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“We don’t Get Drugs Targeted for Us:” Applying the Integrated Behavioral Model to Understand Why Black Women Chose to Participate in a Breast Cancer Clinical Trial

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ABSTRACT

Guided by the integrated behavioral model, the authors interviewed 14 Black breast cancer survivors ($N = 14$) who had participated in a breast cancer clinical trial. This study aimed to better understand what may motivate Black women to engage in medical research and decide to participate in medical research. Findings revealed that Black women’s altruistic desires to serve others and their communities are greatly influenced by the need to leave a “legacy” of better treatment for other Black women. The participants mostly learned about clinical trials through communicating with friends, family, or other breast cancer patients and survivors, rather than from their physicians. Many were influenced to participate by other Black breast cancer patients they knew, suggesting that social norms messaging may help alert other Black women about the continuing disparity in clinical trial participation. Finally, the participants in this study demonstrated high levels of involvement not only in seeking out clinical trials, but also in engaging in informed and shared decision-making with their providers about participating in the trials. The findings from this work illuminate important reasons Black women chose to participate in breast cancer clinical trials. Additionally, we offer robust and valuable theoretical and practical implications for researchers, so they can work toward successfully increasing Black women’s participation in clinical trials.

Breast cancer (BC) alone accounts for 32% of all new cancer diagnoses for women in the United States (Siegel et al., 2024). Although Black women have a slightly lower breast cancer incidence rate versus white women, the racial disparity in BC mortality has not wavered. Black women are 40% more likely overall to die from the disease (Giaquinto et al., 2022), have the lowest 5-year BC survival rate of any racial or ethnic group, and experience recurrence rates higher than all other racial groups (Breast Cancer Research Foundation, 2024). Additionally, Black women develop triple negative (TN) BC (an aggressive, harder-to-treat form of the disease) 20% more often than white women (Siddharth & Sharma, 2018). Although some of these anomalies can be partially elucidated by science (e.g. racial-genetic differences in risk), and others by systemic racism, many of the causes behind these statistics are still unknown. Despite the reasons, there is clearly room for improvement in addressing BC disparities among Black women.

Clinical trials (CTs) focused on addressing pharmaco- (e.g. chemotherapy, oral medication) and non-pharmacotherapies (e.g. fitness/physical therapy, natural supplements) that might help improve these discrepancies exist, but several factors must be considered to facilitate successful recruitment of Black women (Reifenstein & Asare, 2018). Importantly, identification of facilitators and motivating reasons for participation serve as important formative research for successful recruitment of Black women into CTs. Therefore, this study, guided

by the integrated behavioral model (IBM) aims to explore why Black women with BC decided to participate in CTs either during or after their specific cancer treatments.

Black individuals’ CT research attitudes and norms

There is a large body of literature outlining barriers faced by Black people regarding CT participation. According to Haynes-Maslow et al. (2014), many Black women associated CTs with negative phrases including “experimentation,” “guinea pig,” and “trial and error.” In the past, Black people have expressed fear, misperceptions, and a sense of fatalism about medical research, which affected their willingness to participate. More recently, however, many also demonstrate a lack of knowledge about CTs and where they can find out about them (Kikut et al., 2022). Black women have listed reasons such as not having strong relationships with medical and/or research communities, expense of CT participation, and personal circumstances that cause them to feel CT participation is out of reach (Le et al., 2022).

Most recently, researchers have proffered a salient communication barrier as another principal obstacle to successful CT recruitment of Black women – they simply are not being asked. The findings of a study by GCI Health (2024) report that rather than being hard to reach, Black women are simply left out of CT recruitment efforts. In August, 2024, GCI Health surveyed 500 Black women ages 18 and up across the United States.

Although there was clear evidence of historical barriers to participation, such as mistrust of the medical community and fear of side effects, the findings were more nuanced. In general, the women surveyed felt that if they were clearly informed about the safety, compensation, and side effects associated with CT participation, and if they were assured of being closely monitored and had support from their own physicians, they would participate. In fact, of the 500 women surveyed, 80% said they were open to CT participation; however, 73% had never even been asked (GCI Health, 2024).

It is important to note that any negative attitudes Black women may have toward CTs are understandable and defensible in light of the well-known historical atrocities inflicted on them and others like them (Washington, 2023). Up until now, researchers have defaulted toward problematizing this issue as a lack of participation on the part of this population and demanding that members of this population change their attitudes, rather than focusing on reducing inequities and increasing motivation in this community (Washington, 2023).

Black women's attitudes toward CTs are clearly multifaceted. Fairley et al. (2024) conducted a mixed-methods study focused on better understanding CT participation perceptions of Black BC patients across the United States. They identified five overall barriers, including fear of BC diagnoses; denial and wanting to live as normally as possible; personal logistical challenges, some of which were self-imposed (e.g. treatment delay while waiting for a CT, disruption of daily lives, proximity to a CT); personal- and culturally related privacy concerns; and lack of/low insurance coverage and access to pre- and post-CT medical care. However, when asked about their expected outcomes of potential CT participation, the study participants shared their beliefs that CTs would benefit themselves and others, and would positively affect accessibility of treatments that were otherwise unavailable to them (Fairley et al., 2024).

Personal agency and Black Americans

According to Ajzen (2020), control beliefs are centered on the presence of influences that may positively or negatively affect the performance of a certain behavior. Bandura (2004) posited that individuals' beliefs about their own capabilities and prospects will influence their behaviors in the future and labeled this human agency "self-efficacy." Little work has been done looking at personal agency and Black women's decisions to enroll in medical research. Our own previous work showed that Black women who chose to donate healthy breast tissue as part of a CT expressed strong self-efficacy beliefs (Ridley-Merriweather & Head, 2017). Importantly, some studies indicate that self-efficacy in Black women is negatively related to fear in mammography conformity (Champion et al., 2008) and breast self-exam compliance (Registe & Porterfield, 2012).

In a study on Black people and organ donation, although study participants had high task efficacy (ability to register as a donor), they showed low decisional efficacy (ability to decide to become a donor), influenced in part by mistrust in the medical system (Williamson et al., 2017). On the other hand, much of the research on Black women and BC CTs has adopted the general sense that these women will not participate,

suggesting a lack of control and self-efficacy (Tanner et al., 2015). Hence, there is need for broader study of the self-efficacy and perceived control beliefs of this population regarding participation in BC CTs, particularly for Black women who have demonstrated self-efficacy in past participation in a BC CT.

Integrated behavioral model

The IBM is a framework comprising fundamentals from several other behavioral theories (Montaño & Kasprzyk, 2015; Montano et al., 2008). Within the IBM, attitudes, norms, and personal agency are shown to predict behavioral intention, which serves as the precursor to actual behavior (Montano et al., 2008). IBM attitudes are described as either experiential (feelings that participating in a BC CT is a positive/negative thing to do) or instrumental (beliefs that participating in a BC CT will/will not lead to positive outcomes). Norms are distinguished as either injunctive (beliefs about whether other people feel I should/should not participate in a BC CT) or descriptive (beliefs about whether other people would/would not participate in a BC CT). Finally, perceived control (beliefs that environmental factors would make it easy/difficult to participate in a BC CT) and sense of self-efficacy (beliefs that the individual possesses the effectiveness and/or skills/ability to participate in a BC CT) combine to define personal agency.

The IBM has been successfully applied in contextual situations, such as examining minority participation in research related to breast tissue and organ donation (Jordan, 2017; Shafer et al., 2018). In previous work, we found that Black women who participated in a preventive BC CT demonstrated positive instrumental attitudes and normative support about participating, and interestingly, felt that they were setting the norm for others (Ridley-Merriweather & Head, 2017). In a study examining the intentions of Asian women to participate in that same preventive CT, Shafer et al. (2018) employed the IBM to illuminate significant differences between Asian and non-Asian women for all three main IBM constructs. They successfully defined Asian women's lack of exposure to other women with BC as a potential key factor and barrier to participation of the population in BC CTs. To guide his study exploring organ donation participation, Jordan (2017) used the IBM as a framework for understanding the decision influences of individuals who register as organ donors and to identify perceptions of the public about receiving information during encounters with their pharmacists. Additionally, Robinson et al. (2017) successfully applied the theory of planned behavior, the original theoretical framework from which the IBM is derived, to increase the intention of Black women with Stage I-III BC to participate in CTs. Post-intervention, these patients expressed a 14% increase in likelihood to enroll in a therapeutic trial (Robinson et al., 2017). These examples support the use of the IBM as an appropriate framework for guiding research that explains, and ultimately predicts, participation in CT research. This study applies the IBM as a framework to examine the attitudes, normative influences, and personal agency of Black women diagnosed with BC who choose to participate in CTs.

Methods

The literature review demonstrated a clear need to increase the number of Black women with BC who might consider participation in medical research and CTs, while acknowledging the abundance of reasons people in this population may not be willing to participate. To help illuminate positive influences to perform the desired behavior of enrolling in a CT, we utilized a qualitative study design to gather Black women's experiences and perspectives. This study is IRB approved and the authors report there are no competing interests to declare.

Participants

The first author recruited participants for this study through convenience and snowball sampling by sending direct e-mail messages to eligible personal contacts and referrals from those women. Recruitment materials were created, and approved language was posted to social media. In large part because it involves networking and is an adaptable process, snowball sampling is a popular recruitment strategy for reaching potential research participants who may be hard to reach or who possess specific vulnerabilities, such as feeling stigmatized or distrustful. Snowball sampling involves the outreach of CT or medical research participants to friends and family to inform them of the study. A participant who reveals the reasoning behind the decision to take part in the study can alleviate distrust and help friends and family members feel safe about performing the same behavior (Wright et al., 2022).

Interested participants were screened for eligibility and sent a study information sheet (SIS) to review. After reading the SIS, the women were invited to voluntarily participate in an interview. Eligible participants for this study were at least 18 years old; biologically female; lived in the United States; and self-identified as Black, Black American, or African American. In addition, they were BC survivors or currently in treatment for BC, and had participated or were currently participating in a BC CT. A total of 14 women from six different states participated. Despite the small overall number of participants, the authors concurred that because no new data or themes were emerging from participant interviews' data, theoretical saturation was reached (Sandelowski, 1995; Saunders et al., 2018). Additionally, the themes that arose from the data holistically explore Black women's motivations for participating in CTs. The first author conducted all interviews, which took place in person, by phone, or by videoconference, according to the participants' preferences. The participants took part in four different types of CTs, including pharmacotherapy (i.e. drug; $n = 5$), invasive (i.e. surgical/blood draw; $n = 4$), alternative (i.e. supplemental/homeopathic treatment; $n = 2$), and informative (i.e. health/survey; $n = 6$). Five of the women had participated in at least two separate CTs (see Table 1 for participant demographics).

Data collection

After answering demographic questions, the participants were guided through an open ended-style interview. Interview questions were informed by IBM constructs (Montaño & Kasprzyk,

2015) and focused on how these constructs naturally emerged in participants' experiences with and communication about participation in BC CTs. The authors included questions addressing experiential and instrumental attitudes (e.g. "tell me about what your CT participation was like" and "when you think about medical research or CTs, do you think they work?"), injunctive and descriptive norms (e.g. "what kind of messages did you get from friends/family about participation, and were they supportive or unsupportive?" and "out of every 10 female BC patients, how many do you think are involved in CTs; of those, how many do you think are Black?"), and perceived control and self-efficacy (e.g. "How were you exposed to the idea of participation in a CT?" and "Describe any interactions you experienced with your family members and social circles regarding your beliefs or ability to participate in a CT."). Participant interviews were audio-recorded and apart from one outlier that lasted 75 minutes, all interviews lasted 50 minutes or less. The interviews were transcribed verbatim by a paid, professional transcription service.

Data analysis

Two authors read the transcripts while listening to the audio recording for accuracy, and then read them all a second time to remove identifying information and assign pseudonyms. Next, guided by Braun and Clarke (2021), the authors read each transcript again to begin thematically analyzing for codes and themes using IBM as a guiding framework. Braun and Clarke (2021) describe the phases of thematic analysis as data familiarization (involving transcribing, reading, and re-reading the data and making note of preliminary ideas); code generation (systematically coding seemingly salient data points across the entire set, seeking codes for as many ideas and categories as possible); searching for, reviewing, defining, and naming themes (including sorting the codes into themes and gathering theme-related data); and producing the report (choosing and analyzing compelling and salient data examples and composing a scholarly statement). Following these guidelines, the first and second author met multiple times to discuss codes and develop themes before moving on to second-level coding.

Guided by Tracy (2012), after completing the primary coding and making note of potential themes, the authors moved into second-level coding. During this process, they solidified themes and chose appropriate sections of the transcript to use as examples of the findings. Before committing fully to the categories leading to the thematic outcomes, they carefully reviewed the data then returned to the transcripts a final time to gather exemplar quotes from participants, and drafted the report of findings, below.

Findings

Motivators for participation

We identified instrumental attitudes suggesting strong altruistic influences and experiential attitudes implying that participants' decision about participation was related to the type of CT in which they wanted to participate.

Table 1. Participant demographics.

Pseudonym	Age	Completed Education Level	Household Income	Type of BC	Description of BC CT	Type(s) of CT(s)
Victoria	65	Bachelor's	25–30K	Stage 1 hER2+ and HR+	wore fitness watch, checked in and was monitored	Informative (i.e. health/survey)
Tamara	55	Master's	50K	Stage 1 invasive ductal carcinoma	2 trials: (1) bone metastasis restricting drug trial; (2) randomized trial about treatment and fatigue	Pharmacotherapy (i.e. IV or oral drug); Informative (i.e. health/survey)
Alberta	55	High School + trade licenses	51K	Twice – (1) Triple negative; (2) HR+	drug trial for nausea	Pharmacotherapy (i.e. IV or oral drug)
Denise	50	Bachelor's	165K	Twice - both were triple negative	2 trials: (1) neoadjuvant chemotherapy drug trial; (2) randomized PARP inhibitor	Pharmacotherapy (i.e. IV or oral drug)
Nancy	58	Bachelor's	90K	simultaneous double diagnosis in both breasts - triple negative & HER2+	weekly surveys + entry and exit interviews throughout duration of initial treatment	Informative (i.e. health/survey)
Danielle	45	Bachelor's	125K	HER2+	wear watch for 3 months to show general activity and go in once/month to ride bike while monitored	Informative (i.e. health/survey)
Earlene	69	Some college	30K	Stage 1 ductal carcinoma in situ	3 trials: (1) took calcium supplement for 3 years; (2) consented to have breast tissue from mastectomy used in trial; (3) donated healthy breast tissue	Invasive (i.e. surgical/blood draw); Alternative (i.e. supplemental or holistic treatment)
Jaleesa	65	Bachelor's	50K	Triple negative	topical cream used daily on breast	Alternative (i.e. supplemental or holistic treatment)
Ronnelle	62	Some college	12K	Stage 1 invasive ductal carcinoma	2 trials: (1) wear fitness watch for 6 months while monitored; (2) donated healthy breast tissue	Invasive (i.e. surgical/blood draw); Informative (i.e. health/survey)
Sylvia	50	Bachelor's	42K	Triple negative	chemotherapy drug trial	Pharmacotherapy (i.e. IV or oral drug)
Mayme	75	High school	20K	Twice – (1) ER+; (2)?	consented to have breast tissue from mastectomy used in trial	Invasive (i.e. surgical/blood draw)
Sharese	61	Some college	110K	Triple negative	2 trials: (1) Drawing and checking blood every 90 days; (2) Blood draw from bone marrow every 90 days to determine if cell dormancy	Invasive (i.e. surgical/blood draw)
Gloria	37	Master's	100K	95% ER-PR+, HER2-	receive total of 6 injections of vaccine for breast cancer with high % PR-ER	Pharmacotherapy (i.e. IV or oral drug)
Sierra	64	Some college	60K	Stage 1 triple negative	survey questions during duration of treatment focused on emotional and physical health	Informative (i.e. health/survey)

Altruistic attitudes

Participants' instrumental attitudes revealed a desire to help themselves, as well as a desire to leave a legacy of better treatment for other women, particularly other Black women. Jaleesa was clear in her motivations for CT participation; she articulated, "I had no problem [participating] because if it would work on me, then I'm hoping it would work on someone else. . .whatever I can do to help someone else." Earlene said, "I was happy to [do it] because it might save some other woman down the road from having to go through what I went through. So that was important to me." Sylvia went a step further, noting that this could even help her leave an important legacy to her children, saying, "if it would be a help to others that will follow me and it would be a help to my children, because I have two daughters, then I'm all for it."

Several participants also mentioned that their desire to participate is in part influenced by an acknowledgment that Black people have historically not been involved in medical research and an understanding that this means they have not always historically benefited from medicines developed as a result of CT as much as other groups. Ronnelle argued, "that's why they don't have a lot of research because most of the time we [Black people] don't participate. . .so I try to do what [I] can to be helpful." Alberta echoed this sentiment by

asking, "How are people going to get new medicines if you don't do a study?" As noted by Victoria, "I've just always had an interest in trying to do what I can to help because I think it's so crucial for African American women. . .because without doing, participating in research, they don't know what works best for us." Denise echoed this sentiment distinctly:

There was nothing targeted for triple negative, and I was a big believer that more research needed to be done and that we, and the fact that it so disproportionately affects African American women, I found even more disturbing. You know, I have long wondered how much race plays a part and what trial drugs get studied for which populations. [It's] troubling that, you know, this breast cancer that disproportionately affects Black women also has no targeted treatment. I have to hold myself partly responsible in that if African Americans don't participate in trials, then we don't get drugs targeted for us.

Gloria articulated her altruistic attitudes by couching them within an acknowledgment that the past crimes against Black people in this country are one of the main reasons that prevent many Black women from participating in medicine and research, and she wants to break that cycle with her participation in a CT. She is a nurse who lives and works in the southern U.S. and she recalls having male patients who were participants in the Tuskegee syphilis trials. Gloria

also noted that the woman who accused Emmett Till of offending her (which led to his lynching at age 14 in 1955) is still alive and lives in the same city as she. She revealed these anecdotes about her life as part of her motivation for participating in this CT, saying, “I can’t be another statistic, because I know when it comes to breast cancer in African Americans, although we’re not the leading cases, we’re the leading cases when it comes to death.”

Clinical trial types

Although all participants in the study had participated in a CT related to BC, it was clear that the type of CT and perceptions about the safety of those CTs was an important factor in their decision. The experiential attitudes expressed by women in the current study were mostly related to whether the CT they participated in involved a focus on pharmacotherapy (e.g. medicine) or non-pharmacotherapy (e.g. behavior tracking, surveys, supplements, non-pharmaceutical topical treatment).

More than one-third of women in our study participated in non-pharmacotherapy CTs, and in discussing their decisions, almost all mentioned the import of whether the CT involved pharmacotherapy. For instance, Victoria remarked,

I am, of course, a little hesitant about taking, doing drug-related [CTs], but anything else I’m open to as long as I know that the confidentiality is going to be adhered to . . . I think you have to be cautious when you’re doing drug-related. [CTs]

In another example, Nancy said she felt safe in her decision because “it was all online.” She went on to explain that she did not know about non-drug related CTs beforehand because “when we think of CTs we always think of [medication].” Danielle expressed similar sentiments, recalling, “I didn’t have to take any type of medication or placebo pill or anything like that. Things I was doing . . . riding a bike and just doing regular exercise, so I felt safe.” Ronnelle also discussed her decision to do a non-pharmacotherapy trial and how the lack of negative side effects was important to her: “I was like, ‘I’d love to do that study [on exercise]. I was like, fitness doesn’t make your hair fall out. It doesn’t make you sick.’”

For participants who decided to enroll in trials with a pharmacotherapy or ingested supplement element, some explained that there was a difference between the types of therapies being tested that influenced their decision. Earlene told us,

I made the decision to [take a calcium supplement] because I thought it would benefit me or at the very least it couldn’t hurt. . . you know, I would not be open to just anything they may have wanted me to do.

At the same time, although a few participants who participated in pharmacotherapy trials demonstrated hesitancy to take unknown or new drugs, most expressed experiential attitudes of feeling safe in their choices. Inherent in these women’s perceptions was a relatively high degree of health literacy and understandings of the way in which CTs function. Tamara explained to us that “It was easier for me to say okay to this [phase 3 clinical drug trial of ibandronate] because it wasn’t at the beginning of a trial or anything. It wasn’t ‘okay we’re going to try this medicine, we’ve never used this before.’ That probably would have been a little more difficult for me.” Alberta

affirmed her belief in the safety of CTs and the safety protocols in place, explaining:

So my perception on CTs is I think, you know, a lot of African American women, they don’t want to do them because, you know, that old thing when they were injected . . . The first thing always come out of their mouth “I’m not going to be a guinea pig” . . . All of that stuff now, it doesn’t happen . . . I always tell them . . . you can look it up.

Normative influences on participation

We found that the participants’ normative influences drove their CT participation decisions, while possibly helping to distort their perceptions of the uncommonality of their behavioral decisions to become CT participants.

The (non) role of supporters

Study findings concerning norms showed that despite the Black population’s instilled community values, decisions about BC CT participation do not seem to be motivated by a strong injunctive normative influence from friends or family. Most women reported sharing their decision to participate in a CT after the fact with their loved ones. Tamara said, “So when I was telling my close friends and family about it. . . I just kind of went to them with ‘okay, this is what I’m doing now, so we’re going to see how this works.’” She went on to clarify: “I don’t know if I presented it to anybody with ‘what do you think I should do?’ It was more of a ‘this is what’s going on.’” Jaleesa recalls a similar experience in telling her husband and mother about her CT. She said, “it was my choice. . . they weren’t trying to talk me out of it, they would not have done that. They were okay with that.”

In addition to delaying telling friends and family about their decision to participate until after they had already done so, participants often expressed that they kept their decision to participate in a CT a private decision. When asked whom she told, Alberta responded, “just my husband. I told him.” Danielle, when asked about conversations she had about the CT, said “my husband. . . I just explained to him what the trial was about.” Pressed to think about any other people she told, Danielle eventually said, “[My best friend] I guess I probably told her about, you know, the study and what I had to do.” Sylvia said, “I didn’t even tell anyone,” a sentiment shared by Victoria who also noted, “I actually didn’t speak with anyone about it. I just made a decision on my own to do it. . . I really didn’t discuss it with family members or anybody.” Rather than seeming like they were being secretive, it instead seemed like these women approached the disclosure of their CT participation as something that was not other people’s business.

Skewed estimation of unique decision conventionality

Although the exact participation rates in BC CTs are not tracked in any national database, a recent review of minority representation of oncology CTs found that participation varies significantly across ethnic groups (Duma et al., 2018). Among Duma’s study participants, over the course of 13 years (from 2003 to 2016), Black women accounted for 6% of all cancer CT participation and 7.2% of BC CT participation. When these rates are compared to the respective cancer incidence

percentages, it can be deduced that Black people are routinely underrepresented in important oncology trials.

From a descriptive normative perspective, most participants in the current study realized that their decision as Black women to participate in a CT was an unusual one. However, they demonstrated low levels of accuracy when asked to estimate how many women, in particular Black women, they believed did participate in BC CTs. The participants approximated that, on average, more than four out of every 10 female BC patients took part in a CT; but in fact, studies on CT enrollment of all cancer patients estimate that only .5 out of every 10 participate in cancer CTs (Unger et al., 2016). Assumption of similar rates of participation for all cancer CTs (Unger et al., 2016) and BC CTs, together with application of the percentage rates from the Duma et al. (2018) study noted previously, provides a supported conclusion that fewer than four of every 1000 female BC CT participants are Black – a number far smaller than the estimate perceived by participants in the current study. Although two of the 14 women did give an answer of “zero” when asked to approximate how many Black women out of 10 took part in BC CTs, the remainder greatly overestimated the number.

Evidence of personal agency

Participants in this study demonstrated clear levels of involvement not only in seeking out CTs but also in engaging in informed and shared decision-making with their providers about participating in the trials. Because this study focused on decisions that have already been made, we were able to observe how these women described their own roles in participating in CTs and the personal agency they exhibited in these decisions.

Seeking out clinical trials

An important factor in CT participation is awareness about possible CTs. Some participants noted that their oncologist or other people within the clinic alerted them to trials for which they may qualify. Tamara recalls that her oncologist alerted her to a potential CT “probably [at] my first appointment . . . gave me information on it for me to take and read.” Earlene recalls that her oncologist told her about the CT and then asked if she would like to speak to the researchers after her appointment.

Much more common, though, was when participants shared that their awareness of CTs was due to friends and family in their social networks or because of their own research. Sierra recalls that her daughter “told me about the trial. I contacted the lady [researcher leading the trial], and that’s it.” She went on to explain that “anything that comes about for breast cancer . . . then she [my daughter] shares with me. So it was just kind of like an organic conversation like that.” When asked how she heard about the CT she participated in, Nancy said, “actually, it was word of mouth. Another friend of mine recently went through breast cancer and she found out that I had been diagnosed and she told me about [the CT].”

Some participants showed a high level of personal agency when they expressed that they are the ones who prompted the conversations and found out about what was

available to them. Denise remembers, “she [oncologist] didn’t push me into it. In fact, I’m the one who approached her. . . I just asked her if she knew of any CTs. . . and she did.” Sharese recalls she “heard about it on Good Morning America and I called [the university hosting the CT] myself and started asking questions. I did my own research on, you know, ‘hey, what’s out there?’” Some participants, like Victoria, described face-to-face interactions where they sought out the researchers doing the trials. Victoria explained:

I volunteer with a [local breast cancer nonprofit] and I was helping with reception . . . I looked at one of the bios of the doctors that was speaking that day . . . So, she came out of her session, I pulled her to the side and asked her: did she have any open CTs? And so, fortunately, she did.

Shared and personal decision-making

Beyond awareness and research about potential CTs, participants also expressed high personal agency in the conversations they had with healthcare providers about making the decision to participate in a trial. In some cases, participants described a shared decision-making approach where they discussed the trials with their doctor. Denise, who is quoted in the previous paragraph about approaching her oncologist, went on to explain that the process involved her initiating the idea of wanting to participate in a trial, and the oncologist helping guide her into the appropriate trial (e.g. discussing potential trials, pros and cons). Sylvia remembered that her oncologist suggested the trial to her: “he just presented me with the information, saying [the academic health center] was doing a CT on triple negative and that things were going really well.” When asked how she would characterize the communication she had with her oncologist about the CT, she explained,

I don’t even know if I was really persuaded, to be honest with you. He told me about it. He told me about the preliminary success rate . . . and I remember asking him some questions about it . . . by the end of our conversation, I told him . . . I’m all for it.

In other cases, participants described that the decision to participate was fully self-driven. Victoria explained that after finding out about the potential study, she “didn’t speak with anyone about it. I just made a decision on my own to do it.” When pressed about whether she asked her own oncologist about it, she said, “I did not . . . I didn’t have to have permission or anything.” Nancy also explained that she made the decision on her own; she recalled, “I shared with them [my oncologist’s office] that I was doing the CT [after the fact].” It’s worth noting that both Victoria and Nancy were participating in non-pharmacotherapy CTs; protocols would likely dictate that participation in a pharmacotherapy CT would require the researchers to contact and coordinate with the patient’s primary oncologist to ensure there would be no contraindications for enrollment. Gloria, on the other hand, researched a pharmacotherapy CT on her own and presented her oncologist with the idea. She recalls, “I approached her with the literature, and she was just blown away by it and said, ‘Let’s do it.’”

Discussion

The purpose of this study was to identify the attitudes, perceived norms, and perceived sense of personal agency of Black women who participated in BC CTs, and to explore how these factors affected their decision to participate. Findings from this study can serve as input in the design of more targeted and effective messaging about CT participation targeted toward the Black community, and ultimately, be used to increase CT participation in this group. The responses of these women indicated solid altruistic instrumental attitudes and clearly delineated experiential attitudes concerning the type of CT treatment. They saw their decision to participate as their own private decision, but ultimately felt supported by loved ones once they disclosed their participation. All women exhibited high levels of personal agency in choosing to take part in BC CTs. There are important theoretical and practical implications of the findings from this study that warrant discussion, and we identify areas for future work.

Altruism

Findings about the participants' attitudes revealed that despite some historical, multifaceted reluctance to be involved in medical research, Black women's altruistic desires to serve others and their communities made them prime candidates for participation in this CT. This supports a growing body of literature on the importance of altruism related to cancer CT-related participation of minorities in general (Trant et al., 2020) and among Black women in particular (Fairley et al., 2024; GCI Health, 2024; Ridley-Merriweather & Head, 2017).

Participants revealed a need to be involved as a way to help themselves and to leave a legacy of better treatment for other women (particularly other Black women), further supporting the "legacy norm" findings of our previous work (Ridley-Merriweather & Head, 2017). In other words, although the current study participants were diagnosed with BC and were naturally interested in seeking out CTs to increase their own health outcomes, they were still equally guided by solid altruistic influences.

From a recruitment and engagement perspective, this finding provides an important cultural targeting strategy. Clinical trials are typically presented as "additional treatment options" to patients, but for Black women, it may be that messaging about the ability to help others in their community would be an important added value for these group members (Ridley-Merriweather & Head, 2017). Although Black women's bodies have historically been exploited, Black women can now exercise personal agency and *choose* to use their bodies to benefit other Black people in the future through medical research participation.

Experiential attitudes—type of clinical trial

These women's experiential attitudes were mostly related to the focus and type of CT in which they took part. This theme describes the commitment hesitation of participants and their ideas about the difference in participation in pharmacological versus non-pharmacological interventions. These women

clearly reported on the idea that the type of CT mattered to their decision. On one hand, their innate sense of altruism guides these group members to participate and help others; on the other hand, many were hesitant to subject themselves to the seemingly riskier choice of pharmacotherapeutic studies. This carefulness is not surprising given the historical atrocities committed on Black people by medical personnel and medical researchers (Washington, 2023).

Although most of the women expressed some hesitancy regarding taking part in drug trials, more than a third of the women in this study did participate in a pharmacotherapy trial. Most women in the current study, regardless of whether their CT participation took a therapeutic form, did voice a guarded interest in drug trial participation if they were able to readily access information about the history and side effects of the drugs. Shiyabola et al. (2018) found that many Black women with diabetes hesitated to take medication due to fear of side effects, but other women in the same study suggested that education and training were helpful to their medication protocol adherence, something that may be evidenced in the current study. As an example, Gloria, as a nurse, demonstrated how Black women who are also healthcare providers can serve as models and educators to facilitate pharmacotherapy CT participation by having experienced it themselves.

Descriptive norms—perceptions of others like them

Surprisingly, 12 of the 14 participants expressed an opinion of Black women's rates of participation in CTs that was an over-estimation when compared to recent studies (Duma et al., 2018). It could be that these women, after having been exposed to their own unique motivational influences, reacted in a way they perceived others like them would also react if given the opportunity. Furthermore, several women in the current study were informed of the opportunity by others in their communities or families, which contributed to their decision to enroll (Kikut et al., 2022) and may have inflated their perceptions of how many Black women around them are participating in such research. Further work exploring this disconnect could be valuable to increasing minority participation in CTs.

Another factor possibly contributing to the participants' skewed CT average participation perception is the high percentage of women in the current study who developed TNBC. According to Johns Hopkins Medicine (2024), TNBC accounts for 10–20% of all BC incidence. Yet at least 50% of the participants ($n \geq 7$; one participant was unsure of her diagnosis) were diagnosed with TNBC, and one experienced a recurrence of the same form. These findings demonstrate that Black women may experience an added level of concern knowing they have much higher incidence of an aggressive form of the disease that is more difficult to treat, knowledge that could ignite the spark that incentivizes CT participation.

Personal agency

Participants in this study demonstrated high levels of involvement in their own health choices not only by seeking out CTs but also through engaging in informed and shared decision-making with their providers about participating in the trials.

Because this study focused on decisions that have already been made, we were able to observe how they thought about their own roles in participating in CTs and the high levels of self-efficacy they exhibited in these instances.

To find out about CTs, participants asked their physicians on their own behalf, or responded to peer group members who sought them out particularly to inform them about CTs. Studies suggest that Black individuals have an interest in participating in research but often lack information about CTs (Fairley et al., 2024; GCI Health, 2024). Therefore, the women in the current study fully demonstrated their strong sense of personal agency by conducting their own research and following up on media stories they had seen about BC research. Despite substantial evidence of the barriers likely in their way, several participants in our study found their own path to knowledge about CTs from sources outside of the medical realm.

The generally exhibited tendencies of the current study's participants toward having a strong presence of self-efficacy is novel, especially when we take into consideration that all but one had at least some college or licensure training, and only 4 of the 14 women (28%) were informed about and asked by their provider to take part in a CT. Keeping in mind that not being asked is a well-documented reason for low research participation among these group members (Fairley et al., 2024; GCI Health, 2024), these findings could suggest that less confident Black women or those with lower levels of education might not have the necessary tools to find out about or get involved in a CT on their own. In that case, the introduction of CT participation by a medical provider or research team member could have a noticeable positive impact.

Support and advocacy groups

Participants in the current study clearly described the importance and value of the communication enabling them to find out about potential CTs from their friends, family, and other BC patients and survivors. This finding supports the work of researchers like Fairley et al. (2024) who found that a general lack of awareness of trials and a communication gap were major barriers to participation.

Many of the women in the current study were involved in organizational support or advocacy groups. This involvement served to increase their knowledge of BC and/or research and CTs and helped to address the known lack of communication surrounding the recruitment of Black individuals to CTs (Robinson et al., 2017). For Black women, choosing to be involved in patient support groups is further evidence of a strong sense of personal agency. Black individuals often feel that support groups are not culturally aware, and groups primarily comprising Black members may not be available (Tate, 2011). It is therefore noteworthy that many of the participants in our study were active in formal and informal support groups with other Black BC patients and survivors.

Theoretical implications

The current study's findings have theoretical as well as practical implications for learning about Black women's

possible motivations for participating in BC CTs, particularly regarding having been influenced by their attitudes, norms, and sense of personal agency. We suggested in an earlier section that, given the participants' awareness of the need to increase CT participation of Black individuals, considering culturally targeted messaging to inform recruitment efforts might be an appropriate next step. Although the IBM does provide some guidance for the consideration of cultural influences, there is need for further study of the role and presence of culture within this theory.

Practical implications

On an applied level, the findings of this study provide practical implications for making information about CTs more targeted and accessible to Black women. In this section, we present three implications.

Implication #1: need for knowledge and awareness of CTs

In our study, Black women's ability to overcome their hesitancy regarding CTs suggests that they are amenable toward participating in both pharmacologic and non-pharmacologic CTs. Therefore, it is critical for health providers and healthcare institutions to ensure they are providing information that increases Black women's awareness of CTs – what they are, where they are occurring, and where Black women can go to find more information about participating. This may be the most significant implication, as any others that follow hinge upon women knowing more about available BC CTs. Overall, our findings suggest that Black female BC patients and survivors are interested in CT participation if given the appropriate information and resources.

Interestingly, most of the participants in this study were not informed about the availability of CTs by their oncologists or personal practitioners, suggesting that healthcare providers seem to play a secondary role in these women's awareness of and decision to participate in medical research, particularly non-pharmacotherapy CTs. However, healthcare providers possess great potential for increasing CT participation of Black women (GCI Health, 2024), as demonstrated by the revelation that three participants in the current study had the same oncologist. As evidenced by this study, one tangible way that healthcare providers can bridge this knowledge gap is by more regularly initiating conversations about CTs in their routine patient appointments.

In their relatively recent review, Duma et al. (2018) noted a decrease in CT recruitment of Black and Brown individuals during the past two decades, supporting the finding that healthcare providers generally fail to mention or recommend CTs to Black patients. Indeed, the current study suggests that for Black women, the norm is to rely on their social networks and communities and their own resources to find out about CTs.

Going forward, our findings suggest that researchers who desire to increase their percentage of Black participants should make better use of already in-place community recruitment channels and methods, including support networks and social media platforms. In addition, employing easy-to-understand

recruitment language about CTs may be beneficial. Connecting Black women with support groups, particularly those comprising other Black women, is another way to increase community and communication.

Implication #2 – consider experiential and perceptual influences

Surprisingly, although these women may well have had the same feelings of distrust and fear of being treated as a guinea pig (Fairley et al., 2024) that deter many Black people from participating in CTs, participants in this study seemed not to allow those apprehensions to prevent their CT participation. It should be noted that although the study participants felt positively about their participation in a BC CT, some of the women still displayed some perceptual concern about the type of CT, suggesting the need for future research parsing how perceptions and motivations differ based on the types of CTs in which Black women with BC are most comfortable participating and why (Fairley et al., 2024).

Addressing the concerns of highly motivated Black women about participation in pharmacologic trials is an important area for future work. Clinical researchers who take care to study and address these concerns to better inform Black women about the great need for both pharmaco- and non-pharmacotherapeutic trials may see a positive difference in the number of group members who would perhaps consider participation in medical research involving pharmaceuticals.

Implication #3 – significance of recruitment methodologies

The positionality of the Black female first author whose day-to-day employment is grounded in the recruitment of minoritized populations into clinical trials and the support of a racially diverse and experienced research team are salient to the methods chosen for the current study. The decision to employ purposeful and culturally sensitive recruitment approaches of engaging personal networks and snowball sampling is directly tied to the racialized contextual issues of mistrust often experienced by these population members when asked to participate in research (Bamidele et al., 2019). Research teams must always recognize the importance of creating safe and trusting spaces for their prospective historically excluded participants, and plan for any associated challenges that may arise (e.g. allowing extra time to recruit). For these reasons, processes to determine recruitment methodologies should begin during the conceptual phases of the study.

Limitations and future research

The small sample size is a limitation of this study; however, the number of participants is likely to be a constraint for this kind of research until greater efforts are made to alert more Black women to the possibility of CT participation. This study is also largely focused on the Black women in the U.S. and does not draw from more global sources; therefore, the historical context, norms, and racial inequities that influence these Black women's decisions to participate in BC CTs may only be applicable in the U.S. and not in other parts of the world. Additionally, the sample comprised many college-educated

women, which may speak to their awareness and positive favor toward CTs. Finally, although we were able to qualitatively draw attention to potentially interesting personal characteristics associated with BC CT participation (e.g. influence of individual oncologists, type of CT), more research is needed to further explore whether these characteristics can explain and predict participation in CTs. Future work should explore whether Black women with BC who participate in CTs do possess distrust and/or fear of medical research participation, and what drivers might compel those who participate anyway.

Conclusion

This study applied the IBM as a framework to identify the influences of Black women who choose to participate in BC CTs, and to explore how their decisions to participate were guided by their attitudes, perceived norms, and feelings of personal agency. We interviewed Black women who were BC patients or survivors, and who had taken part in, or were currently enrolled in, at least one BC CT. Continuing to understand how historically excluded population members are motivated to participate in medical research is important, particularly so for BC, since it affects women of diverse racial and ethnic heritages differently. The findings from this study not only elucidated some of the reasons Black women chose to participate in BC CTs, but also informed important implications for increasing Black women's participation in BC CTs.

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