8]. Additionally, Bains et al. [9] further explored the possibility that race or ethnicity concordance amongst researchers and patients could be associated with improved recruitment of minoritized population members. In their study focused on recruitment of patients into ophthalmologic CTs, the authors found that research team members of the same race or ethnicity as the potential participant were more likely to gain consent than those whose race differed from the patient.

These studies demonstrate that applying a cultural competency lens when partnering with minoritized communities enables researchers to more successfully and respectfully engage Black women in CTs. Increasing evidence shows that if Black women are given the information and resources to make thoughtful decisions about their health and CT participation, they will come. Next, we will look at cultural practices that influence Black women's medical decision-making.

2. Cultural influences on black Women's health decision-making

Various aspects of group members' cultural outlooks can be

important contributors to their medical research and CT participation choices. Storytelling, faith, and community interaction are cultural constructs often considered to be valuable for Black women.

2.1. Storytelling and black Women's health

A culture-forward (culturally informed decision making) method for Black women to make thoughtful decisions about their health is to communicate with each other through storytelling [10]. Because the ancient practice reduces stress and resists class, gender, and race distinctions, storytelling can positively impact health outcomes. Ballard et al. [10] designed a storytelling study intended to promote the cultural bonding that can influence Black women to adjust and/or change health intentions and behaviors. Individuals who speak of their health with providers or friends can weave a story that helps the listener to comprehend fully, a process that has been reported to have healing effects. Research shows that these narratives seem to increase culturally influenced attitudes, leading to healthier behaviors [11,12]. Another healing process in which Black women participate is cultural expression of faith, which we will explore in the next section.

2.2. Faith, black women, and breast cancer

Prior research has established that Black women with BC have a higher sense of "religiousness" when compared to white women with BC [13]. Although we could not find updated definitive statistics comparing Black and white females in particular, a recent Pew Research study [14] determined that Black Americans are more religious than other groups in the United States overall. Another Pew Research study [15] found that women demonstrated higher church attendance than men (40 % vs 32 %). Torres et al. [16] concluded that when working to understand a diagnosis and subsequently undergoing treatment for BC, relying on their strong beliefs for comfort and strength is normal practice for Black women of faith. In addition to relying on God for a sense of hope and resiliency, participants in the Torres et al. [16] study found it important that their faith and beliefs were not only condoned but respected by their healthcare providers.

Ko et al. [17] held focus groups with, and subsequently surveyed, 43 Black women BC survivors who had been diagnosed with invasive BC in the last five years. They found that resilience, strength, and an ability to cope were supported by spirituality and faith. Black women's historical use of prayer as an essential coping mechanism for BC is well documented [18,19]. Study participants also often relied on their spiritual families for motivation to help them stay strong while progressing through treatment [16,17]. Faith communities are only one example of how BC CT participants look to members of their community for support. In the next section, we will examine research that expands on the idea of Black women with BC utilizing their support systems.

2.3. Community, black women, and breast cancer

Previous literature suggests that community members and social support systems play a significant role in many aspects of the BC survivorship experience. In a study about recruiting Black women into BC CTs, Fairley et al. [20] found that two-thirds of participants surveyed received information about CT participation from community sources outside of their healthcare providers. Two notable sources of information about CTs were social media posts and groups, and engagement with other breast cancer survivors [20].

Community organizations and affinity groups can be trusted sources of information about BC CTs for potential research participants. However, misinformation and other group members' mistrust of the medical community can negatively influence an individual's perception of CTs and dissuade participation (Fairley et al., 2023). The negative experiences of friends and family members can also create hesitation around engaging with the healthcare system and participating in research [21].

Overall, the CT perceptions and experiences of other community members can be an influential factor in whether Black women learn about BC CTs and decide to participate.

3. Black Women's BC provider communication needs

Literature exists recognizing differences based on racial and/or ethnic influences in women's perceptions of interactions with their providers [22,23]. Awareness and acknowledgement of these differences can be significant for maintaining and/or increasing the physical well-being of Black women with BC as they interact with their providers. According to Check et al. [22] there is a need to improve the patient-provider communication experiences of Black women with BC.

Mott-Coles [23] addressed the need for healthcare providers to consider culture when communicating with Black BC patients about treatment options and a care plan. That study determined that providers considered communication with their Black BC patients to be generic; in other words, no particular cultural awareness was taken into account when caring for and treating these patients. However, as the STAR study [5] has shown, an understanding of the cultural background of a patient is vital for effective healthcare and research recruitment communication to take place. In light of all these nuances, careful consideration was given to choosing a theoretical framework that could help us understand the breadth and depth of communication needs of Black women who chose to participate in BC CTs.

4. Theoretical framework

The current study takes a Grounded Practical Theory (GPT) approach. GPT proposes that communication studies should be pursued as a practical discipline rather than a traditional, scientific one [24]. GPT highlights both the important procedural role of communication in practice and its ability to present intricate complications that echo society's norms and values [24]. In this case, GPT is an approach to cultivating practice-based theories as a lens for determining how the communication practices between providers and Black women might be enhanced to boost BC CT participation.

GPT makes use of theoretical reconstruction [24]) wherein particular features of an ideal social practice are redefined in general terms, to clarify the inherent values and principles of that practice. These values and principles are critically assessed and appraised, and ultimately used in the development of a normative model applicable to circumstances similar to those in the original setting [25]. GPT seeks to reconstruct communication practices at three correlated conceptual levels: the problem, the technical, and the philosophical [24].

The problem level comprises the tensions and/or dilemmas considered as the entry point. Identifying these tensions can result in "digging deeper" to arrive at the technical level, where the discourse actions that reveal and manage those tensions are pinpointed [24]. At the same time, naming the tensions or dilemmas can also result in "thinking higher" to reach the philosophical level, where the situated ideals (the participants' views about how they or others should perform inside a communication practice), that guide choices about the management of the tensions/dilemmas, are identified (Tracy, 1997).

In the current study, the tensions and dilemmas become evident through careful excavation of the participants' recollections of discourse with their providers. Applying GPT as a lens to these interviews allows participants to engage in storytelling about their experiences with their providers throughout their journeys as BC patients. Therefore, the purpose of this study was to use the GPT framework in engaging with Black women who have participated in a BC CT and explore their recollections of conversations with their providers to better understand how providers can more effectively engage these women in ways that will positively influence their perceptions of BC CT participation.

5. Methods

Data for the current study come from a larger study that applied the Integrated Behavioral Model to examine the recruitment of Black women to BC CTs. This larger study will be subsequently referred to as the IBM-BCCT study. Employing GPT as a framework and applying thematic analysis techniques as described by Braun & Clarke [26], we re-coded the IBM-BCCT interviews, focusing on patient-provider communication details. All procedures for this study were approved by Indiana University's Institutional Review Board (IRB; protocol #1810768959).

5.1. Participants

We recruited participants for this study through convenience and snowball sampling by sending direct email messages to eligible women known to the study team and to other women they referred. We also posted the IRB-approved language to social media platforms and asked contacts to share the recruitment criteria. We screened interested participants for eligibility and issued a copy of an IRB-approved study information sheet for them to read. Eligible participants for this study were biologically female BC survivors or patients who were at least 18 years old, self-identified as Black, Black American, or African American, and lived in the United States. In addition, they had participated or were currently participating in a BC CT. Fourteen women (N = 14) who resided in six different states in the United States were successfully recruited (see Table 1). The interviews took place in person, by phone, or online, depending upon the participant's preference, availability, and location.

5.2. Data collection

The interview guide contained open-ended questions, resulting in a depth of data and opportunity for analysis. Questions were structured to encourage general thought about the interpersonal relationships and communication the women experienced with their medical providers (e.g., "Describe any interactions you experienced with your personal care providers and oncologists regarding your decision to participate in a clinical trial."); and to promote wide ranges of thought about communicating with their research providers (e.g., "How were you exposed to the idea of participation in a CT?" and "What types of communicative interactions did you experience with your oncologists and/or radiologists regarding your decision to participate in a clinical trial?"). Participant interviews were audio-recorded and transcribed verbatim by a paid, professional transcription service. The names used in this manuscript were changed and are unrelated to the participants' names. A set of standard demographic questions concluded the interviews.

5.3. Data analysis

Sections of the participants' transcribed interview responses were coded as data to identify the existing tensions and/or dilemmas [24]. From the interview transcripts, the first author sorted the data into similar themes in Excel using complex color coding and labeling. In this system, each color coordinated to a theme category and in the case where multiple participants mentioned similar ideas, the responses were coded as the same categorical theme. Themes were often designated by a similar word or idea used by multiple research participants when describing their experience with BC CT recruitment. These themes were then compared and evaluated by the other authors to ensure inter-rater reliability among the theme designations. Reaching the GPT philosophical level involved thinking through and drawing out the tensions described by participants (e.g., inattentive providers, perceived racial overtones) and dilemmas (e.g., how to handle a second opinion). The findings in the next section reflect how the tensions and dilemmas experienced by these Black women in their patient-provider

Table 1
Participant demographics.

Pseudonym	Age	Completed Education Level	Household Income	Type of BC	Path to CT
Victoria	65	Bachelor's	25–30K	Stage 1 HER2+ and HR+	self-approach
Tamara	55	Master's	50K	Stage 1 invasive ductal carcinoma	Oncologist
berta	55	High School + trade licenses	51K	Twice - 1) Triple-negative; 2) HR+	Oncologist
Denise	50	Bachelor's	165K	Twice - both were triple-negative	self-approach
Nancy	58	Bachelor's	90K	simultaneous double diagnosis in both breasts – triple-negative & HER2+	friend or flyer
Danielle	45	Bachelor's	125K	HER2+	friend or flyer
Earlene	69	Some college	30K	Stage 1 ductal carcinoma in situ	Oncologist
Jaleesa	65	Bachelor's	50K	Triple-negative	radiology clinic
Ronnelle	62	Some college	12K	Stage 1 invasive ductal carcinoma	friend or flyer
Sylvia	50	Bachelor's	42K	Triple-negative	Oncologist
Mayme	75	High school	20K	Twice – 1) ER+; 2)?	tissue procurement
Sharese	61	Some college	110K	Triple-negative	self-approach
Gloria	37	Master's	100K	95 % ER-PR+, HER2-	self-approach
Sierra	64	Some college	60K	Stage 1 triple-negative	friend or flyer

relationships manifested as similar experiences that were categorized as themes.

6. Findings

This study's findings were organized into three categories, or themes. The first theme revolves around the participants' perceptions and classifications of their providers. The second theme focuses on the journeys that led these Black women to eventual CT participation. In the third theme, the presence or lack of cultural constructs in the conversations these participants held with their providers is discussed. By understanding the types of providers who interact with Black women entering BC CTs and the pathways of communication between this patient population and their providers, we can postulate ways to improve these methods of communication to increase the participation of Black women in BC CTs.

6.1. Black Women's provider typologies

The first category reflects the differing perspectives the participants held toward their providers. Six archetypes of providers were identified as themes within this category: (a) The Attentive Provider, (b) The Matter-of-Fact Provider, (c) The Warm Provider, (d) The Above-And-Beyond Provider, (e) The Disinterested Provider, and (f) The Discouraging Provider. In the following sections, we closely examine each of these determined themes.

6.1.1. The Attentive Provider

The attentive provider was highly valued among the participants. Healthcare and research team personnel deemed to be attentive by their patients explained medical concepts well by taking the time to patiently give clear, concise information. The attentive provider was diligent, took time to clarify, and never rushed the patient. One participant, Sierra, enjoyed her oncologist because he took the time to give thorough explanations but remained upbeat. She felt a bond with him:

I like all my doctors. I've got so many. But I like [my oncologist] a lot. I feel very comfortable with him. His bedside manner is second to none. He's just very – you know, explains things and very patient and, at the same time, he's not gloom and doom... I have a lot of respect for him, too. [We have a good] patient/doctor relationship.

Tamara said she loved how her oncologist and the research nurse took the time to answer all of her questions. "There was a study nurse involved and I received her information. And then I read through everything and had a million questions, and they answered all my questions, and we went from there."

In both cases, the providers showed behaviors characteristic of an attentive provider by focusing on the patient's needs first. The attentive provider allows the priorities of the patient to guide their

communication and care.

6.1.2. The Matter-of-fact provider

The attentive providers' conversations seemed to be guided primarily by the patient's expectations of the discussion; however, matter-of-fact providers tended to communicate in a more direct, information-driven manner. Several participants experienced providers of this type. Due in part to a previous negative experience, Denise found great value in her straight-talking oncologist:

I needed an oncologist that I really did feel would be honest with me. I did not want sugarcoating, you know, the oncologists who say as much as they think you can handle – my first oncologist was like that. He said just as much as he thought you could handle. I found that I was stage four by taking my chart off the door and reading it myself. And I decided after that first cancer experience that I didn't ever want a doctor like that again.

Most participants who experienced this type of provider found it to be a positive experience. Mayme thought the same, but was also slightly flustered by the directness of her CT research nurse and the number of things she needed Mayme to do:

The nurse came in and I had to sign some papers and then they asked me a lot of questions and – had a stack of questions that tall, you know, that they asked me, you know. And I answered them to the best of my knowledge, you know, like: Has anybody in my family had breast cancer? And, you know, they filled out a lot of papers and – saying that, uh, what kind of study they was going to do and everything.

Matter-of-fact providers could be identified from other providers because they offer information in a direct manner to their patients without trying to add their own interpretation or emotion to the information. These providers were not rude or careless in giving information, which can create a hostile environment for the patient, but they kept the conversation focused on factual information.

6.1.3. The Warm Provider

A warm provider's conversations extend beyond simple statement of fact; these providers seem to purposefully adapt their communication style to focus on developing close relationships with patients. We describe warm providers as kind, supportive, and trustworthy. Most participants did not use the words "nice" or "kind" to describe their providers, usually opting for more detailed descriptions. Alberta had good things to say about the support offered by her oncology nurse, who became her cheerleader. "She really discussed this stuff with me, and she always made me feel comfortable when I came, you know, to get chemo. She'd be like, Alberta, you can do this. Look, you can do this." Another participant, Tamara, also found the supportive natures of her oncologist and her nurse to be very beneficial to the patient-provider relationship.

He would say things like, you know 'If you ever have questions, you know you can call us. [My nurse] will always be checking in with you and you can have her direct line' which I did. So, I felt comfortable that if, you know, if a question or problem came up they would be on it like immediately.

Warm providers were remembered because of the personal connection they established with the patient. This type of provider established feelings of trust in the patient, which can facilitate better channels of communication.

6.1.4. *The above-and-beyond provider*

The above-and-beyond provider exhibited similar characteristics to a warm provider, but also exceeded the patient's treatment expectations. Gloria had a great relationship with her oncologist, who gave patients her cell phone number so she could always be reached for questions.

[My oncologist is] completely open. I have my oncologist's cell phone number, her personal cell phone number. Anything that I could ever think or need or [be] concerned about, she calms me down. She always says, "Gloria, always remember, it's God, family, everybody else," because she already knows how my brain is thinking. She goes, "Ah, God, family, everything else, okay?" So I adore [her] for that because I need that. I definitely need that because my mind does wander off and I need to bring it back on in.

Tamara and her oncologist talked about everything. At one point, Tamara's brother was admitted to the oncologist's hospital, and the physician went to visit him. Tamara reflected on that time: "That's the kind of doctor he is. He didn't have to do all that."

Patients may have held preconceived notions about their provider's demeanor and what would be discussed. The above-and-beyond provider took positively received actions that the patient viewed as outside the scope of their expectations.

6.1.5. *The Disinterested Provider*

In contrast to the above-and-beyond provider who exceeded a patient's communication expectations, the disinterested provider exhibited minimal interest in their patient's decision to participate in CTs. Sometimes, particularly when the participant had become involved in research through other sources, the oncologist seemed not to be interested in the CT involvement as part of the participant's BC journey and made little to no effort to show interest. Ronnelle described her oncologist as only superficially supportive of her desire and decision to participate in a fitness CT.

Um with my physician, we talked about it, that I was doing the study and they were like "good for you." And basically, I think [it was] because when I was in treatment, I still worked out until I couldn't, so my physician just knew that I was going to keep moving.

Jaleesa was first approached by research study team members to take part in a CT while she was waiting for a radiation session. She was excited to be offered the trial, which was focused on a cream to use on the sensitive skin of her breast. She used the cream for months, and it helped, but she did not understand why her radiation oncologist never reached out to follow up after the study. She was confused about why he would approve recruitment in his office but did not seem to care about any results.

6.1.6. *The Discouraging Provider*

The disinterested provider expressed minimal interest in the patient's decision to participate in a CT; however, the discouraging provider actively communicated with the patient in a way that attempted to prevent or dissuade the patient from seeking out CTs. Women in the current study often described these providers as negative, and they leave feeling disheartened after encounters with their providers. Sharese described her oncologist as discouraging and inattentive. Sharese

divulged that she had searched out a CT to give herself hope because she heard nothing positive from her providers about her diagnosis of triple-negative BC.

No one, none of my doctors or no one I came in contact with said anything positive about triple negative. I mean, in my opinion they had you dying already. There was nothing positive. My surgeon would shake his head. I said, "Oh, it's triple negative. That's great, I'm triple, right?" And he's like, "No" It was just nothing good.

The next theme focuses on the potential importance of recognizing the different paths through which the participants joined a CT.

6.2. *Black Women's paths to CT participation*

The participants in this study exhibit a range of formal education. Several hold college degrees, others have at least some college experience, and still others have high school diplomas. In interactions with providers, the women clearly demonstrated variance in levels of health literacy (HL). For example, while recalling a conversation with her oncologist, Denise illustrated her high level of HL through her comfort with medical terminology and pharmaceutical nomenclature:

So, the first conversation was with my physician... I already had a great deal of a drug called Adriamycin, which was the first line for triple-negatives. So, I already had Adriamycin when I got stage four non-Hodgkin's lymphoma, a lot of Adriamycin, and then I had Adriamycin's wicked cousin, daunorubicin, when I got leukemia. So, we knew we couldn't use Adriamycin because there was too much of a risk of it damaging my heart. We knew we couldn't use Adriamycin in the treatment of the triple-negative breast cancer.

In contrast, Mayme struggled with understanding the details of her disease and treatment and was always grateful for assistance. Here, she explained why she enjoyed a particular healthcare provider, "the, the lady – I guess she was a nurse. She was a– she was most [helpful] because, you know, she explained things to me so I can understand, you know, why. That is very important."

6.2.1. *Reactive patient recruitment*

For the purposes of this research, recruitment strategies were categorized as reactive when the patient reacted to a system or presentation of information established for them; therefore, the work and responsibility of finding the information about CTs was removed from the patient. Some participants were invited to a CT by a provider, usually their oncologist, as was the case for Earlene, whose oncologist actively supported CTs, and suggested them to patients. Earlene revealed:

I believe that in the oncologist's office they would have researchers speak with you or speak with the patient. So, someone asked if they could speak to me and if I was interested in participating in a trial and I listened to what they proposed and I thought it would be okay to do, so I agreed to participate.

6.2.2. *Proactive patient recruitment*

Other participants were informed about CTs by a friend, or, like Victoria, sought one out on their own. These women were not presented with the option of a CT in the clinical setting but had to proactively search for the opportunity on their own. While attending a conference on BC, Victoria did not hesitate to engage in conversation with the physician running a fitness CT. She shared her story:

So, when [the study PI] came out of her session, I pulled her to the side and asked her did she have any open clinical trials? And fortunately, she did have. So, I was able to actually get enrolled right away.

6.3. Cultural constructs in patient-provider conversations

Two particularly well-known cultural constructs that often are present in health communication scenarios involving Black Americans—expressions of faith and reliance on word of mouth—were both reoccurring factors throughout these interviews. Ronnelle relied on both factors for support during her BC treatment. When asked about how she had chosen her providers, Ronnelle responded, “well, the surgeon was recommended. Um, I had never been to [that hospital] and so [I asked around] and the surgeon was recommended to me.” Ronnelle reported that she enjoyed a great relationship with both her surgeon and her oncologist. Once, after being told that her care plan would go on well into the next year, and Ronnelle began to cry, the nurse mistook tears for distress over the cancer, but Ronnelle corrected her:

I looked at her and I said, ‘I’m not crying about cancer,’ I said, ‘I’m crying because my plans and God’s plans are not on the same page. I’m supposed to be going to Georgia. Now I got to, you know, do this.’ And she didn’t understand—she didn’t understand my faith... I was like there’s nothing too big for my God, and things are going to happen that may hurt, but you still got to trust Him, you know, and that’s what I do. And you don’t know how God is going to use you and that’s why I just feel like He uses me in his own [way]... I keep on moving forward, not trying to acknowledge cancer all the time because I don’t do everything with cancer patients... I’m going to keep on being me.”

The importance of addressing the disparities faced by Black women who develop BC was also repeated in the related experiences of the participants. Gloria’s oncologist, who was also a black female, was well aware of, and spoke up about, cancer’s different presentations in members of racialized populations. The oncologist was in the habit of engaging in clear, real-talk conversations with participants and their families. According to Gloria:

My oncologist here, she said that African American women are at an alarming rate of dying from this disease. And she literally had to tell—like my mom was against chemotherapy. She didn’t want me to go through chemotherapy. She didn’t want me to go through radiation. She wanted to just do the clinical trial, that’s it. And my oncologist had to tell my mom, “If your daughter had not [found] it when she [did], she would not have seen the end of this year because that’s how aggressive [it is].”

When she was diagnosed with BC at a local hospital, Earlene knew some people who worked at that institution and inquired about the oncologist. They thought highly of him and considered him to be a good oncologist. “That’s why I said I heard good things about him; that he was compassionate and a good doctor, and I believe that to be true. I would cosign on that,” Earlene declared. Earlene used the recommendations of her community as a system of checks and balances when making decisions about her BC care.

7. Discussion

In the current study, we have discovered findings that are especially important for helping to guide healthcare providers toward a better understanding of their responsibility to their patients to become a larger, more helpful part of the research recruitment process. These findings were elicited through analyses of the communication occurring between Black women diagnosed with BC who decided to participate in a BC CT and their healthcare providers and research teams. The findings were sorted into three categories including these participants’ provider typologies, their paths to CT participation, and the cultural constructs of their conversations with their providers. The importance and impact of these findings will be expanded upon in the following sections.

7.1. Participants’ provider typologies

Six archetypes of providers were identified in this study including (a) The Attentive Provider, (b) The Matter-of-Fact Provider, (c) The Warm Provider, (d) The Above-And-Beyond Provider, (e) The Disinterested Provider, and (f) The Discouraging Provider. The women primarily had positive experiences with most of the provider archetypes. However, two of the archetypes—the disinterested provider and the discouraging provider—did not promote CT participation or support the women’s interests in CTs. The disinterested provider did not discuss CTs with the women in the current study even though they were involved in a CT. The discouraging provider archetype attempted to dissuade or prevent patients from seeking CTs without discussing with the patient why she should or should not participate.

Several previous studies have described some of the characteristics of the disinterested and discouraging provider such as lack of clarity, discrimination, and lack of focus on patient’s input; these studies have shown that these communication styles are associated with poor patient-provider communication quality and decreased trust in providers [5,22,27]. The women in the current study who had disinterested or discouraging providers may have felt unheard or that they were not allowed to tell their stories. To promote participation of Black women in BC CTs, providers should actively engage in discussions with women who are currently involved in CTs, exploring the role of the CT in their overall care and any results of the trial that are available. Providers should also discuss with their patients why they may or may not be eligible for a CT and engage in shared decision making about their participation in a CT. For women who are not eligible for a CT they are interested in, providers should consider helping their patients find other research possibilities.

7.2. Examination of individual paths to CT participation

As Black BC patients who made decisions to take part in a BC CT, these women are unique enough that it took over nine months to enroll fourteen participants to interview for this study. Through examining these women’s stories, we discover they took three different paths to gain access to their CTs; they themselves aggressively sought out a trial, they were invited or informed by a friend to participate in a trial, or they were introduced to the possibility of a trial by their providers. Of the fourteen participants, four (~29 %) were invited or introduced to a BC CT by their oncologists. However, as was discovered during the interviews, three of those four women had the same oncologist, making this number less impressive than it may seem at first glance. We find it important to point out that although providers practicing in academic settings might be more likely to promote CTs to their patients as a function of the research environment, the above-mentioned proactive provider practiced in a community setting, making their dedication to CT recruitment noteworthy.

A study by Walker et al. [28] also demonstrated that Black women often do not receive information about CTs from their providers. In this study surveying women with metastatic BC, 40 % of Black women were not told about CTs by any member of their care team, although over 90 % of Black women completing the survey expressed interest in learning about CTs [28]. Proactive patient recruitment requires patients themselves to assume the responsibility of a research recruiter by finding a study and reaching out to get more information. Self-motivated patients and/or those with higher levels of health literacy may participate in proactive patient recruitment, but individuals who have very little or no knowledge about the possibility of CT participation may not think to seek out these opportunities, essentially shutting them out of the recruitment process. Shifting the standard strategy of research recruiting to a patient reactive system instead of the proactive system that currently exists could increase the number of Black women participating in BC CT research.

7.3. Cultural constructs within conversations with providers

For the most part, with a few exceptions wherein the patient and provider did not share communication style preferences [29], the current study's participants experienced positive professional relationships with their healthcare and research team providers. However, many providers did not acknowledge the cultural aspects of what these Black women with BC diagnoses were facing. This omission could have led to care that was culturally "generic" and subsequently to less effective communication between patient and provider [5]. Providers' poor communication strategies can place unnecessary obstacles in the paths of Black BC patients regarding possible CT participation.

We found that including faith in the communication experienced with their providers was a driving force in supporting the decision making of these Black women who participated in CTs. Several previous studies have shown that Black women are likely to turn to spiritual communities for support at many stages of their BC journey [16,17]. By understanding and respecting that many Black women could not envision surviving their BC journeys without their strong sense of faith and prayer practices, their providers could be better equipped to care for them and include this in their communication with Black BC patients.

Other cultural constructs such as storytelling were also strong motivators in the decision of the women in the current study. Some participants in the current study used their community members as a resource for information gathering and responded positively to providers who were attentive to the members of their communities. Ballard et al. (2020) conducted a meta-analysis of studies analyzing the effect of health narratives on persuasion (measured by reported changes in health-related attitudes, beliefs, intentions, and behaviors) of Black women. This meta-analysis showed that both audio-visual and written health narratives had a statistically significant positive impact on health-related changes for Black women; therefore, Ballard's study supports the role of storytelling in health communication that was also shown in the current study.

It is important for providers and researchers to see the value of community support for Black women undergoing BC treatment and realize that these communities can be an asset to research recruitment. The willingness to acknowledge and validate these communication needs, among others described in the following section, is a trait that Black women have expressed they find valuable in their healthcare providers.

7.4. Call to action for providers and researchers

The results of this study support and deepen the import of previous studies that have highlighted and suggested clear implications for the significant work that remains to be done by healthcare providers to inform Black women with BC of the importance and availability of CTs [30]. If there is no local CT availability, the patient—after being informed about CTs, what they are, and what benefits they may offer—may have an interest in searching for and traveling to participate in one. As was demonstrated by some of the women in the current study, culturally competent healthcare providers and healthcare systems should be prepared to provide guidance in this situation or be willing to direct the patient to resources to assist with her search [4].

It is also particularly important to study the place and value of cultural norms and habits in the conversations of Black women diagnosed with BC and their providers. For example, the participants in the Torres et al. [16] study wanted their culturally influenced sense of faith to be not merely tolerated by healthcare providers but respected and validated. Members of racialized populations are all too familiar with disrespect [31]. They will not only avoid it but will rely on another cultural norm presented in these findings, passing information through word of mouth to in-groups.

Despite variances in formal education and HL of the women in the current study, each of the women found a path to a CT, supporting the

results of previous studies that have shown that Black women with BC, even at low HL and/or low-income levels, will participate in CTs if the opportunity is made available [4,5]. It is our conclusion that in recruiting patients for BC CTs, providers need to understand their patient's level of HL and comfortability with CT research to successfully initiate conversations in a way that patients can understand.

Historically, researchers have approached the problem of unethically low and inappropriate percentages of minoritized population members in CTs by highlighting myriad studies identifying the cultural and social barriers to cancer CT participation faced by these group members. Several studies, including systematic literature reviews [32,33], reviews targeting recruitment obstacles [34], and single studies [35], all revealed multiple participation barriers. Many published explanations for low racial/ethnic minority CT participation could be interpreted as placing blame on the members of underserved populations who possess undeniably sound reasons for not participating in CTs. The researchers in the current study want to suggest that we as a research community take strides to remove the onus of recruitment responsibility from racialized population members, and instead leave it with the members of academia and the healthcare industry who hold the power to make change.

7.5. Study limitations

As with all research, there were limitations to this work. The sample size for this study was small and therefore unable to fully represent a larger community regarding this complex dilemma. Though small, our sample size is generally aligned with the standards for saturation in qualitative research [36]. However, previous research exists that clarifies and supports the challenges of finding and recruiting Black women diagnosed with BC to a study for which the main eligibility requirement is that they have participated in a BC CT [1,37]. Also, because the data for this research was originally collected for a larger study, affordances for posing follow-up questions to participants for purposes of gaining any additional data about provider types or patient-provider relationships do not exist, possibly creating gaps in the reported data.

7.6. Conclusion

This study sought to understand the relationships between Black female BC patients and/or survivors and their providers for purposes of exploring ways that researchers could increase the participation of Black women in BC (and other) CTs. We engaged these women in interviews focused on their recollections of communication interactions with members of their healthcare and/or CT research teams. Our team then applied the lens of GPT to analyze their responses and arrive at findings that were placed into three categories. The themes and insights from these findings have important implications for health communication scholars, healthcare providers, and BC CT research PIs and team members.

CRediT authorship contribution statement

Katherine E. Ridley-Merriweather: Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Oseme Precious Okoruwa:** Writing – review & editing, Writing – original draft, Investigation, Formal analysis, Data curation. **Katherine Vogel:** Writing – review & editing, Writing – original draft, Investigation, Formal analysis, Data curation.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence

the work reported in this paper.

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